msa news

MSA Trust Members Magazine | Issue 61 | June 2021

# Making the Most of *Summer's Bounty*

## CONTENTS

BANKING YOUR VOICE - PAGE 18

**CHIEF EXECUTIVE OFFICER:**
Karen Walker

**MSA NEWS EDITORS:**
Andy Barrick
Emma Rushton

**ALL ENQUIRIES TO OUR ADDRESS:**
Multiple System Atrophy Trust
51 St Olav's Court
City Business Centre, Lower Road
London SE16 2XB
Tel: 0333 323 4591
www.msatrust.org.uk

## *Welcome to* Issue 61

*A very warm welcome to your MSA News for Spring/Summer 2021.*

*Thanks again to all of those who have supported us and our MSA community through unprecedented times. It certainly feels like most of us have been in hibernation for a while, but with fingers crossed, arms vaccinated and restrictions gradually easing we may find our way back to some sort of 'normal' life. This will hopefully include running some face-to-face Support Groups and we are planning to have a few running from the Autumn (see page 16).*

*As usual this edition has a wide mix of articles relevant to life with MSA, amongst them tips on handling fatigue and getting better sleep, both of which we know are issues for many people.*

*In our News Roundup we are asking for your views on MSA News so please let us know what you think and what you would like to see covered in your magazine.*

*We also still have tickets remaining for our MSA Study Day (see overleaf) so please tell any professionals supporting you about this.*

*We hope you enjoy reading this issue. Emma and Andy.* msa news

Registered Charity Number 1137652. Scottish Charity Number SC044635. Company Number 7302036
We endeavour to ensure the accuracy of articles in MSA News. Please note, however, that personal views and opinions expressed are not necessarily endorsed by the Trust. Designed by Base Media www.base-media.co.uk. Printed by INQ Design 020 7737 5775.

# NEWS ROUNDUP

## Care Workers Guide

Our Guide for Care Workers has now launched. This resource is aimed at formal carers working inside peoples homes or in Nursing Homes. It gives a description of MSA, the symptoms people may experience and how to manage these. Please direct carers to our website where they can download a copy or email us at **support@msatrust.org.uk** and ask for some to be sent out. msa *news*

## Goodbye to Trustees

The MSA Trust Board of Trustees and all staff would like to say "thank you" to two members of the Board who have served their allotted terms of office and will be standing down this Summer. Our gratitude goes to Helen Craik and Amy Couture, both of whom have given six years of great service. Their unstinting support and help in all matters of Governance have been hugely appreciated.

Our **Services Committee** meets twice a year, helping us ensure our services are geared to providing what people affected by MSA need from us. If you know anybody who might be interested in joining we have two spaces available. We would particularly welcome expressions of interest from people who might increase the diversity of our membership. Please contact **support@msatrust.org.uk** and we will get back to you about how to apply. msa *news*

## Update Your Address

It's really important that you let us know if you have moved to a new home. If our MSA Nurse Specialists or Social Welfare Specialist are communicating with health and care professionals on your behalf, they will need up to date contact information for you. If you have moved address, and not told us your updated details, please contact **support@msatrust.org.uk** or call 0333 323 4591. msa *news*

## Local Runs

Local non-virtual runs are ideal if you don't wish to travel long distances to take part in big events such as the Manchester or Edinburgh Marathon. It's the best way to get back into running with spectators cheering you on. From the Bournemouth Half Marathon to the Leeds 10k, you, or the running enthusiast in your family, can easily find a local run on our website - **www.msatrust.org.uk/get-involved/events/running-events-2-2/#tab7** msa *news*

## What do you think of MSA News?

We are always looking at ways of improving the information and support we give to our members. Our MSA News magazine has been produced since the 1990's, and while it has had a couple of re-designs, we are keen to know how we can make it better for you.

