

## Cheshire Branch

December 2011 Issue No 1104/16



### A Review of 2011

By The Chair of the Branch, Joel Millet

I find myself writing the years review once again, it does not seem 5 minutes since I was writing my first review last year. Again it has been a very busy year and kept our hard working committee members on their toes.

Firstly I would like to thank everyone who has supported the Branch, but I would especially like to say thanks to all those individuals who have gone out of their way to raise funds for the Branch and the Association. Without your effort and the funds that they generate we could not provide the support for our members living with MND and their carers.



A review of our activities was recently undertaken by National Office and our Support Meetings were singled out as the 'jewel in the crown' I said it last year, and I make no apology for saying it again the backbone of our activities has to be the Support Meetings for our members living with MND and their carers, and our thanks must go to Marion and Margaret for organising and running these meetings, which are held at different venues across Cheshire.

In the year there have been 1 Carers lunch and 9 Support Meetings, plus a narrowboat trip in the middle of May and the regular events, the Strawberry Evening and the Christmas Party, all of which have been well attended, the highest number of people attending was in September when a total of 37 people attended (16 of those were people living with MND). I believe that they are really positive events with lots of important dialogue between plwMND, and because they are relaxed events people keep coming back.

Let's not forget the effort that goes into our fund raising events which enable the Branch to produce this newsletter, hold our support meetings, and more importantly enable the Branch to assist our members who are living with MND. Our thanks must go to Hazel and all of you who helped and attended these events.

As we are attracting more people to help with fund raising, so are hopes that we can organize more events. Although we haven't put anything in the diaries as yet, we hope that 2012 will be even busier than this year. Amongst our plans for next year, as well as our normal functions, are a fashion show, a golf day, and a Branch Ball.

I hope to see you at our Christmas Party which this year is being held in the Peggy Killick suite at the Nantwich Civic Hall. The only thing left to say is



*The Branch Committee would like to wish you a Merry Christmas and would like to extend a very Happy New Year to all our readers, and we hope to see you all at our support meetings in 2012.*



Diary Dates	
Dec 5 <sup>th</sup>	Christmas Lunch, at The Golden Pheasant Hotel
Dec 11 <sup>th</sup>	Christmas Party at the Nantwich Civic Hall
Jan 9 <sup>th</sup>	Support Meeting at The Swan Hotel Tarporley

For further details go to [www.mndcheshire.org](http://www.mndcheshire.org)



## Food for thought

To my darling husband,

Before you return from your overseas trip I just want to let you know about the small accident I had with the pickup truck when I turned into the driveway.

Fortunately not too bad and I really didn't get hurt, so please don't worry too much about me. I was coming home from Sylvia Park and when I turned into the driveway I accidentally pushed down on the accelerator instead of the brake.

The garage door is slightly bent but the pickup fortunately came to a halt when it bumped into your car.

I am really sorry, but I know with your kind-hearted personality you will forgive me. You know how much I love you and care for you.

I am enclosing a picture for you. I cannot wait to hold you in my arms again.

Your loving wife. XX



*P.S. Your girlfriend phoned.*

## Launch of new carer's pack

(Extracted from the MND Associations publications)



**A NEW pack for family carers called *Caring and MND: support for you*, has been launched at the end of October.**

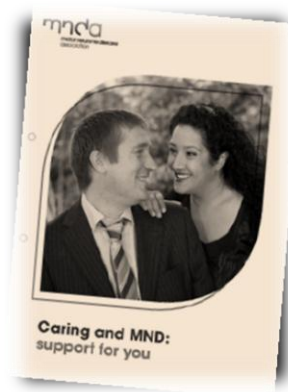
We recognise carers may have a particularly challenging time when faced with the unpredictable and progressive nature of MND, and the pack is designed to support their specific needs.

Awareness of available support is important, not only to help a carer support someone with MND, but also to look after a carer's own health and well-being.

Research and development of the pack has been shaped by the views of many carers, including those who shared their experiences of caring, both positive and negative, in our recent Carer's Survey.

The pack is divided into three, with clear sections to help the reader easily find the subject matter they need:

- Part One Practical support
- Part Two Emotional and personal support
- Part Three Additional information.



