msa news

MSA Trust Members Magazine | issue 53 | October 2018

Keeping all lines of communication open

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Welcome to issue 53

A warm welcome to your Autumn MSA News. In this issue we focus on communication, something which members tell us is of vital importance.

As ever, we also have lots going on. Jane Stein, our new Advocacy Officer, has been supporting a growing number of people with a range of non-medical issues. These include benefits, accessing equipment and grants and liaising with carers organisations. Look out for her article on Page 11.

We also welcome Marina Frias Padron our new Services Assistant and Henry McGinty our new Community and Events Fundraiser. No doubt you will be speaking to them if you call us in the future.

We know it seems early, but please do look at our Christmas card order form on our back cover. The Trust relies on these cards to both support Fundraising and to raise awareness, so buying them really helps us.

Finally, we were successful in getting an environmental grant from the City Bridge Trust. They noted our existing good work but proposed other things that could help us become carbon neutral. We will take these forward and if any of you have any other suggestions, please do let us know. With best wishes, Emma and Andy. msa *news*

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Sarah's Wood *Summer* Event

Karen Walker, CEO of the Trust, reflects on our Sarah's Wood summer event and outlines arrangements for the winter tree planting dates.

"What an incredibly hot, dry summer it was and how clearly this was demonstrated at our summer event at Sarah's Wood.

We gathered at the Wood on a Saturday in July to unveil our new signage, kindly donated by Sarah's sister, Margaret. Not only will the sign mark the Wood, we also hope it will encourage people walking by to find out more about MSA.

Our host, Hugh Matheson, explained that although the wood looked parched, the Oak trees would be conserving their energy in their base root and would be working hard to stay alive under such harsh drought conditions. This certainly appeared to be the case as after my return visit in August (and following lots of restorative rain) many green shoots were spotted on the saplings.

As you can see we had a lovely afternoon of conversation, tea and cake in the garden at Thoresby Park. Many thanks to our volunteer Stella Herbert, her grandchildren and members of the Sherwood Rotary Club, who provided cake and served tea to our guests. Your help was very much appreciated.

At the gathering the possibility of 'naming' a stone or brick was discussed amongst those who have planted trees in the wood. These would be laid into a path which would enable people with MSA to get deeper into the site and enjoy the tranquility that being in Sherwood Forest offers with their friends and family. The stone would have a person's name on it, but no other information. They would be of a standard to be wheelchair accessible and would be smooth to ensure all could access the site. At present we are preparing costs and logistics, so please bear with us and we will get information onto the website soon." msa *news*

In the meantime, we do hope that many of you will come along to our tree planting days this winter and put a sapling in the ground. The planting dates we are offering for this year are:

24th November 2018 & 25th January 2019

Registration for these and information about how to access the Wood at other times of the year, is available on our website - **www.msatrust.org.uk/get-involved/sarahswood**.

Communication Matters

Gradual but growing difficulties in communication, both speech and non-speech, can be a common theme for people living with MSA. Jill Lyons, our MSA Nurse Specialist, looks at how support can be provided if this starts to become an issue for you.


PICTURE COURTESY OF ABILIA

Many people with MSA experience difficulties in communicating with others. Speech impairment can be an issue, as can the fact that communication can become extremely tiring and take a lot of effort.

Whilst responses to these issues are invariably specific to the individual, there are a range of options that might help.

The very first step if you are having difficulties is to be referred to a Speech and Language Therapist (SLT). Our interview with Anna Pandanjac on page 8 explains how to go about this but essentially you should ask your GP or healthcare professional to refer you. Your SLT will be skilled in assessing any individual challenges you may have and will be able to suggest potential solutions. For example, they may recommend things that are specific to you such as making the most of your body language, pointing, signing and facial expressions. They may also suggest vocal exercises that you can practice to make your speech clearer and stronger.

There are other simple techniques that can facilitate better speech communication. For example, you may find that you have times of the day when you feel more able to talk, so make the most of these. A quiet and well-lit environment where people sit at the same level can help, as can making sure there is ample time to speak about the things that are important without rushing or feeling under pressure.

There may also be low-tech and high-tech communication aids that can help. Low–tech aids include simple, non-electronic tools such as word or image pointer boards, notepads and whiteboards. Have a look at a members' communications booklet on our website for a good example - **www.msatrust.org.uk/support-for-you/living-with-msa/communication**.

High-tech communication aids include speech-to-text and text-to-speech communication devices and software for smartphones, tablet computers, laptops and personal computers. Some equipment can also be controlled by eye-gaze, although this can sometimes be difficult for people with MSA.

Augmentative and Alternative Communication (AAC) services can be funded by Health Authorities. They may also integrate with other services that use technology to allow people to control other devices such as computer equipment, TV controls and light switches. Below outlines the process to see if you would benefit from a communication aid:

- ***Your SLT and any other relevant professionals should undertake an assessment and offer any suitable communication aids they offer locally***
- ***If they feel you would benefit from referral to further AAC services, your SLT should complete this referral***
- ***If accepted, a member of the AAC team will visit you and undertake an assessment of your needs***
- ***They will write to you with the results of this assessment***
- ***If they have recommended any loan equipment for you, they will visit again and work together with you to train and assess you using the equipment***
- ***If suitable, they will provide loan equipment for your use, and review this regularly to check that your needs are being met.***

Our MSA Nurse Specialist, Emma, recently sat in on an assessement. She said:

"I observed this process with a person with MSA; a full assessment of needs was performed, and equipment controlled by a button, or switch, recommended and tried. After further assessment, it was felt that rather than using a switch to control the speaking aid and environmental control equipment, some eye-gaze technology equipment would be more suitable. This was provided and assessed, and the person with MSA is now able to control the TV channels and music player, turn light switches on and off, and communicate using this specialist equipment. Such equipment can also provide the opportunity for the user to make phone calls, browse the internet, read e-books, or listen to audiobooks."