We would like to gather your views on the content and style of the magazine. Please fill in this short survey, which should not take more than a few minutes **www.surveymonkey.co.uk/r/XJN3WXZ**. msa *news*

## MSA Study Day

We still have some tickets remaining for our MSA Study Day, specifically for Health and Care Professionals. This will be held on the 16th September 2021 in St Neots, Cambridgeshire. Book your place here - **www.msatrust.org.uk/2021-study-day**. msa *news*

# Twenty years of MSA Research at Queen Square Brain Bank

**Janice Holton, Emeritus Professor of Neuropathology and Former Director of Neuropathology reflects on her career at Queen Square Brain Bank...**

My journey into MSA research began when I joined the Queen Square Brain Bank (QSBB) as a Consultant Neuropathologist in 2001. QSBB holds a renowned collection of brain tissue generously given to research by people throughout the UK who have had a neurodegenerative disease, such as MSA. I was fortunate to join this dynamic and inspirational group and quickly learnt that QSBB has a culture of collaboration, both nationally and internationally. This background, together with the substantial collection of MSA tissue in the brain bank, provided a fertile environment and a key resource for research into MSA.

Dr Tetsu Ozawa working with Professor Niall Quinn and Professor Revesz gave me an invitation to join the study team looking at the clinical and neuropathological features of MSA. Glial cytoplasmic inclusions (GCIs - pictured above), the neuropathological hallmark of MSA, represent clumps of abnormally twisted proteins accumulated in oligodendrocytes, a cell type that supports nerve cells. A prominent protein in GCIs is alpha-synuclein, and we think it has an important role in damaging brain cells in MSA and Parkinson's Disease. A key finding of Dr Ozawa's study was that increasing numbers of GCIs relate to the length of the illness and the severity of nerve cell loss. The pivotal role of GCIs encouraged us to strive to understand how they are formed.

Supported largely by a series of grants from the MSA Trust we were able to employ post-doctoral scientists and a PhD student to investigate several aspects of GCI formation. We showed that precursor cells of oligodendrocytes are not affected by GCIs, giving the possibility that they may be able to replace damaged oligodendrocytes. Brain inflammation may play a part in initiating or promoting the pathological process, however, reduced degradation of alpha-synuclein is unlikely to contribute to its accumulation in GCIs. We also found that mitochondrial activity, which provides energy for cells, is altered in MSA.

JANICE HOLTON

More recently we have pursued a new area of research, studying changes in DNA methylation in MSA. Methylation chemically changes DNA but does not alter the genetic code, switching on or off the amount of protein translated from the gene. DNA methylation is important in development and, crucially, can be altered by drugs making it a possible treatment target. We are the first group to work on DNA methylation in MSA and this is proving fruitful in highlighting novel disease mechanisms and supporting our previous findings that mitochondrial function and inflammation are important in MSA.

Other important areas of research are studies that combine neuropathological information and clinical details of the brain donor (clinicopathological studies). Such studies have been a major strength of the QSBB since its foundation in the 1980s and are possible due to the detailed clinical information available. Recently, analysis has been undertaken to understand why MSA is so hard to diagnose and to provide better guidance for neurologists to improve diagnostic accuracy.

> ***Over the years support from the MSA Trust has enabled the employment of research scientists creating a critical mass of MSA researchers at QSBB and supporting our collaborations. Our work has led to some 50 publications in MSA, many representing research at QSBB and others from our wide network of collaborations. It has also been a privilege to present our work at many scientific conferences, meeting many colleagues around the world.***