Toolkit items are included to help guide carers through the complex requirements they may need to consider for assessments and appointments. We hope these tools will also help Association visitors, to assist their discussions with carers about the challenges they face.

The theme of this year's AV Forums is carers, and will include workshops on working with carers, carers' rights and the carer's pack.

We have listened to repeated requests for openness and honesty, to help carers *before* the point of need. As a result, we have tried to be as direct as possible to help carers plan ahead, to reduce the potential stress they may experience.

In line with our new accreditation through the Information Standard, *Caring and MND: support for you* has included extensive input from carers, staff, volunteers, and health and social care experts from across England, Wales and Northern Ireland.

Our deepest gratitude goes to all those who have contributed with such enthusiasm and passion. Every comment and suggestion has helped to qualify, inform and improve the pack.

Early reviews from carers have been very positive: *"...very informative to those affected by MND giving very detailed information and contacts."*

*"This is going to be a very useful document and I wish I had this available when I was a carer."*

*"How invaluable this is for carers, as sometimes isolation makes you lose your own sense of being...so much time and effort is spent just trying to tick over and get through such a disabling disease which has such varying progression, from person to person so comparisons from others to help you gauge what the next step may be is not usually possible."*

This pack is our acknowledgement that carers do deserve, need and have the right to personal support. To order a free copy of *Caring and MND: support for you*, please contact MND Connect on 08457 626262, email [mndconnect@mndassociation.org](mailto:mndconnect@mndassociation.org)

## Newsletter

### This is your newsletter

So please let us have your contributions. These can take the form of 'humour', 'personal experiences', 'hints and tips', 'questions', 'holidays' 'photographs', and any other information that you might think of interest to our members.



Austen



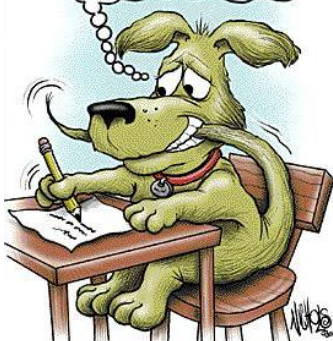
Shakespeare

You do not have to be a Jane or a William to submit any of the above.

So please do submit your contributions

And make this newsletter work for everyone in Cheshire

Dear Diary-  
You'll never guess what  
I FINALLY caught today...



## Hints & Tips

### North West Assistive Technology

Changing lives through technology. Northwest Assistive Technology is a specialist NHS regional service providing assistive technology and advice to people with disabilities and associated professionals. It serves a population of 6.6 million people in the Greater Manchester, Cheshire and Merseyside, Lancashire and South Cumbria regions.

- **Specialised Access:**  
Customised solutions can allow individuals who are unable to access computers using a standard keyboard or mouse the ability to access the internet, reader software and entertainment functions...
- **Environmental Control Systems:**  
These are multi-purpose infra-red and radio switching systems offering control of electrical equipment such as heaters, lights, televisions and telephones...

Northwest Assistive Technology is happy to receive requests for assistance from colleagues working in health and social care, as well as from potential users and their carers.

More information can be found on the website at [www.northwestassistivetechology.nhs.uk](http://www.northwestassistivetechology.nhs.uk)



## Benefits and entitlements: New information

(Extracted from the MND Associations publications)

FOUR new information sheets have been produced to accompany sheet 22 – *Benefits and entitlements*.

The aim is to provide a suite of social care information to support people living with or affected by MND. The information now includes:

- 22A – *Benefits and entitlements*
- 22B – *Direct payments and personalisation*
- 22C – *Disabled Facilities Grants and housing issues*
- 22D – *NHS Continuing Healthcare*
- 22E – *Work and MND*.



These sheets will automatically be included in our new carer's pack. You can download most of our publications from our website: [www.mndassociation.org/publications](http://www.mndassociation.org/publications) or to order printed copies, please contact MND Connect on 08457 626262, or email [mndconnect@mndassociation.org](mailto:mndconnect@mndassociation.org)

## Benefits Renewal

(By Trevor Druce)

In particular with Disability Living Allowance (DLA) and Attendance Allowance (AA), if you are asked to complete a benefits renewal form, a DS1500 Special Rules Certificate may exempt certain questions. This form is available from your GP or hospital Consultant.