There is no 'best' type of communication aid as individual preferences, abilities and needs can vary. Assessment by a qualified SLT is important as some aids can be very expensive and will not suit everyone.

There are new developments with communication aids all the time. Communication Matters run roadshows that offer the opportunity to look at the latest equipment from different manufacturers. You can find out more about these here - **www.communicationmatters.org.uk/page/road-shows**.

We are also able to loan out communication aids called Lightwriters which are helpful for some people. A Lightwriter is one piece of equipment which might be recommended after an SLT assessment. In certain circumstances we can offer help with small grants towards the cost of communication equipment.

Some people find it useful to have care and daily life preferences in a booklet or folder to save repeating information. This is useful for professional carers to help them get care right and it may help if the number of carers is limited so they can get to know the person and their communication techniques better. It is important to remember that not all communication is verbal or text based and people communicate in other ways. Family members and friends are often able to understand each other with minimal words or text and this is really important when verbal communication is difficult.

msa *news*

If you have any questions about anything included in this article please contact your MSA Nurse Specialist at **support@msatrust.org.uk**.

ARTICLE BY MARK FIDLER

Back to the Skies

Having been diagnosed with MSA in 2016, I never thought I would fly again. That was until a good friend drew my attention to 'Aerobility', the flying charity based out of Blackbushe Airport in Camberley, Surrey. After one email was sent, I got a fast, simple response "we'll get you flying again".

> ***Flying was always my passion.*** *Fifteen years as a commercial pilot and with approximately 7,500 flying hours, I guess you would call that fairly experienced. I have flown Trilanders, Boeing 737s and was latterly on Boeing 777s.*

One quick phone call arranged a trip on a PA 28 Warrior (similar to the aircraft I had trained on in Florida, seventeen years before).

I didn't know if I could still fly. "Would the acceleration forces be too great? Had I forgotten what to do? How would I get myself into the plane?"

All these thoughts raced through my mind, plus more.

On the day, my instructor JJ was ultra-patient with me. I have little mobility in my legs, so I got stuck half way up the wing opposite the door!

How was I going to get in the cockpit? It all looked tantalisingly close, the cockpit layout still very familiar after all these years. If required 'Aerobility' would have used a full hoist to get me in. My instructor, screwdriver in hand, was prepared to take the door off! No need, motivation drove me to find my way.

I got in and settled down, everything was familiar, a promising start. Finally, pre-flight checks done, it was time to start the engine. I'd forgotten how loud it was being right in front of your face! Then it was time to take-off, the moment of truth! We opened the throttle and sped down the runway. I shouldn't have worried, all was OK, taking off was as exhilarating as ever.

I was fine, half an hour later I found I could still hold a heading, hold an attitude and altitude, so very pleased. It felt wonderful to be airborne again.

I did some turns successfully, and I felt like a pilot again. We landed uneventfully, and I taxied in, parked and turned the engine off.

It brought back a lot of good memories, from the beginning of my flying career fifteen years ago. I had done it… not a bad performance for a first flight post diagnosis. Next time I'll do the landing and take-off.

You don't have to be a commercial pilot to fly with 'Aerobility' they can get you airborne at any stage- especially absolute beginners. So, if this has been your ambition, there is every encouragement, Aerobility will completely support you and I thoroughly recommend them.

"Aerobility strives to remove the barriers - physical and financial- that prevent individuals with any form of disability from enjoying the thrill of flying" (Aerobility 2018) - **www.aerobility.com**. msa *news*

FEEDBACK FROM OUR RESEARCH COMMUNITY

Research Round Up

With our funded projects all underway we have much to report in this edition. From the work of our MSA ABN Research Fellow, the Prospect study and other research studies, four of our researchers share their updates with you:

PROJECT 1

***Professor Houlden**, currently carrying out a study looking into the 'Identification of Longitudinal Biomarkers in MSA':*

"Collaboration has been established with the Institute of Neuroscience in Gothenburg, Sweden and the UCL Leonard Wolfson Biomarkers Lab for the project into developing wet biomarkers. At the moment we are focussed on recruitment and so far over 50 people with MSA have donated their blood. We are extremely grateful to all the participants and hope others will follow."

PROJECT 2

MSA Research Fellow, Viorica Chelban:

"The PROSPECT-M study has reached its third year. Over 50 patients have joined the longitudinal arm of the study and over 90 patients are involved with the cross-sectional study at the seven recruitment centres. We have started the MRI scans for the third-year follow-up. This is the first longitudinal imaging data that extends to three years that we have conducted to date. Once all the patients involved in the study have had their scans completed we will start analysing the results. In addition to the imaging data, we are assessing the natural history of the disease and early signs that can differentiate MSA from other synucleinopathies."

PROJECT 3

***Professor Pavese**, was awarded funding this year to complete a MRI (Magnetic Resonance Imaging) project looking to improve initial diagnosis of MSA:*

The project had a short delay while a software update was implemented for the MRI PET scanner. While this was happening, the team were recruiting a Clinical Research Associate to undertake the study and develop the ethics application. In addition to this study, Professor Pavese has received a grant from Parkinsons UK to use a similar imaging approach in patients with REM Sleep Behaviour Disorder (RBD). This has great potential benefit for MSA, as he explains: "We feel that these two studies strongly complement each other and together, if performed in parallel, will significantly increase our knowledge of the early pathological changes occurring in these different types of synucleinopathies."

