



RIP Doddie

The MND Association is saddened by news of the death of Doddie Weir OBE.

After announcing his MND diagnosis on Global MND Awareness Day in June 2017, Doddie became an inspiration to so many people by sharing his story, raising awareness and campaigning tirelessly on behalf of people with MND.



A former Scotland lock who won 61 Test caps and played in the British and Irish Lions rugby team, Doddie set up the My Name's Doddie Foundation which has gone on to fund research projects across the UK and generously donated to the MND Association's support grant programme.

Doddie's determined attitude became a driving force in the #United2EndMND campaign – a collaboration between people with MND, My Name's Doddie Foundation, MND Association, MND Scotland and neurologists – which resulted in the Government announcing, in November 2021, it would invest £50 million over five years into targeted MND research.

"As long as we have hope, tomorrow waits."

The privilege of being a volunteer MND Association Visitor

My husband died 13 years ago after living with MND for 6 years. We had spent our lives working in developing countries, him as a civil engineer, me as a teacher. We considered ourselves adaptable and able to get the best out of any situation these countries threw at us!! But then...

As you know, the whole family lives with MND. Getting to grips with it was a steep learning curve. There were times when we laughed and times when we cried. All in all, we learnt so much about each other, our family and our friends.

One day not long before he died he said to me 'you are quite good at this caring lark. I think you should make use of the experience and help other people when I've gone!!' At the time, that really wasn't on my mind. In fact, I couldn't really see anything in the future but the next couple of hours of hoisting and massaging feet!

But here I am and have been for 12 years- an Association Visitor. It's very difficult to give you a job description as the task is a bit of a bottomless pit. Sometimes you can help, but sometimes you just can't. I'm told though that having someone to talk to who has experienced the situation as a partner/carer is very comforting.

'You are the only person who really understands how things are.'

Most volunteers have had direct personal experience of MND or have worked with people affected by MND as a health care professional. The tireless members of the MNDA branch committee have similar qualifications.

Unfortunately, there are not enough of us. Many people like to volunteer when they retire but they see it as spending a few hours a week on a particular day. It doesn't quite work like that in this MND role. Each volunteer offers different skills to the role and gives as much time as they can afford.

We would love to welcome more people to our team.

I have met the most inspirational people over the years and made new friends. I've sometimes thought of walking away from this commitment, but I can't quite do it! Even though my life has changed in the 13 years since I lost my husband (I am fortunate to have found a new partner to share it with) I am still very much attached to my MND family.

Sue Hallifax
Association Visitor

For more information about being a volunteer Association Visitor please contact Liz Cooper, Area Support Coordinator, East Anglia on 01604 800620 or liz.cooper@mndassociation.org

Cambridge Concert Orchestra

Concert in aid of Cambridgeshire Branch
MND Association

Saturday 1st July 2023

Timing to be confirmed: possibly 7.30pm

This orchestra was due to hold a concert in March 2020 in aid of Cambridgeshire Branch but due to Covid at the very last minute the decision was taken to cancel.

They will now be putting on a concert for us on 1st July next year. More details about the timing and programme to come in due course but thought advance notice would be helpful so those interested can get the date in their diary.

Cynthia George Branch Chair



How to text to donate

Text MND4CAMBS to 70085 to donate £5
(Texts cost £5 plus one standard network rate message.) To donate more, add the number to the end of the text e.g £20 = MND4CAMBS20
Help us improve the lives of people with MND in Cambridgeshire

www.mndassociation.org
MND Association Francis Crick House, 6 Summerhouse Road, Northampton,
NN3 6J Registered Charity no. 294354 Created in RightMarket - 5/6/2021 - 07:43:28



Cambridge Branch MND Justgiving Page

If you would like to make a donation to the Cambridgeshire Branch why not do this through our Justgiving webpage.

Just scan the QR code below with your phone's camera. This will take you to the webpage on your phone where you can donate.