Otherwise complete the form fully and within the time limit. The Employment Support Benefit is calculated on a points system, so don't leave any question unanswered.

Ensure the "all work test" is fully completed and supported by all medical evidence of your worst day scenario.

## Humour!

As we Silver Surfers know, sometimes we have trouble with our computers.

I had a problem yesterday, so I called Eric, the 11 year old next door, whose bedroom looks like Mission Control and asked him to come over.

Eric clicked a couple of buttons and solved the problem.

As he was walking away, I called after him.



'So, what was wrong?  
He replied, 'It was an ID ten T error.'

I didn't want to appear stupid, but nonetheless enquired, 'An, ID ten T error? What's that? In case I need to fix it again.'

Eric grinned .... 'Haven't you ever heard of an ID ten T error before?

'No,' I replied.

'Write it down,' he said, 'and I think you'll figure it out.'

So I wrote down:

**ID10T**

I used to like Eric.

## Support Meetings (aka socialising)

(By the 2 M's)

The Support Meetings have this year gone from strength to strength and the credit for this has got to be given to those who attend, those living with MND and their carers.

Whilst we organise the venues for the meetings they would not be successful without the positive attitude displayed by all who attend.

They are not only social occasions, and this plays a big part, but the wealth of information gained, and the experiences of those who attend are shared, so everyone who attends gains from the social gatherings.



Rowton Hall Country House Hotel

Although they are called "Meetings" they are "Social Gatherings" as there is NO formality whatsoever. At most of the events you can just turn up and enjoy the friendliness, even when we do ask for numbers attending exceptions can and are made for those who haven't returned the 'slip'

The meetings during 2011 have been at:

- The Grosvenor Garden Centre, near Chester
- The Swan Hotel, Tarporley
- Rowton Hall Country House Hotel, near Chester
- The Abbeywood Estate, Delamere

Unfortunately the venue we used in Holmes Chapel has closed, but we are hopeful to find a new venue early in the New Year.

At the last 3 social gatherings we have had in excess of 30 people, and it is a sign of how friendly everyone is that new people attending are returning.

We also arranged in May a narrowboat trip from the Cheshire Cat at Christleton to travel on 2 narrowboats named "The Pot of Gold", and "Michael Hayes" to travel through 5 locks to Cow Lane Bridge in the centre of Chester, and back again. We try to arrange 1 or 2 specials each year and these are normally a 'day out'

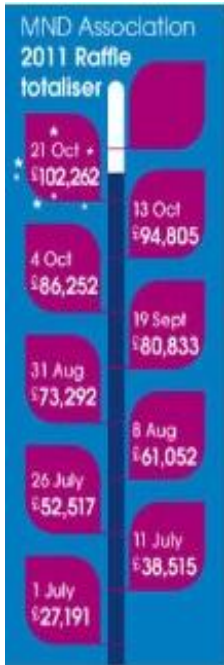
Probably by the time you read this we will have enjoyed meeting at The Golden Pheasant Hotel in Plumley for our Christmas lunch. But maybe it isn't too late to join us at the Christmas Party, this year being held on 11<sup>th</sup> at Nantwich Civic Hall.

*Whatever your plans are for 2012, please join us at one of the 'gatherings', we can't guarantee you will enjoy yourself, but like everything else in life if you don't try it you will never know.*



We never lose hope. We strive to find a cure for MND and to support everyone affected by this devastating disease

## MNDA Raffle



Every raffle ticket sold this year through the branch has helped raise much needed funds for the Cheshire area, while increasing awareness of MND and the work of the Association.

This year's raffle has now closed (28<sup>th</sup> October) and the winners and the draw took place Monday 7<sup>th</sup> November.

The raffle winners and final income total was published on the MND Association website shortly after the draw date - so please do visit soon.

[www.mndassociation.org/get-involved/fundraising/raffle-2010](http://www.mndassociation.org/get-involved/fundraising/raffle-2010)

Finally, we would like to thank you so much once again for your support.