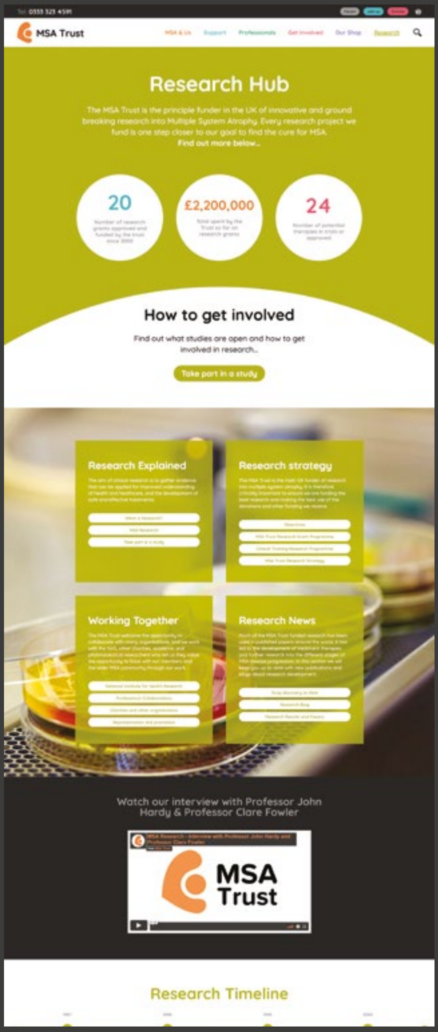
Despite the difficulties of the past year due to the Covid-19 pandemic, the team have continued their research output. Since retirement in 2019 I have stepped back from day-to-day involvement in the research programme, but I am confident that we can look forward to an exciting future in MSA research at QSBB. A new grant from the MSA Trust will explore whether there are DNA methylation signatures of MSA that distinguish it from other neurodegenerative movement disorders, perhaps indicating whether there are unique or shared disease mechanisms in neurodegeneration. As we continue to piece together the jigsaw puzzle of MSA we will use our fantastic resources to take advantage of new scientific techniques and support these with established methods in neuropathology and biochemistry.

The support of the MSA Trust, brain donors, their families and carers has been pivotal in the advances made to date and we look forward to their ongoing involvement in facilitating future MSA research. I am pleased to continue my contribution as a member of the MSA Trust's Scientific Advisory Panel. I would like to thank the staff of the QSBB and the many colleagues and collaborators, too numerous to mention by name, who have contributed, supported and helped me in this work over the last 20 years, it has been an honour to work with them all. I remember with affection and gratitude the contribution to our MSA team made by Professor Robert Balazs (1923-2020). His guidance, encouragement and knowledge were an inspiration to us all. msa *news*

## RESEARCH NEWS

We are delighted to say that our updated Research Hub on the website is now live for exploration at **www.msatrust.org.uk/cause-and-cure**. Please regularly check back for updates on research, both funded by us and from our colleagues around the world.

**Stop Press:** We are delighted to report that the Association of British Neurologists have recruited a new MSA Research Fellow. We look forward to introducing you to Dr Yee Yen Goh in the next edition of MSA News. msa *news*



Research Hub

The MSA Trust is the principle funder in the UK of innovative and ground breaking research into Multiple System Atrophy. Every research project we fund is one step closer to our goal to find the cure for MSA.
Find out more below...

20

£2,200,000

24

How to get involved

Find out what studies are open and how to get involved in research...

Watch our interview with Professor John Hardy & Professor Clare Fowler

Research Timeline

# Planning for the Future: *A lot to think about?*

**Yvonne Radford (pictured) and her husband Terry** have completed Lasting Powers of Attorney (LPA). These documents allow you to nominate someone to act on your behalf should the need arise. Yvonne says: ***"My advice would be for everyone to have LPA's in place. We decided to get LPA's done as Terry had a heart attack in January 2020 and I was diagnosed with MSA-C around Easter 2020. I knew someone who, because she and her husband did not have anything in place, was unable to get any money out of the bank when her husband had a massive stroke. It took two years before it was sorted out. Everything was in his name."*** Even if a couple have their finances and property in joint names problems can arise. There can also be difficulties in making decisions about a person's welfare and health if they have lost mental capacity and no LPA is in place. As Yvonne explains ***"Our families have enough on their minds. Our two sons and their families do not need any more worries. Terry and I feel so much better now we know things are sorted."*** msa *news*