If you're using your computer go to www.justgiving.com/team/TeamCambridgeshireMNDBranch where you can donate.

If you are a bit more old school, you can post a cheque to; Branch Treasurer, MND Association, 5 Churchyard, Mildenhall, Bury St. Edmunds, Suffolk, IP28 7EE.

Make cheques payable to "MNDA Cambridgeshire Branch.

All funds go directly towards helping our members living with MND in the Cambridgeshire area.

QR Code for Cambridgeshire MND Branch Justgiving page



Sponsored Walk at Grafham Water

On 25 October we organized a sponsored walk, in memory of Andrew Norton, a former Branch Chairman and prolific fundraiser. Andrew passed away earlier in the year from Covid with underlying health issues.

Andrew was the original organiser of our annual walks at Grafham Water and it was fitting to raise funds in memory of him. It is also a lovely venue for our walkers/fundraisers, particularly if the weather is kind to us which it was on this occasion.

Thirty-eight walkers started off at 10 am in sunshine to walk either 9 miles around the perimeter or 2 miles across the dam and back, together with children and dogs, wheelchairs and pushchairs. When arriving back at registration there were lots of chats going on all around and some of us had a meal as well. It was a great day out for everyone.

The staff at Grafham Water were very helpful both in the initial setting up, and on the day and we are very grateful to them for their support.

We have so far banked £500, plus registration fees taken on our new

SumUp machine and there will be more on JustGiving when it is collected for us by National Office. At present this page shows an amount of £320.

My thanks go to the Committee and AVs for all their help both before and on the day.

Maire Collins
Branch Secretary



Andrew Norton



Living Well

In the early days of Rick's illness we had a friend called Martin who lived near us and had Multiple Sclerosis. Rick and Martin used to do things like race each other on their mobility scooters to the weekly café in the Village Hall (Rick was always faster – not sure whether it was because his scooter was faster or whether Rick was simply more reckless!) Martin used to try and encourage Rick to be referred to the Arthur Rank Hospice because they offered all sorts of treatments, including symptom management and activities, but Rick was a bit hesitant because he, like many of us, felt that hospices were places where people went at the end of their lives and he didn't feel ready for this. Martin explained that it wasn't just to do with dying well; it was also to do with living well. Rick did eventually decide to give the hospice a go.

So, one morning we found ourselves walking through the doors of the hospice, full of fear and trepidation. Obviously, Rick wasn't really 'ill enough' to be there was he? What would they be able to offer him?

By now you will have presumably realized that our initial fears and concerns were wide of the mark. We talked to various people that morning, all of whom understood the sorts of thoughts and fears that were going through our minds and they initially offered Rick a course of sessions of Living Well (formerly known as day therapy).

Living Well brings together groups of people for 8 sessions at a time for activities such as relaxation, creative activities, use of the gym, massage plus the opportunity to make new friends. Different groupings exist to help people with different levels of need; some might need nursing input whereas others are stable and do not. After the initial 8 weeks, people take a break and then can re-apply after another 8 weeks. Some patients have really interesting stories to tell and some discovered a renewed purpose to their lives.

The MND clinic takes place at the hospice rather than Addenbrookes, and has all sorts of benefits for people, who are encouraged to engage with the services offered. In addition to the Living Well sessions and the in-patient palliative care, the

hospice can be incredibly persuasive when it comes to sorting issues with one's GP, providing food at the bistro, counselling for both patient and family, faith support via the chaplaincy, input from its specialist lymphoedema clinic and many other activities to try and improve the quality of life for those using their services. One of our friends had been told that Addenbrookes could provide no more care for him; Arthur Rank worked with him and after a while he was able to return home to his family!

Unlike so many medical and care services, the Arthur Rank Hospice is like an extended family. The staff care about their patients and go the extra mile for them. We have got to know many lovely people, all with really interesting life experiences to share. Some of these friendships are not long-lasting, but our lives are enriched by them and the pain of loss is worth the privilege of knowing the people concerned.