## My UK Ironman 70.3 2011 Experience

Daniel Knox completed the Ironman 70.3 which he did way back in June, in doing so he made over £1,800 in sponsorship of which 70% was donated to MNDA & 30% to NE Wales Search & Rescue.

The following account is a synopsis of his story, the full account can be read on the website at <http://mndcheshire.org/3.html>

I saw the 2010 coverage of the Ironman 70.3 on TV one Saturday morning whilst eating my breakfast. Wanting a change from rowing after doing it for the best part of 10 years this gave me the push to enter the event. And that was it I was signed up for the UK Ironman 70.3 in 2011.

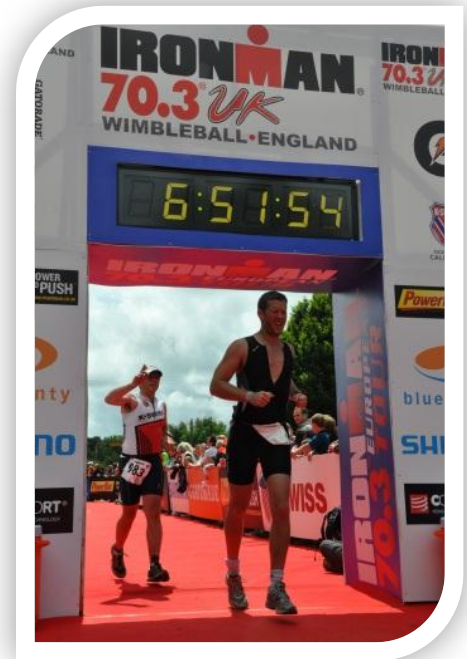
My girlfriend and I travelled down to Devon, and we went straight to the Ironman site where I was required to attend a briefing for the race. On race day I rose at 4am to shower and eat some breakfast which mainly consisted of carbohydrates! I was at the Ironman site at 6am where at 6.30am they started walking us down to the lakes edge to start the swim. I said my goodbyes to my girlfriend Donna and then plunged in to the cold water ready to tread water for a good 30 minutes (the amount of time it took the 1600 entrants to get in position by the start line).

The 7am starting gun took me by surprise, so we were off and the swim part had begun. 1.2 miles of swimming in a lake, a mass start! The whole way I was jostling with people to find some clear water. I was glad to reach the shore but soon after followed a 400m run (or walk) to the transition area where we doffed our wetsuits and donned our cycling clothing ready to take on some food and water and ride the 56 miles of the very hilly bike course.

By this time it was only 8am and the sun was low. Due to my pretty good swim I was up at the front with the majority of people and feeling good. I had my breakfast which consisted of some sort of energy bar and rode the 2 laps of the bike course as fast as I could. I was struggling to digest some of the food I had been consuming on the bike which I think was due to the riding position which made me dread the run that was slowly approaching. But I completed the cycle in approximately 3 hours and 38 minutes which I was really happy with and faster than I thought I could do.

I was now in transition 2 which basically required me to put my bike on the rack and swap my clip in cycling shoes for my running shoes quickly after scoffing and banana and a mars bar. Luckily the energy bars and gels decided they could be digested now and my stomach cramps went. I really struggled to run up the hills, and like the bike course the run course was also very hilly! The run involved 13.1 miles of a 3 lap course. After almost 2 hours I could see the finish line and I was almost home. I knew my girlfriend would be waiting at the finish line and I couldn't wait to see her and say thank you for all her support.

There was a commentator who was reading out names and numbers of all the athletes and it was great to hear my name as I crossed. I had had a target of 7 hours and so to complete it in 6hours 52 minutes was a great accomplishment for me and I felt really proud that I had raised so much money for my mum's charity and more than I had ever thought I could.



## Afternoon Tea

On Wednesday 26<sup>th</sup> October Karen Simmonds invited a few friends round to her house in Hale for afternoon tea, and raised £105 from the sale of second hand books and Christmas cards.



Karen, who is a retired Speech Therapist, in donating this money to the Branch has asked that the money be used supporting communication aids.

## Queens Park Crewe

(By Hazel Francis)

The Cheshire Branch supported the Grand Opening of Queen's Park in Crewe.