**Terry McCaw and his wife, Jacqui**, have arranged adaptations to their home. For Terry, as for most people with MSA, stairs are a problem. They felt a through-floor lift would be the best solution and worked with the Occupational Therapist to get one installed. It was quite a complex and lengthy process. As Jacqui says ***"Things aren't always straightforward. The sooner you do it the better, then you're not desperate."*** Another advantage of planning ahead as Jacqui points out, is that if there is a delay in getting things done it's ok, even valuable, because it gives you time to research options and to learn from others. Terry and Jacqui found the insights and advice from another member of their MSA Trust Digital Support Group very helpful. Jacqui explains that having the lift installed ***"takes away the enormous worry of what happens if Terry can't get up and down the stairs."*** Although he was initially reluctant to have a through-floor lift, thinking perhaps a move was better, Terry is now pleased with it. ***"I feel reassured, I'm glad we made room for it. I've tried it out on my own and it's completely ok. I don't need to use it at the moment but it's there if I have a difficulty."*** msa *news*

## Planning for the Future… that can sound scary, especially if you are living with MSA and know there will be challenges ahead.

To help people maximise their independence and choices we have created a new web-based resource called Planning for the Future. Here a few of our members tell us about things they have done to plan ahead…

**John Carroll** decided to have a PEG fitted. A PEG is a tube that enables you to be fed directly into your stomach replacing the need, when necessary, to take food and liquids by mouth. John explains that when his voice and swallowing started to be affected his Speech and Language Therapist (SaLT) spoke to him about the possibility of having a PEG fitted. They recommended that if he did decide to do this it was better to do it 'sooner rather than later' so that he was as fit as he could be. So, 18 months ago, John attended the hospital for discussions with the specialists and decided to book in for the procedure. He felt the procedure, at least from his point of view, was quite a simple one. John says about his PEG ***"It's there now if I need it. I'd recommend others who are starting to have speech or swallow problems talk to their SaLT."*** Although John can still eat and drink for pleasure he says ***"I feel having the PEG gives me more options – it's useful if I'm struggling to take in enough liquid, if my throat is sore or I have a chest infection."*** Bags of food (in the form of a special liquid that contains nutrients for PEG feeding) are prescribed for this purpose. John explains that it was very much his choice to have a PEG fitted and he is pleased he had it done. Obviously decisions like this are personal ones but early discussions can be helpful. msa *news*

**Hayley and Colin Tamplin** have had contact with two local hospices since 2018. Hayley saw a Clinical Nurse Specialist at one of the hospices and had a few sessions discussing her wishes in respect of her future medical management. This led to Hayley deciding to complete an Advance Decision to Refuse Treatment (ADRT) form as well as an Advance Care Planning document. Hayley says ***"I felt more secure after doing this - more in control. It was a great relief to have it all done and signed off."*** Hayley felt she could talk openly with the Nurse as she was very sensitive but direct. The couple then got involved with another hospice after attending an MSA Trust Support Group there. Hayley was attending their weekly exercise sessions and although these have had to cease, the team stay in touch and the couple have lots of confidence in the hospice responding when help is needed with any aspect of Hayley's care. As Hayley explains ***"Hospices now like to engage early to encourage 'good living'."*** msa *news*

The web link for the resource can be found here:
**www.msatrust.org.uk/planning-for-the-future**
or phone us on 0333 323 4591 for information.

# In Memory

*April Sanford*
*Desmond Sturgess*
*Shaun Arnold*
*Patricia Norris*
*Margaret Owens*
*Alan Burrows*
*Steven Goodhead*
*Linda Vowles*
*Christopher Saxby*
*Alan Butler*
*Rod Thomson*
*Harry Holland*
*Alexander Devanney*

*Leonard Pepper*
*Christine West*
*John Fennymore*
*Gerard Finbow*
*Eileen Anderson*
*Elizabeth Hazle*
*Duncan Strang*
*Alan Ford*
*Brian Johnston*
*Dee Wade*
*Derek Clowes*
*Pamela Pringle*
*Diana Burn*