Recently Dr David Oliver gave the annual Arthur Rank Hospice Lecture. He started supporting people with MND in 1982 and talked about the changes in care that had taken place since then. He was frustrated by the things that people are told (for example by the media) which are simply not true and emphasized that it is important to help them to hear the right information. He described palliative care as being available to all people, aiming to reduce the effects of the disease, maintain the patient's power and enable the patient and family to live as full a life as possible. He stressed that it is not just end of life treatment, it is about building a relationship and that effective palliative care improves the experience and quality of life of the patient.

We are always happy to talk about our experiences with the Arthur Rank hospice so please feel welcome to ask any questions you have. You can contact us by phone on 01223 262661 or email at nelmsmissus@gmail.com if we can help at all.

The Arthur Rank Hospice can be contacted at www.arhc.org.uk/supporting-you/care-services/living-well/ or by telephone on 01223 675820.

Sue Nelms

Social Gatherings

August and October Histon & Impington Royal British Legion Hall

For these two afternoons we met at this hall. Many of you joined us at this spacious and easily accessible venue with plenty of onsite parking.

September Hemingford Abbots Village Hall

Another popular venue where we spent a very pleasant afternoon. The chat flows so easily at these events with many topics covered, ideas exchanged and new bonds formed.

November Ely Methodist Church Hall

This is proving to be another popular location even with the issue of needing to park in a public car park and having a shorter meeting time.

Many of you joined us for what was an enjoyable afternoon with so much chatter I felt I was interrupting everyone when I took a couple of minutes of your time. I wanted to get your thoughts on the format for these afternoons going into next year. Many suggestions and ideas were put forward and as many as possible will hopefully be incorporated into the 2023 programme.

The important thing is these afternoons are for you as members and the overwhelming theme which came out of that discussion was forming new friendships and chatting to each other was important.

To this end some afternoons will have a speaker or other entertainment, some will be left clear for you to chat between yourselves.

Cynthia George Branch Chair



Introducing our new CEO...

Tanya Curry has been appointed as the new Chief Executive Officer of the Motor Neurone Disease Association.

Tanya is a highly experienced leader, with a background in healthcare, who has worked in the voluntary sector for more than 20 years. After a decade as the CEO at an independent hospice, Tanya has most recently utilised her extensive skills and knowledge in charity leadership roles on an interim basis, including at The Ramblers and Impetus.

Tanya will be starting with the Association on Monday 9 January.



"I am hugely excited to be joining the MND Association. I began my career as a nurse and specialised in palliative care, so I feel I am going back to my roots, working with a community I care about deeply. After leading clinical services and several national charities as Interim CEO, including The Ramblers and Impetus, I am thrilled to be able to use my skills as a CEO to lead the MND Association on the next stage of its journey."

... and bidding a fond farewell to outgoing CEO Sally Light



Sally Light is leaving the Association at the end of the year after an amazing 10 years as Chief Executive of the MND Association.

We would like to thank Sally for the dedication she has brought to the Association as well as her hard work and vision.

I'm sure we all wish Sally well in whatever she does in the future.

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Mrs Maire Collins (contact details above)

AGM Wednesday 22nd March 2023

Dates of Get-Togethers in 2023

January 18th Royal British Legion, Histon

February 8th Hemingford Abbots Village Hall

March 2nd David Raynor Building, Scotsdales

Garden Centre, Great Shelford

May 17th Salvation Army Church Hall,

Peterborough

June 15th David Raynor Building, Scotsdales

Garden Centre, Great Shelford

July 12th Ely Methodist Church

August 16th Hemingford Abbots Village Hall

September 21st David Raynor Building, Scotsdales

Garden Centre, Great Shelford

October 18th Royal British Legion, Histon

November 15th Hemingford Abbots Village Hall

December 7th David Raynor Building, Scotsdales

Garden Centre, Great Shelford