The branch had a "Surprise Parcel's" Stall and spinner for the children which proved very popular.

This was a good opportunity to promote the awareness of Motor Neurone Disease; we gave away hundreds of balloons to children.

I would like to say a big thank you to Sue Raynor and John Francis who blew up the balloons and helped put up the gazebo on a windy day, this time the gazebo did not blow away as previously experienced in Crewe.

(By Amy Phillipson)

In April this year I thought it would be a good idea to sign up to the Great North Run – a half marathon from Newcastle to South Shields - in a bid to get fit and raise money for the MNDA in the process. Coming from a girl whose main form of exercise was walking from the sofa to the fridge was sure to be quite a challenge! I was lucky enough to secure a 'golden bond place' through the association, running for the Cheshire branch specifically.

On the 1<sup>st</sup> May 2011 my 20 week training program began. I was full of excitement, enthusiasm and energy and headed out for my first training session. Unfortunately it only lasted 11 minutes before I genuinely thought I was going to pass out. I was even more unfit than I first thought.

I ran four times a week and swam once, increasing my distance and speed gradually. My fitness did start to improve and I was soon running for 30 minutes at a time AND enjoying it! Unfortunately it wasn't all plain sailing though - I injured my ankle during a run which resulted in six weeks out of training.

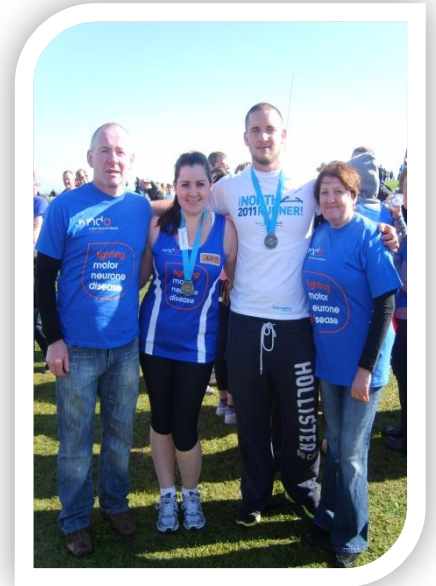
When I finally got back into training I took it slowly but my fitness soon began to improve and I was able to achieve 10 – 12 miles each Sunday with some shorter runs in the week. Two weeks before the race I injured my foot (the opposite one to the original injured ankle) so I rested until the day of the race to make sure I'd be able to compete – I was determined all my hard work would not be for nothing!

The weekend of the race arrived, myself and my family (including my sister's boyfriend, Nick Askey, who also ran for the Cheshire branch of the MNDA) travelled to Newcastle full of excitement and on my part, nerves!

I was one of 54,000 runners on the day and the atmosphere was incredible. Before I knew it we were off – a mass of people running in unison through the streets, cheered on by spectators at the side of the road, on foot bridges and from nearby house windows and it didn't stop there. The last few miles of the race is through residential areas and in true community spirit local residents had set up tables outside their houses with a variety of goodies to keep us going – water, juice, sliced fresh orange, homemade sausage rolls and jelly babies to name just a few! Some had even brought their hosepipes out in an attempt to cool us down as we ran (or in my case, staggered) past.

There was one moment at about mile 10 where a lady in a wheelchair handed me a much needed bottle of water and whilst cheering me on told me if she could run the last few miles for me, she would. This was all the encouragement I needed to remind myself how lucky I was to even be attempting such an event and allowed me to pull together the last bits of energy I had left in me and cross the finish line in a time of 2 hours and 42 minutes.

Despite all the blood, sweat and tears that went into the training for this I really did enjoy myself and I am proud that I was able to complete it both on a personal level and for the amount of money raised. My original target was to raise £400 for the MNDA. To date I have raised £1678 – a figure I had never dared dream of. Combine that with the £500+ Nick has also raised and we have smashed the £2000 mark – all coming back directly to the Cheshire branch of the association.