*Daniel Burnett*
*Mark Rivers*
*Anne Rafferty*
*Melvyn Donaldson*
*Steven Mera*
*Peter Sutcliffe*
*Freda Hewitt*
*Jeffrey Bell*
*Adrian Johnson*
*Peter Newman*
*Andrew Aldridge*
*Rita Cheatle*
*Barbara Martin*

*Diane Matthews*
*Elizabeth Major*
*Roderick Campbell*
*John Hodson*
*Valerie Walker*
*Stephen Kirkaldy*
*Chris Gane*
*John Gladstone*
*David Higgins*
*Elizabeth Garbutt*
*David Yates*
*Truyen Tran*
*Tom Murphy*

# CELEBRATING THE LIFE OF A LOVED ONE

Last year, so many families were unable to give a proper farewell to their loved ones due to restrictions on gatherings for funeral services. This was an extremely difficult experience and our thoughts go to all those who had to endure it.

As more restrictions are eased, family and friends can hopefully meet again and give a more fitting tribute to their loved one through a 'Celebration of Life' event. This doesn't have to be a formal occasion, such as a memorial service, but might be something simple like starting a memorial garden, lighting candles or a group walk to retrace or visit your loved one's favourite route or place. You might even consider organising an activity around hobbies they enjoyed, such as a charity auction of their artwork or handmade items.

Whatever your event, we are here to help. We can provide our orange MSA ribbons and leaflets to raise awareness, can help with the wording in the programme (if you choose to have one) and can send collection boxes and donation envelopes to boost participants support on the day.

Please email **fundraising@msatrust.org.uk** if you are considering such an event for someone you have lost. msa *news*

# Share *Your* Experiences

We know from our Support Groups and from our MSA HealthUnlocked forum how valuable the sharing of experiences is for our members. We are very keen to try to expand our opportunities for doing this and really need your help.

If you might be willing to 'tell your story' about a specific issue, for MSA News, for use on Social Media, a blog or for campaigning, please let us know. We are looking for common experiences that others may identify with and learn from. For example, maybe you have tried voice banking, or you have had adaptations made to your home. Perhaps you have attended one of our Support Groups. Maybe you are fairly newly diagnosed or you live alone and face extra challenges because of this. You may have moved into a nursing home and can give an insight into this. The experiences of carers and professionals are very much of interest to us too.

It does not matter if, at this stage, you do not have a particular 'story to share'. We will always talk through with you any article we plan to use, to ensure you are happy with the content and where it will be used.

If you think you may be willing to help us please get in touch with Jane Stein at jane.stein@msatrust.org.uk or on 0333 323 4591 for a discussion. One lovely example of a couple sharing their story and spreading awareness of MSA is Charlotte and Iain (pictured above) who got married in lockdown earlier this year. msa *news*

