

Northamptonshire Branch

Autumn 2020



**Welcome to the Autumn edition of
our local branch newsletter**

WELCOME

Welcome to the Autumn edition of the Northamptonshire branch of the MNDA. It is continuing to be a very difficult year for everyone and I am sure that we are thinking about each other and how well we are all keeping.

I must apologise for the late arrival of the newsletter but there were a couple of items that needed to be included so I had to wait for them. Please let me have anything which you think might be of interest to others in the group. We are in the process of getting an accessible shower room installed and I know that I would have valued other people's ideas and experiences (not to mention problems!) If you have found anything helpful I would love to include your stories. I will certainly let you know how we get on.

A big thank you to Pat for her article on voice banking. It is wonderful to have a personal account of what it is like and Pat's is very entertaining as well as informative. Also, we have a recipe from the archives! If people are interested, we will include more in the future. I think simplicity is the main factor. Whether our own ability to cook is diminishing, as it is in my case, or someone is having to cook for perhaps the first time, it would be good to find a few easy and fairly fool-proof recipes.

Very best wishes to everyone. Keep safe and hopefully we will meet again in the not too distant future.

Margaret Waller

MESSAGE FROM KATE

Hello Everyone

Another 3 months have passed and we are still in lockdown in one way or another, taking care, and staying safe whatever we are doing and wherever we go. We hope you are all keeping well and not getting too bored. We are not yet able to meet in our groups either at our open meetings or at the Drop-in, which I know is sadly missed by us all. We were hoping that it would be possible to make our first full meeting our Christmas Buffet Lunch but, as things are, that will not be possible. The next thing we may be able to aim for is the Annual General Meeting that takes place in April 2021. We will, of course, let you know of any changes made either by phone, email, newsletter drop or website so keep checking www.mndnorthants.org.uk

I know our AVs are keeping in touch with you all, but please let us know if there is anything we can help you with in the meantime.

Kate Inchley

Review of Regional Roles 2020

Reviewed roles at National Office

SERVICE DEVELOPMENT MANAGERS (SDM)

To create, manage and develop relationships with key national (Wales and Northern Ireland) and regional service providers, commissioners, stakeholders, partners and policy decision makers in order that services can be developed and improved by using evidence gathered locally to identify gaps, delivery issues as development opportunities and to resolve or address them through.

The SDM outside London is:-

Scott Maloney 01604 800634

AREA SUPPORT COORDINATOR (ASC)

The ASC covers a distinct area or patch and, through prioritised deployment of volunteers, services and their own time ensures that people affected by MND are supported and empowered in accordance with their needs.

The ASC for Central Midlands is

Neil Penson 01604 611893

Mission 5000

WE are on a mission and we need your help to join us. Together we want to cover 5000 miles for every person living with MND in the UK today. Take part and run, walk, swim, cycle or even scoot however far you can. Mission begins on September 13th 2020 and runs for 5 weeks. Cover as many miles as you can over the period or on a single day or week. HOW FAR WILL YOU GO?

We expect to lose 2million pounds this year due to the Coronavirus pandemic. Our fight against MND cannot be delayed: people affected by this disease need our support now, they need their voices heard today; people facing MND in the future need vital research to continue. Every penny raised from Mission 5000 will bring us closer to achieving our ultimate mission:

A WORLD FREE FROM MND

Have a look and register at the website

www.mndassociation.org/mission5000

We're looking for people to join a brand new virtual fundraiser to support the Northants branch called Mission 5000. Along with the MND Association, national office branches and groups across the country we want to unite the whole MND community and cover 5000 miles. That represents a mile for every person living with MD in the UK. Participants can join the challenge and run, walk, swim, cycle or scoot (any way you choose) to do their miles between September 13th and October 18th. Every penny raised will help us achieve our ultimate mission- A world free from MND

Sign up by visiting www.mndassociation.org/mission5000

Kate Inchley

Just Giving

In the light of the present situation, the MND Association, along with many other charities, and our local Northants Branch are not able to fundraise in the usual way with face to face events. The Northants Branch have set up an Emergency Just Giving Page, as we still need to support people living with MND and their families in the county by providing vital equipment needed to make their lives more comfortable. This is needed more than ever. Should anyone wish to support us in this way so that we can continue this support please go to

MND Association Northants Emergency Appeal.

Thank you.

Kate Inchley

Christmas Cards

As usual, we will be selling our MND Christmas cards etc. You should have received a catalogue in your latest edition of Thumb Print. Have a look at the catalogue and, if there is anything you fancy, you can order online, by telephone, by post or send an order to us at

inchley@gmail.com or 01966 667616

And we will make sure they are delivered to you. Please be sure to indicate Northants Branch on your order if you order direct.