PROJECT 4

***Professor Holton**, based at the Queen's Square Brain Bank, is conducting a study into 'Understanding selective brain regional vulnerability in MSA':*

"We are continuing our work investigating whether epigenetic changes, that may influence the activity of genes and thus alter the amount of proteins produced from the DNA code, are important in causing nerve cell damage in MSA. We have put together a team of researchers with complementary experience in this developing field and we are very pleased to welcome Dr Conceição (Sao) Bettencourt, who has been employed using this grant to work on the project. Sao has extensive experience in the field of MSA and genetics and she has the necessary bioinformatics skills to analyse further the data that we have already generated." msa *news*

THE ROLE OF A SPEECH AND LANGUAGE THERAPIST

How I help people

Anna Pardanjac is a Speech and Language Therapist (SLT) working within an NHS Trust in the South East of England. Anna has been a qualified SLT for four years and is community based, which means she works in hospital wards, clinics, and visits people where they live. Here she explains her role and how she can help people affected by MSA - Thanks Anna.

ANNA PARDANJAC,
SPEECH AND LANGUAGE THERAPIST

1

What's the route you've taken to become a SLT?

I completed a four year undergraduate degree with Cardiff Metropolitan University and qualified four years ago. You'll often find that most community based SLT's have more generalised expertise working with a variety of conditions, although there are some that sit within a Multi-Disciplinary Team (MDT-a group of Health and Care Professionals) who focus on neurological conditions.

2

Where do SLT's sit within the NHS/ community?

Some SLT's sit within a larger MDT team which may consist of a Dietitian, Physiotherapist, Occupational Therapist etc. This is a great way of working as there is often an overlap between the roles of the professionals and it facilitates a collaborative approach to assessment and management. However, this isn't the case where I'm based as we are spread across a large county. We do still liaise closely with the other professionals, but the difference is that we are not based in the same room. It all depends on the Trust that you come under as they all have slightly different ways of working – which can be confusing!

3

How can people get a referral to a SLT?

Any healthcare professional can make a referral to a SLT service, so this could be your GP, District Nurse or MSA Nurse Specialist.

4

At what stage should people think about getting an SLT referral?

I would recommend that you get involved with an SLT as soon as possible after getting your diagnosis of MSA if you have noticed changes in your communication or swallowing. You might ask for a referral if you notice changes in your voice or speech, or you're having issues with swallowing certain foods or fluids. Another sign could be that you're not able to finish all your food, are experiencing weight loss or are getting recurrent chest infections.

5

What will SLT's do to support people with MSA?

Initially an assessment will be carried out to identify any current needs. We'll be looking at things like the consistencies of your food and drink and if these are easy to swallow. Education around swallowing and aspiration (which is when food or fluid has not fully cleared from the food pipe into the stomach and enters the lungs) will be given about how to look out for the signs and symptoms of this. We'll look at how your communication may be affected and think about future planning for this. We can also help explore what might be the best communication aid option for you. This could be voice banking (see more info on page 19) or equipment such a Lightwriter or apps for a tablet. We would support you with learning to use the communication aid and can also create paper based communication aids if these are more suitable for you.

6

What's the average length of time you work with people?

It completely depends on the person and what their individual needs are. If there are ongoing needs we would continue to work with you as long as needed but sometimes people just need advice on one particular issue, such as swallowing. However, again different areas of the country may work differently and give you a block of sessions. If you ever need a re-referral because things have changed then just go back to your GP or healthcare professional and ask to be referred again.

7

Is there anything friends and family can do to support people with speech and language therapy?

If a loved one's speech is affected then it's easy for you to try and help by finishing sentences or guessing what the person is trying to say. However, it's best to allow the person time to speak and respond in a conversation, try to reduce background noise and speak face to face to facilitate the communication. Part of an SLT's role is to support family members too, so we can help with things like training for communication aids.

8

What do you like best about your job?

I like how varied the role is and that no two days are the same. We are lucky to work alongside like-minded health professionals. We are focused on empowering the person with their communication and swallowing problems and we aim to support them through providing education and advice to aid in their decision-making around how best to manage these issues. This is very rewarding.

In Memory

Linda Warlow
Dorthe Gibbs
Robert Veness
Kathleen Brennan
Robert Cox
Gareth Williams
Debbie White
Raymond Hall
Janet Warrington
Fred Purvis
Irene George
Rosemary Jones
Brian Dalby
Raymond Whitcombe
Ron Emmerson
Alan Nicklin
Ian Welsh
Gordon Dunn
Graham Carter
Betty Osborne-Hewitt
Derek Littlewood
Gill Jones
John Hockaday
Catherine Russell
David Jones
Gillian Hastings
David Coomes
Jacqueline Copplestone
Kathleen Hawcroft
Malcolm Unett
Denise Precious
Ellis Jenkins
Mitchel Dunin
Reinhard Werner
Sylvia Kemsley
Maureen Winter
Veronica James-Thomas
Daniel McNally
Denise Thomas
Razia Mir
Naresh Sharma
Ann Yates
Robert Thompson
Allan Davis
Mavis Holland
Elizabeth Brown
Fay Fox
Margaret Goodman
John Vickers
Colin Amery
Neville Mayall
Judy Eleanor Williams
Brian Corry
Colin Newbury
Ron Jenkins
Pamela Webb
Ian North
John Bayliss
Judy Field

Regularly *supporting* the Trust

We are always very grateful for one-off donations to the MSA Trust which can make a big difference to our daily work. However, it's regular donations that really allow us to plan and execute long term projects and give our work secure foundations. This is because we can be confident that you are committed to supporting us with your regular donation, both now and in the future.

Setting up a regular donation is easy, we provide the Standing Order form for you to complete, sign and return to us. We can also Gift Aid all the money you donate if you are a tax payer.

Setting up regular giving keeps our administrative costs to a minimum so more of your donation is used for our work supporting people affected by MSA.