Amy with Nick Askey and her mum and dad

## Newsletter

If you would like to receive your newsletter by email then please contact Hal Bailey on

[hal@mndcheshire.org](mailto:hal@mndcheshire.org)

## Committee Stuff

We have a vacancy on the Committee, so if you know of anyone who would like to fulfill the role of Publicity Officer please contact anyone on the committee



**Cuts Watch – Act now to protect vital services**

The Association has launched a new online interactive map [www.mndcampaigns.org/cutswatch](http://www.mndcampaigns.org/cutswatch) showing essential services that are being cut, reduced or changed and as a result are impacting negatively on people with MND.

If you are affected, or know people with MND who are, please tell us your story anonymously, if preferred, by completing the enclosed leaflet

The date of the next committee meeting is 2<sup>nd</sup> February 2012

## Financial Stuff

Summarised Accounts as at 31 <sup>st</sup> October 2011			
Income		Expenditure	
Item	Year to Date	Item	Year to Date
General Donations	6,228.79	Financial Support	5,103.48
In Memoriam Donations	1,739.98	National Office	17,854.10
Corporate Donations	613.35	Support Meetings/Admin Cost	987.25
Fund Raising	3,495.94	Publicity	1,538.81
Gift Aid	12.20		
		<b>Total Expenditure</b>	25,483.64
		<b>Surplus/Deficit</b>	<b>-13,393.38</b>
<b>Total Income</b>	<b>12,090.26</b>	<b>Total</b>	<b>12,090.26</b>

## The €uro Bailout Explained

It is a slow day in a damp little seaside town. The rain is beating down and the streets are deserted. Times are tough, everybody is in debt, and everybody lives on credit.

On this particular day a rich German tourist is driving through the town, stops at the local hotel and lays a €100 note on the desk, telling the hotel owner he wants to inspect the rooms upstairs in order to pick one to spend the night.

The owner gives him some keys and, as soon as the visitor has walked upstairs, the hotelier grabs the €100 note and runs next door to pay his debt to the butcher.

The butcher takes the €100 note and runs down the street to repay his debt to the pig farmer.

The pig farmer takes the €100 note and heads off to pay his bill at the supplier of feed and fuel.

The guy at the Farmers' Co-op takes the €100 note and runs to pay his drinks bill at the pub.

The publican slips the money along to the local prostitute drinking at the bar, who has also been facing hard times and has had to offer him "services" on credit.

The hooker then rushes to the hotel and pays off her room bill to the hotel owner with the €100 note.

The hotel proprietor then places the €100 note back on the counter so the rich traveller will not suspect anything.

At that moment the traveller comes down the stairs, picks up the €100 note, states that the rooms are not satisfactory, pockets the money, and leaves town.



[mndconnect@mndassociation.org](mailto:mndconnect@mndassociation.org) MND Connect offers support, information and advice to: People living with MND, Health and Social Care Professionals, staff and volunteers

Kathy James is the Association's **Regional Care Development Adviser** (RCA) working in the Branch area, who has detailed knowledge of the care and management of MND.

Kathy can be contacted on 0845 375 1832, or email: [kathy.james@mndassociation.org](mailto:kathy.james@mndassociation.org)

## Branch Contacts

Chair	Joel Millett	01625 525409	<a href="mailto:joel@mndcheshire.org">joel@mndcheshire.org</a>
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## Association Visitors

Ann Barlow	01606 891027	<a href="mailto:ann@mndcheshire.org">ann@mndcheshire.org</a>
Joel Millett	01625 525409	<a href="mailto:joel@mndcheshire.org">joel@mndcheshire.org</a>
Amy Phillipson	07870 199435	<a href="mailto:amy@mndcheshire.org">amy@mndcheshire.org</a>

## Important Notice

*If you know anyone living with MND or a carer of someone living with MND and they have not had any contact with the Branch, please pass on your copy of the newsletter and encourage them to make contact with us. All our contact details are shown above.*

*Would you like to meet us at one of our informal get togethers for tea and cake in and around Cheshire – two of our venues are Hotels and one is a Garden Centre. These are very friendly and positive meetings with an exchange of ideas and hints and tips.*

*Again we would love to meet you, and if you think this is for you please contact us.*



We never lose hope. We strive to find a cure for MND and to support everyone affected by this devastating disease