Kate Inchley

'The Voice will be with you– always'

(My apologies to Star War fans for the corrupted quote)

Soon after my MND diagnosis I read about Voice Banking. It sounded (no pun intended) a good idea and I was keen to have a go at it while I still had a voice.

Scott Maloney arrived at our home with a computer already set up with the 'Model Talker' program and a headset– all courtesy of MNDA. All I had to do was record my voice. Simple? Well, yes and no. The first step was for the computer to measure the silence in the room. It had to be at a certain level or recording could not start. There followed a trial to make sure my voice was suitable. About a dozen or so sentences appeared on the screen and I had to repeat these to the computer. The computer decided I *was* a suitable candidate so then the real work was about to start.. Scott left me with written instructions and assured me he could be contacted if any problems arose.

The first stage consisted of recording 250 sentences. On the left of the screen were 3 columns of dots and these changed colour according to the quality (clarity/sound level/pronunciation etc) of the recording. If they showed green, the recording was perfect; red, it was no good and had to be done again; yellow– acceptable but could do better! I was told the first column must *always* be green but not to worry too much about the others. (You may have read an article on voice banking in the recent edition of Thumb Print where the system had 4 columns of dots.) A (misplaced) sense of pride meant I was determined that all 3 columns would be green– something I achieved at the beginning but later came to abandon.

I raced through the 250 sentences (all 3 columns green!) and when complete they were submitted to a 'Model Talker' for approval. A voice could have been 'built' from these but to get a better result, it was recommended I continue to the next stage comprising 3000sentences/phrases. This was a bit daunting and this is where my enthusiasm and desire for 3 dots started to fade– except in the first column where they were essential. If I didn't get that green dot, I'd repeat the sentence. To me, it sounded exactly the same the second (or third, sometimes fourth!) time but the computer obviously thought otherwise.

The upside is that this doesn't have to be done in a hurry. I'm told many people do about an hour a day. The computer remembers exactly where you stop each time. Silence is measured at the start of each session so it's probably best not to have the builders in the house as we did! Our house was being adapted at the time so I always had to wait for the workmen to leave each day. It was lucky for voice banking– if not so good for building progress– that the men usually left early afternoon.

Most of the sentences and phrases seemed to be taken randomly from children's books. 'Little Women' with the March sisters featured heavily. Apparently it's not the *words* themselves that matter but these sentences encompass all the *sounds* in our speech and the voice is made from these sounds. Towards the end of the exercise the phrases became shorter and in some cases there was just a single word.

Phew– recording complete at last. This, however, was not the end. There was then the opportunity to add family names along with any phrases I often use. The family were quick to make suggestions for those! My grand-daughter was keen that I include "Not funny, Grandad", which is our regular joint response to my husband's frequent "jokes".

At last the whole thing was complete and submitted to 'Model Talker'. After a few weeks I was sent 2 versions of the voice. Each could still be tweaked a little and I had to choose which was the nearest to my voice. It's recommended that several people are involved in this stage so assorted members of my nearest and dearest aged from 17 to 70+ gathered for what turned out to be an hilarious evening with much good-natured disagreement on the best version of the voice. In the end we settled for a majority verdict rather than a unanimous one before pressing the button to complete the process.

My synthetic voice is now banked and will remain so until such time as I need it. When that time comes I sound a bit like me rather than Darth Vader. If you can, do have a go at voice banking, then *your* voice will be with you– always.

Patricia Blenkinsop

Carer's Bed for sale



Leeann Mann has a carer's bed which she is hoping to sell. It is only 6 months old and has had little use. It is 6ft in size and it is a full carer's bed for sale with or without the mattresses. It is offered for sale at £1700 or nearest offer but must be collected from Brackley.

If you are interested, please contact Leeann at leeannmann76@icloud.com

Or 07415103644 or 07590 609173

Request from Head Office

Juliet Seward, Trusts Fundraising Officer at Francis Crick House, has asked me to ask for people to share their experiences of being helped by the MNDA. Obviously, when trying to raise money, it is good to be able to show how people have benefitted from funds raised. I am sure that we have all been helped in many different ways by the MNDA in our daily struggles and if you feel able to share these stories then Juliet really wants to hear from you. She quoted one example where someone made a large donation and, when shown the impact on someone's life of the rise and recline chair he had donated, promptly put his hand in his pocket again!