Another effective way to donate regularly to the Trust is through Payroll or Workplace Giving. This allows you to give a portion of your salary to us before taxes are deducted. This means we receive a larger donation at no extra cost to you. To find out how to set up payroll giving just contact your employer's Human Resources or Finance Department for more details or have a look at our FAQ document on Payroll Giving for more explanation.

To receive the document or the Standing Order form email **fundraising@msatrust.org.uk** or visit **www.msatrust.org.uk/regular-giving**.

Whichever way you donate, please know that you are making a real difference to everybody affected by MSA.

msa *news*

For your benefit

Our Advocacy Officer, Jane Stein, is able to support people with their benefit entitlements. There are two main disability related benefits that people affected by MSA are likely to be entitled to, either Personal Independence Payment (PIP) or Attendance Allowance (AA), and Jane can advise about these. Here she looks at two other benefits available in the UK which may help you.

Council Tax Reduction and Exemption (England, Scotland and Wales only)

Council tax reductions and exemptions are not well known about or understood which means you could be paying more than you should. You may be eligible to a reduction in your council tax payments if you:

- ***Have made adaptations to your home specifically for the use of someone with a disability or your home is wheelchair accessible***
- ***You have a room (other than a bathroom, kitchen or toilet) needed by the disabled person***
- ***You or another adult in your home is 'severely mentally impaired'***
- ***You are on a low income***
- ***You or another adult in your home is a carer (and they are not your partner)***
- ***You live alone.***

The rules vary across England, Scotland and Wales (and between different councils in England and Wales) so do check with your local council. Schemes tend to be more generous if you are over pension age and if you live in Scotland or Wales.

A very useful website: **www.counciltaxhelp.net** shows your local council, explains the local schemes and identifies where to get further advice. Just type in your postcode and click 'Go'.

Pension Credit

Pension Credit is a means tested benefit which often goes unclaimed. Receiving it can make a very significant difference to your weekly income. It can be paid to people who have reached the pension 'qualifying age' (which varies according to your date of birth). You can check your qualifying age by using the government calculator: **www.gov.uk/state-pension-age**.

Pension Credit is quite a complex benefit to explain but checking your eligibility for it is very easy. Just call the Pension Service on 0800 99 1234 and have to hand your National Insurance number and details of your income, savings and which benefits you currently receive. They will then check your eligibility and calculate any benefit due. **There is nothing to be lost by checking and maybe a lot to be gained.**

Pension Credit has two parts to it, Pension Savings Credit and Pension Guarantee Credit - Both can be paid together.

Pension Savings Credit (which rewards those who tried to save for retirement) is only available to people who reached state pension age before 6th April 2016 but claims can still be made.

Pension Guarantee Credit tops up income (not including Attendance Allowance, Personal Independence Payment or Disability Living Allowance amongst other things) to a minimum of £163.00 a week for a single person and £248.80 a week for a couple. It can be further topped up by additional amounts if you are in receipt of certain disability benefits, are a carer, or if you have housing costs.

Different benefits exist in Eire and some changes are being made to benefits in Scotland so please contact Jane on **0333 323 4591** if you would like information on this or on any other benefits issue. msa *news*

Finding a catheter that's right for you

Bladder difficulties and discomfort are to some degree experienced by almost everyone with MSA. Our Nurse Specialist, Katie Rigg looks into one particular option which can help people affected…

There are a range of medications that can improve bladder function and reduce discomfort and you may already be taking some of these. Alongside medication, people with MSA often need some form of urinary catheterisation to enable their bladder to empty properly. Using any catheter reduces the stress of making it to the toilet but with all catheters it is imperative to drink plenty to keep them working well.

There are three internal catheterisation options which the urologist will advise you about:

1. ***Intermittent self-catheterisation which is a thin plastic tube passed by yourself or your partner through your urethra into the bladder (the passage your urine normally flows through when you go to the toilet). This is removed each time after the bladder is emptied.***

2. ***A urethral indwelling catheter passed through your urethra by a healthcare professional, which is left in your urethra and held in the bladder by a water filled balloon. It is changed every 6-12 weeks.***

3. ***The final option is supra-pubic catheterisation, which this article focusses on.***

For many people the thought of having a supra-pubic catheter is daunting, as it can feel un-natural and more invasive. However, it can be a really good solution in the following circumstances:

- ***If you are struggling to continue to self-catheterise***
- ***If you have been getting lots of urine infections or blockages in your urethral catheter***
- ***Your urethra may be hypersensitive and not be able to hold a catheter***
- ***You are sexually active but you need a catheter***
- ***You need an option which makes a catheter easier to take care of, especially for wheelchair users***
- ***It's less likely to get sat on, caught or pulled when dressing or moving about***
- ***It's less likely to get blocked as larger catheter size can be used through the urethra.***

Insertion of the catheter

A Urologist will use ultrasound and special X-rays to determine the safe placement of the catheter, which is usually inserted using local anaesthetic. Once the area is numbed the Urologist uses a guiding device to pass through the abdominal wall into the bladder and feeds the catheter in over this then removes the guide. There is a balloon at the end of the catheter in your bladder that is filled with water and holds it in place.

You may be given a bag that is attached to your leg for the urine to drain into or you may simply have a valve on it that allows you to drain the urine into a toilet whenever needed.

Key care tips

If there are problems with drainage through the catheter within the first 4-6 weeks after insertion then the catheter should **not** be changed or removed. If necessary a urethral catheter can be sited temporarily and advice sought from the urology team.

The first catheter change, at around 6-10 weeks after insertion, should be done by the urology team because it takes a little while for the skin tract to form. After this your District Nurse will be able to do changes for you at home every 6-12 weeks. Any blood in your urine after a catheter change should settle after 24-48 hours.