# Fire Safety - *Have You Got a Plan?*

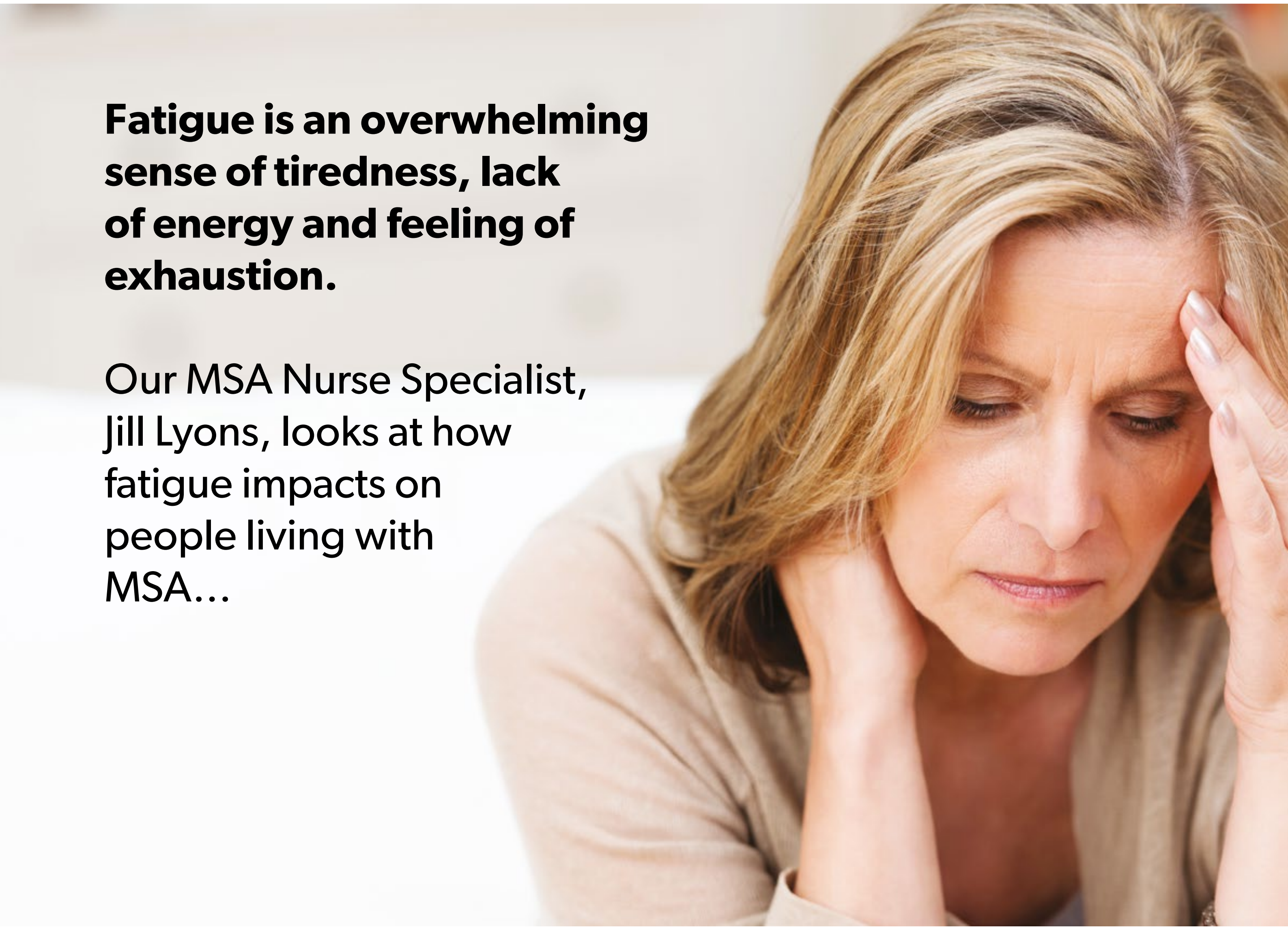
We asked firefighter, Luke, for this piece on what you should plan for regarding safety from fire in your home.

Have you thought about what would happen if there was a fire in your home? Would you be alerted early and would you be able to easily get out? Having working smoke alarms and testing them regularly is crucial and could save your life. Living with MSA can mean extra equipment in the house so it is vital to keep exits clear and to plan your escape route if you did need to leave in an emergency. Your local Fire Service will provide useful information on fire safety on their website and will also explain how to contact them for a free home fire safety visit. They can assess the safety of your home, including advice on such things as escape routes and your bedtime safety routine. They can also install smoke detectors if appropriate, and record on their database that there is someone with mobility difficulties at the address. More information can be found here:

www.fireservice.co.uk/information/ukfrs

www.citizensinformation.ie/en/government_in_ireland/security_and_emergency_services/fire_services.html#lfdce1. msa *news*

# Fighting Fatigue



**Fatigue is an overwhelming sense of tiredness, lack of energy and feeling of exhaustion.**

Our MSA Nurse Specialist, Jill Lyons, looks at how fatigue impacts on people living with MSA…

Our 2019 Needs Survey responses highlighted fatigue as being a significant symptom for people living with MSA, with 96% of respondents saying it was a problem. As fatigue can impact upon other symptoms and quality of life it is worthwhile looking at what you can do to minimise it.
A good starting point is your Occupational Therapist (OT) who will be good at assessing your fatigue and helping you plan a strategy, taking into account some of the suggestions below.