She is particularly keen to hear about how AVs have helped people so that they can continue to fund recruitment and training of AVs. If you feel able to share your stories, then please contact Juliet at Francis Crick House or get in touch with me (Margaret Waller). Thank you.

Juliet Seward
Trusts Fundraising Officer
Motor Neurone Disease Association
Francis Crick House, 6 Summerhouse Road,
Moulton Park, Northampton, NN3 6BJ, UK
Tel: 01604611821
juliet.seward@mndassociation.org
www.mndassociation.org

Cookery Corner

(from the archives!) The recipe for this newsletter comes from Marion Lees. She assures us that, surprising as it seems, this pie really works.

Impossible Pie



Ingredients

4eggs	1/2 tspn baking powder
1/4cup (2oz) margarine	2 cups milk (3/4– 1scant pint)
1 cup white sugar	1 cup (3oz) coconut
1/2cup (2oz) plain flour	1 tspn vanilla essence
1/4 tspn salt	

Method

Blend ingredients together and pour into 10” buttered pie dish. Bake for 1 hour at 180°C or 350°F or gas mark 4

When cooked, the crust will be at the bottom, custard in the middle and browned coconut on the top, exactly as they should be!

SERVICES EXPLAINED

Motor Neurone Disease Association, PO Box 246, Northampton, NN1 2PR

Telephone: 01604 250505

Membership—This is free to people living with MND and their carer. As a member of the Association you will receive a membership card, our regular magazine *Thumbprint*, full of information—the latest news in care and research as well as features on how some families cope daily with MND. Automatic link to your nearest branch/group and opportunities to get involved at a local level. Invitations to the conferences and seminars we organise. Our *Annual Review/Impact Report* which outlines our progress made over the last financial year and our plans for the year to come. Full membership also entitles you to elect Association trustees and vote at the Annual General Meeting. If you are interested in becoming a member, please contact MND Connect.

MND Connect— 0808 8026262—a helpline available Monday-Friday 9am-5pm, 7pm-10:30pm (charged at local rate) and email service mndconnect@mndassociation.org. Provide advice on all aspects of MND. They can also post information about MND and support available.

Regional Care Development Advisor (RCDA) Scott Maloney— 07501 682095 scott.maloney@mndassociation.org— assisting with advice and support on care management and service development in your area.

Volunteering Development Co-ordinator (VDC) Neil Penson 01604 611686

neil.penson@mndassociation.org VDCs work with existing branches and groups to develop and build on good practice. This includes the recruitment and induction of branch officers.

Equipment Loan— a limited range of equipment is available where not obtainable from statutory services. Requires a written referral from the relevant health or social care professional.

Financial support— towards items not available from statutory services. Requires referral from relevant health or social care professional.

Registered Office: Motor Neurone Disease Association

David Niven House, 10-15 Notre Dame Mews, Northampton, NN1 2BG

Registered charity number— 294354

Northamptonshire Local Branch

Open Meetings Local support from people in the area who are familiar with the effects of MND. The branch holds bi-monthly meetings for anyone with, or interested in, MND at St Matthew's Church Parish Centre (Contact details on next page)

Association Visitors (AVs)— are volunteers who offer advice and support to anyone affected by MND, either face to face, via telephone or by email. Please contact your RCDA on the number above for more information.

Social Gatherings are occasional opportunities for people affected by MND to come together informally in a safe, friendly environment. Transport can be arranged if necessary.

Lunchtime Support Group is another opportunity to meet informally to share experiences.

It is usually held on the 1st Wednesday of every month at the restaurant in the Garden Centre (next to Waitrose), Newport Pagnell Road, Wootton, Northampton, NN4 6HP. There is no need to book— just come along but, if possible, arrive by 11:45. Free for anyone with MND and their carer.

NORTHAMPTONSHIRE BRANCH CONTACTS

Patron: Dr John Smith

Chair	Kate Inchley	0193366716 inchleyk@gmail.com
Vice Chair	Robert Nixon	01933 229602 robchnixon@talktalk.net
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Branch Contact	Kate Inchley	01933 667616 inchleyk@gmail.com
Newsletter	Margaret Waller	07460 670655 margaretmwaller@hotmail.co.uk

Association Volunteers (AVs): Joan Randell, Angela West, Margaret Robinson, Annette Liddon, Heidi LeBon and Deborah Bull

Committee Members: Kevin White, Jackie Atkins, Dave Atkins, Maureen Sanders, Priscilla Davies, Sally Wilkins and Diana Smith

Website: www.mndnorthants.org.uk **email:** enquiries@mndnorthants.org