The insertion site may be a bit sticky and weepy initially so a light dressing can be used and daily cleaning with cooled boiled water is best. If the site is still sore and weepy after ten days a light smear of Sudocrem around the site after cleaning may help.

You can bath or shower as normal, though avoid soaking the site especially, in the first two weeks. Whilst in the shower, clean from the site down the catheter and gently rotate the catheter to keep it free within the bladder and help the skin tract develop.

Always wash your hands thoroughly before and after handling the catheter and bag tubing and try to avoid the connecting ends touching on anything.

Don't let the catheter bag get overfull as this will put pressure on the catheter and the skin site and reduce drainage. However, leaving a very small amount of urine in the bag can prevent the sides of the bag sticking together and forming a vacuum that prevents the catheter draining.

Strapping the catheter to the abdomen reduces pull on the catheter within the bladder and protects the skin site. Also, it is best to use alternate legs to attach the leg bag to as this slightly alters the catheter position in the bladder, so keeping it free and reducing pressure on the site.

Always carry a spare catheter with you in case your catheter falls out unexpectedly. If this happens you can go to the nearest emergency department, your GP surgery or call the District Nurse to replace it as soon as possible. msa *news*

For more information about catheters please contact one of our MSA Nurse Specialists:

Katie Rigg
North of England, Scotland and Ireland
01434 381 932
katie.rigg@msatrust.org.uk

Emma Saunders
Midlands and North Wales
0330 221 1030
emma.saunders@msatrust.org.uk

Jill Lyons
West of England and South Wales
01934 316 119
jill.lyons@msatrust.org.uk

Samantha Pavey
East of England
0203 371 0003
samantha.pavey@msatrust.org.uk

You can see an area map at: **www.msatrust.org.uk/nurses**.

IN YOUR COMMUNITY

Our Glasgow Support Group leader **Corinne Ingram** (middle) organised a Masquerade Ball in support of her brother, Leslie (also pictured) who has MSA. The evening was a great success raising £400.

Emma Jennings and **Kaye Jackson** organised a fundraising night in memory of their father, Jim Carruthers. The event took place at Kaye's Greenhill Hotel in Cumbria and raised more than £2,000.

Earlier this year, **Joanne** and **David West** hosted a barbeque and Afternoon Tea in memory of William Brooks, raising £560 for the Trust.

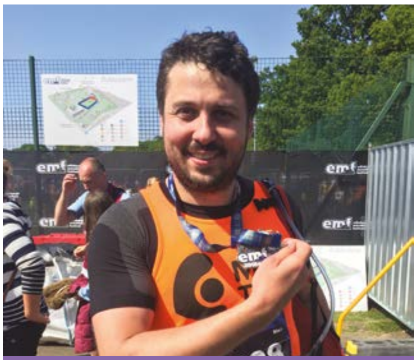
Rachel Bache has been kindly organising a Speed Quiz the last few years in memory of her mother Elaine Bache. The fundraising is closing in on £3,000 so far – well done!

Delia Kelly hosted a **M**ilk **S**ugar **A**nd **T**ea party in memory of Christopher Byrne, with her sisters, Laura and Lisa and mother, Bridget. They had an auction and raffle as well and raised a fantastic €1,800.

Below our MSA Nurse Specialist, Katie Rigg, collects the cheque.

Fundraising from tea parties goes towards our MSA Nurse Specialist service. To order your Tea Party pack email **fundraising@msatrust.org.uk** or visit **www.msatrust.org.uk/raise-a-cup-for-msa** for more information.

EVENTS THIS SUMMER



*Janice MacInnes's nephew, **Nik McKenzie** ran the **Edinburgh Marathon** in memory of Janice's father, Donald. It was a great day with more than £500 raised.*

__The British 10k__ was a great success this year. Our team included our very own Deputy CEO, __Andy Barrick__ and some of his friends.

The MSA Trust cheering team was at the 2018 __Great North Run__ this year, supporting our fantastic team of 15 runners!

__Ride London__ this year was a wet day but __Victoria, Heather, Amy, Charlotte, Andrew__ and __Alastair__ (in action!) all finished the 46 or 100 miles for MSA Trust. Well done and sorry it was so soggy!

TREKKING TO BEAT MSA

__Faye Coates__ and 12 of her family and friends climbed Pen y Ghent, Whernside and Ingleborough in memory of Faye's father Maurice Coates. They raised over £1,500.

__Suzanne Black__ and a team of 20 completed the Yorkshire Three Peaks Challenge in under 12 hours. They raised more than £2,000. The challenge was for Suzanne's mother, June, who has MSA. Well done Team June!

__Kelly Parkinson, Stacey Watkins, Nicki Stafford__ and __Kacey Jade Dent__ walked 84 miles of Hadrian's Wall with their dogs. This was in support of Christine Humpleby who has MSA. The walk was followed by a car boot sale organised by the community champion at Tesco Barnsley Extra where Kelly works. In total over £2,000 was raised.

__Sarah, Heath, Tom__ and __Tony__, from our corporate partners Dixons Travel, did the annual 100km endurance challenge called __Race to the Stones__. They crossed the length of the Ridgeway, the oldest path in the UK. Later in August __Debi Freeland__, branch manager at Dixon's Liverpool airport store, abseiled down Liverpool Cathedral.

EMMA RUSHTON PRESENTS HER REGULAR ROUNDUP OF YOUR TOP SUPPORT GROUP TIPS

Supporting & Helping Each Other

As we approach the end of 2018 we're on track to have run the most Support Groups ever in a year – approximately 140 meetings. Each one means that people affected by MSA have a place to share their experiences. That's all down to our fantastic Support Group Leaders and Nurses who organise meetings all around the country. Here is a selection of things that have been raised at recent Groups but please do also look on the next page to find a meeting near you.

At the Limerick Support Group a member spoke about an organisation called Family Carers Ireland which is a national organisation that provides advice and support to carers. They can assist with benefits claims - helping with completing forms, checking eligibility and will also support people through appeals if necessary. They also offer a free CareLine which offers practical help on a range of topics including respite care and available support from your local authority. The CareLine number is 1800 240 724 (Freephone) and further information is available on their website - **www.familycarers.ie**.

Katie Rigg, MSA Nurse Specialist, also visits Northern Ireland three times a year and at the Belfast Support Group issues around housing adaptations were discussed. Some people at the Support Group advised anyone having difficulties to contact the Lisburn Housing Executive. The organisation gives recommendations and advice on adaptations and grants for the whole of Northern Ireland. More information can be found here - **www.nihe.gov.uk**.

Difficulties understanding what might be the best car adaptations for people with MSA is a common theme at Support Groups. At the most recent Etton Support Group in East Yorkshire our MSA Nurse Specialist, spoke about a move within Motability schemes to steer people towards purchasing hoist attachments on the passenger side to get people in and out of car. This is cheaper than a wheelchair adapted vehicle (WAV) adaptation however, this can be a difficult option to manage as the person is in a hoist in a confined space and getting them positioned well can be tricky. The key message here is to make sure you try it out at the centre before committing to anything. Whilst WAV's are more expensive it might still be the best option as they will last a long time, the person with MSA can sit comfortably in their wheelchair for the journey and it's easier to manage for carers. You can find out more about adaptions to vehicles here - **www.motability.co.uk/cars-scooters-and-powerchairs/adaptations-overview/adaptations-available-on-the-scheme**.

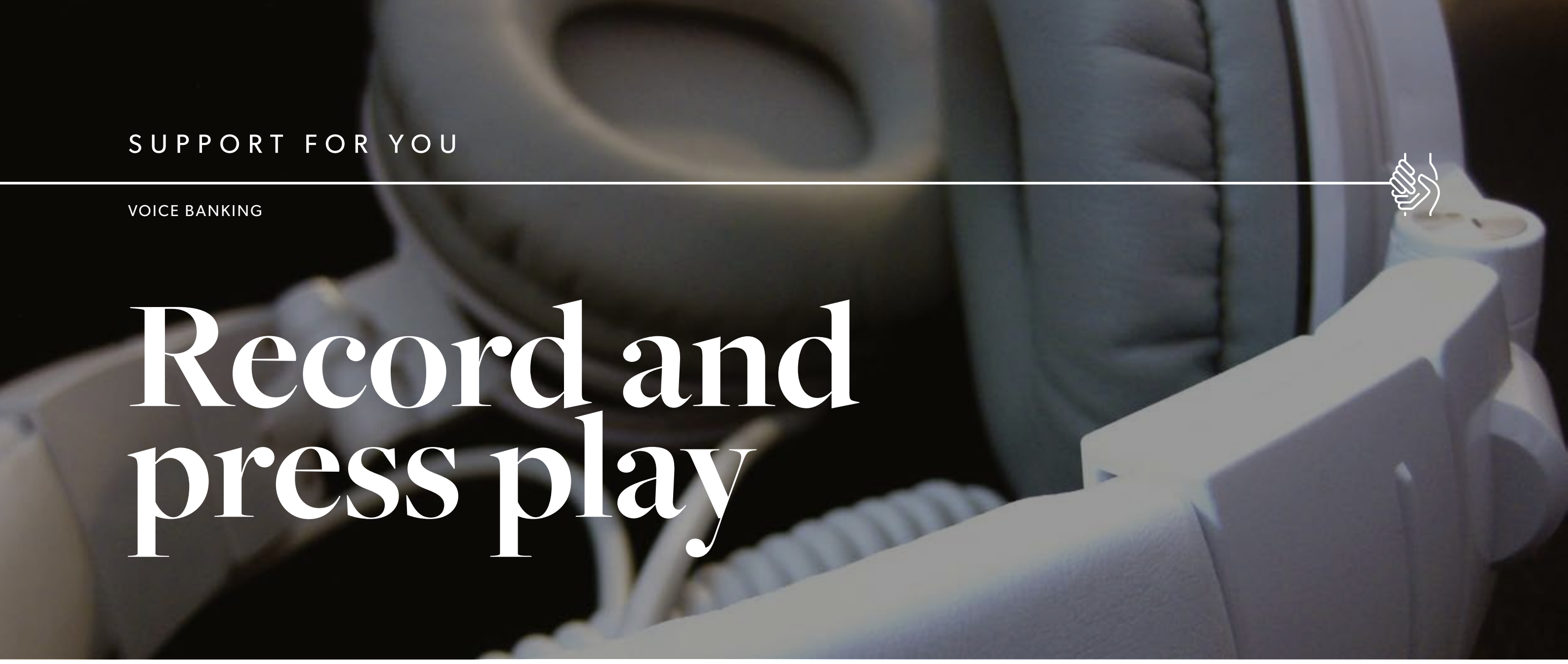
At both the West Yorkshire and Cumbria Support Groups the management of saliva was discussed. If too much saliva is a problem then Atropine eye drops can be helpful when used under the tongue. These are used because a side effect of the eye drops is the drying of secretions. Most GPs will prescribe these drops for this purpose though they are not obliged to as this use is not what they were licensed for. Discuss this with your GP or Neurologist as it has positive results for a lot of people and could be an option for you.

The South London Support Group held its second meeting and a very useful, practical tip from a member was to use 'grabbers' to help with picking up things if bending down is difficult. The family found it helpful to keep one in every room so they were accessible at all times. These can be bought online from a range of websites and cost around £7-10. msa news

If you have any questions about anything included in this article please contact your MSA Nurse Specialist at **support@msatrust.org.uk**.

Support Groups are a great way to meet other people affected by MSA, listen to presentations from healthcare professionals who can support you and meet our MSA Nurse Specialists. Please contact the Trust's office on 0333 323 4591 or email support@msatrust.org.uk for more details. These groups are subject to change, so please check the Trust's website or ring the office for up-to-date information.

GROUP	VENUE	DATE & TIME
Dublin	St. Francis Hospice Raheny, Station Road, Raheny, Dublin 5	Tue, 16 Oct - 1pm
South Yorkshire	St Peter and St Paul Church Hall, Todwick, Sheffield S26 1HN	Wed, 17 Oct - 1.30pm
County Sligo	Therapy Room, St John's Community Hosptial, 8 Ballytivanan Road, Sligo	Wed, 17 Oct - 1.30pm
County Limerick	Nurses Residence, Western Regional Hosptial, Limerick	Thur, 18 Oct - 2.00pm
Kent	Room B028 Blake Building, Medway Campus, University of Greenwich, Central Avenue, Chatham Maritime ME4 4TB	Thur, 18 Oct - 11am
Essex	Great Tey Village Hall, Great Tey CO6 1JQ	Mon, 22 Oct - 2pm
Cornwall	Carnon Downs Village Hall, Tregye Road, Carnon Downs, Truro TR3 6GH	Tue, 23 Oct - 1:30pm
Devon	Baptist Church, High Street, Cullompton EX15 1AA	Wed, 24 Oct - 2pm
Norfolk/Suffolk	Roydon Village Hall, High Road, Roydon IP22 5RB	Wed, 24 Oct - 2pm
County Durham	Chester Le Street Hospital, Day Room, Front Street, Chester le Street DH3 3AT	Mon, 29 Oct - 1.30pm
Lincolnshire	Tesco Superstore, 186 Wragby Road, Lincoln LN2 4QQ	Mon, 29 Oct - 2pm
West Sussex	Worthing Quaker Meeting House, 34 Mill Road, Worthing BN11 5DR	Tue, 30 Oct - 2pm
East Yorkshire	Etton Village Hall, 37 Main Street, Beverley HU17 7PG	Wed, 31 Oct - 1.30pm
Cumbria	Burton Memorial Hall, Main Street, Burton in Kendal, Carnforth LA6 1NA	Thur, 1 Nov - 1.30pm
Scottish Borders	The Old Gala House, 8 Scott Crescent, Galashiels TD1 3JS	Mon, 5 Nov - 1.30pm
Glasgow	Alexandra Court Care Home, 332 Edinburgh Road, Glasgow G33 2PH	Thur, 8 Nov - 1.30pm
West Yorkshire	Small Hall, Kirkgate Centre, 39a Kirkgate, Shipley BD18 3JH	Fri, 16 Nov - 1.30pm
Dorset	The Grove Hotel, 2 Grove Road, East Cliff, Bournemouth BH1 3AU	Mon, 19 Nov - 11am
Merseyside	St John the Baptist Church Hall, Forest Road, Meols, Wirral CH47 0AF	Wed, 21 Nov - 2pm
Hertfordshire	Hospice of St Francis, Spring Garden Lane, Off Shootersway, Berkhamsted HP4 3GW	Wed, 21 Nov - 2pm
County Tyrone/ Strabane	Please contact the Trust's office on 0333 323 4591 or support@msatrust.org.uk for more details	Mon, 26 Nov - 12pm
Belfast	Marie Curie Hospice, 1A Kensington Road, Belfast BT5 6NF	Tue, 27 Nov - 1.30pm
Greater Manchester	St. Andrews Church, Hope Centre, 27 Tattersall Avenue, Bolton BL1 5TE	Wed, 28 Nov - 1.30pm
County Down	Downe Hospital , Primary Care Confernece Room 1, 1st floor, 2 Struell Wells Road, Downpatrick BT30 6RL	Wed, 28 Nov - 1.30pm
Shropshire	The Lantern, Meadow Farm Drive, Shrewsbury SY1 4NG	Mon, 3 Dec - 1.30pm
Northumberland, Tyne & Wear	St. John's Church Community Hall, West Lane, Killingworth, Newcastle upon Tyne NE12 6BL	Mon, 3 Dec - 11am
North Yorkshire	St Columba's Church, 119 Dean Road, Scarborough YO12 7JH	Thur, 6 Dec - 1:30pm
Surrey	Shalford Village Hall, Kings Road, Guildford GU4 8JU	Thur, 6 Dec - 2pm
Lancashire	Tesco Extra branch at Clifton Retail Park, Blackpool FY4 4UJ	Fri, 7 Dec - 1.30pm
West London	St.Paul's Centre,Queen Caroline Street, London W6 9PJ	Fri, 7 Dec - 2pm
Cardiff	City Hospice, Whitchurch Hospital Grounds, Whitchurch, Cardiff CF14 7BF	Wed, 9 Jan - 11am
South Yorkshire	St Peter and St Paul Church Hall, Todwick, Sheffield S26 1HN	Wed, 20 Feb - 1.30pm



Record and press play

Samantha Pavey, MSA Nurse Specialist, looks at how voice banking can be an option for people with MSA when speech becomes difficult.

What is Voice banking?

Voice banking is a process that allows a person to record a set list of phrases with their own voice. This is then converted to create a personal synthetic voice. It can be used to create an infinite number of words and sentences. It will not be a perfect replica of your voice but it will sound similar.

How does it work?

You will record a number of different phrases that are then combined to create a synthetic voice. This voice will then be used to vocalise any sentence using a speech-generated communication device. The number of phrases varies depending on which service is used, but it can be up to 1,600 sentences. The process can take six to eight hours to record, which can be exhausting, so it is usually done in small sessions, over a number of weeks or months.

It doesn't work for everyone

Not everyone will be able to bank their voice for future use as it will depend on your speech difficulties. If your speech is slurred, it may not be suitable for you. Ideally you should consider voice banking before speech becomes problematic. Of course, the voice you put in will be the one you get out, not an improved version of your speech. If your voice is quiet, it might be possible to make it louder with an amplifier.

What equipment is needed?

Voice banking services are accessed online, so a PC or laptop is required with internet access. A suitable microphone is also important. This should be a headset model and individual companies can advise you on which works best with their software. The recording environment should be quiet with no background noise so voice banking can be done at home but you will require specialist support in order to do this. Tablets do not usually have the processing power that is needed, but they can be used with a synthetic voice as a communication aid if voice banking doesn't work for you. Voice Banking equipment varies in price ranging from £499 to £1,685. There are some voice samples on the websites below you might like to listen to:

www.cereproc.conm/en/products/cerevoiceme
www.modeltalker.org
www.acapela-group.com/voices/voice-replacement

How do I access it?

Your Speech & Language Therapist may need to support you for voice recording to be successful, so do speak to your Speech & Language Therapist in the first instance. If you haven't seen a Speech & Language Therapist, you should ask your GP to refer you to one locally. msa *news*

If you require any further information please contact your MSA Nurse Specialist at **support@msatrust.org.uk**, who will be happy to discuss voice banking with you.

TWC's Lyke Wake Walk Challenge

John Hindmarsh was a prominent figure in his local health community, spending much of his career at the Friarage Hospital, Northallerton and James Cook Hospital, Middlesbrough as a consultant Urologist. He was diagnosed with MSA in 2014 and sadly passed away in February this year.

John's family pledged to raise awareness and funding for research into MSA. So began the fundraising journey of his daughter Rachel, and the company she co-owns, TWC Facilities Ltd, which is a hygiene services company in North Yorkshire. Rachel, her husband Martin and TWC Facilities Ltd staff decided to take on the Lyke Wake Walk in aid of MSA Trust in June.

The Lyke Wake Walk is a complete crossing of the North Yorkshire Moors from Osmotherly in the west to Ravenscar in the east. The challenge involves completing the 40 mile route in under 24 hours. The team did it in 19 hours - setting off the night before and finishing the following evening. Sponsorship money has continued to come through steadily and the Walk has raised close to an incredible £10,000 so far - Well done everyone!

Rachel said "We knew nothing about MSA at the time but have witnessed its nature and the speed in which it can take hold. We did the Lyke Wake Walk so that one day, others don't have to go through the same ordeal". msa *news*

OUR NEW PARTNERSHIP

We are delighted to announce a new partnership with the Bag It Up (BIU) Group. BIU is a textile recycling organisation that provides recycling banks across the UK. Donated clothing and shoes from these banks are then resold and the Trust receives part of the proceeds. There is no cost involved for the Trust or the venue hosting the clothing bank as BIU provide all the equipment and services needed to operate the recycling scheme. BIU only sell to recognised sorting or grading partners who in turn sell in markets where trade is free and fair. They have internal audit procedures that ensures these standards are maintained. Clothing and shoe banks are placed across the UK ideally in busy public places like supermarkets or car parks. Private sites like community or garden centres, pubs, local shopping arcades or post offices are also all good locations. BIU makes every effort to secure new venues for placing the banks but would appreciate your local knowledge. This is where you, our community supporters, come in. If you know of any such venue which might be willing to host one of the clothing banks, please email **fundraising@msatrust.org.uk**. We will then forward your suggestion to BIU who will contact the venue. Unfortunately, BIU have partnerships with other charities in Dorset, Somerset, Berkshire, Oxfordshire, Buckinghamshire, Bristol, Bath, South Gloucestershire, Gloucestershire and Yorkshire. Therefore, sadly we cannot place banks in these locations. So, if you can think of any other locations, please get in touch. This would be an amazing way to support the Trust, while helping people to 'declutter'. msa *news*

Support the Trust this *Christmas*

Give our cards this Christmas and help raise awareness of MSA.

Night before Christmas

Santa & Reindeer

Robin in the Snow

Silent Night/Holy Night
(5 of each design)

Our cards have the following greetings inside: Night before Christmas *and* ***Silent Night / Holy Night -*** *"Wishing you a Merry Christmas and a Happy New Year".* ***Santa and Reindeer*** *and* ***Robin in the Snow -*** *"Season's Greetings and Best Wishes for the New Year".*

Each Christmas card design comes in a pack of 10 and costs **£4.00** plus postage and packing. If ordering from Ireland, please email **fundraising@msatrust.org.uk** for price of P&P. Please see our cost table for prices if buying multiple packs. Order online at our website, call 0333 323 4591 or return the slip below with a cheque.

Pack(s)	1	2	3	4	5	6	7	8	9	10
COST incl. P&P	£5.00	£9.30	£13.30	£17.30	£22.65	£26.65	£30.65	£34.65	£38.65	£42.65

If you live outside of the UK, please contact the Fundraising team for P&P costs: **fundraising@msatrust.org.uk**.

Multiple System Atrophy Trust Christmas Card Order Form

Name:...

Address:...

....

Postcode:.................................... Telephone:...

Night before Christmas (Qty):.......... Santa & Reindeer (Qty):............ Silent Night/Holy Night (Qty):...............

Robin in the Snow (Qty):................ Total payment enclosed £..

Due to changes in regulations, you need to let us know how you want us to keep in touch for fundraising news and events. Please fill out your contact preferences below.

Telephone ○ Post ○ Email ○ .... I prefer no contact ○

*Please return slip to **MSA Trust, 51 St Olav's Court, Lower Road, London SE16 2XB** with payment by 10th Dec 2018.*