## Nutrition

A good balanced diet is important to provide the body with energy and decrease fatigue. Six small meals a day can help reduce drops in blood pressure. If you are losing weight or having difficulty getting a good diet, due to swallowing difficulties, ask for a referral to the Dietitian. Try to avoid too much sugary food.

## Hydration

Drinking plenty of fluid (but not too much caffeine) is important. This will help with blood pressure and avoiding urine infections but also help you feel less fatigued.

## Constipation

This symptom also needs to be managed well. Please see an article on managing bowels in Issue 60 of MSA News or read the 'Bowel Management' factsheet on our website.

## Pain

Pain can be exhausting. Talk to your doctor or specialist about the best way to manage any pain you have. This may include seeing a Physiotherapist, applying heat, using massage, as well as pain medication.

## Other Conditions

There are a number of causes of fatigue which are treatable, and these should be screened for and treated before assuming that the fatigue is part of MSA progression. These include hyperthyroidism, anaemia, coeliac disease and liver disease. Ask your GP to check for conditions that could be making your fatigue worse.

## Sleep

If you are not sleeping well at night this will of course impact your fatigue. See the article on page 12 for advice on getting a good night's sleep. Even if you are sleeping well at night you may need daytime nap(s). Set a timer so you don't sleep too long and try not to nap after 3pm to minimise disrupting your night sleep.

## Exercise and Fresh Air

Exercise increases your circulation and therefore helps fatigue. Finding the right level of exercise that helps you but doesn't over exhaust you is important. Seated exercises in the fresh air can be helpful and lift your mood.

## Depression and Anxiety

These symptoms can also cause fatigue so talk to your GP or specialist if you are experiencing either. Plan things that make you happy into your daily routine.

## Breathlessness

If you are experiencing problems with breathing this may also make you more tired. Some people with MSA experience sleep apnoea, where your breathing stops and starts when you sleep. Talk to your GP if you have either of these problems. You may be sent for a sleep or breathing assessment and a CPAP machine may be recommended overnight, this is likely to improve your fatigue.

## Postural Hypotension

If your blood pressure is very low or drops low on standing or sitting up, this will increase fatigue. See our Postural Hypotension factsheet and leaflet for tips on how to help improve this symptom.

## Infection

If you have a sudden worsening of fatigue or any of your MSA symptoms, always consider if you have an infection, most commonly a urine or chest infection. If you think you have an infection speak to your GP promptly and get treatment as soon as possible as people with MSA may not show a high temperature.

## Managing Your Energy

Perhaps the most important consideration in terms of managing your fatigue is planning and conserving your energy. You will need to work out the right level of activity for you, and this will change over time. You may well find that if you have a demanding day, you will need to plan a quiet day the next. You may find that you have times of day when you have more energy, and you can plan to do things then and perform less demanding activities when you need to.

Try to avoid the Boom-Bust cycle, this is where you have peaks of overactivity and then troughs of underactivity. For example, on a good day, it is tempting to do all the jobs you have put off. If you do this you may do more than your body is used to and become fatigued. This leads to the bust phase where you have no energy and are forced to rest, after a few days you feel better and start the overactivity again. Try to pace yourself in order to avoid this Boom-Bust cycle.

Many people with MSA find it difficult to pace themselves and view this as 'giving in' to MSA. It is important to talk to your family and friends about managing your fatigue so they can support you. You may also find it helpful to talk to a counsellor as you come to terms with the changes MSA brings.

Here are some tips that may help you conserve energy:

- Bathroom - electric toothbrush, shower seat
- Bedroom - front fastening clothes, non-iron clothes
- Hallway - mail basket on the door, helping hand aid
- Lounge - phone and remote by chair, internet shopping
- Kitchen - ready meals, microwave, perching stool.

Talk to your Occupational Therapist or MSA Nurse Specialist for more ideas and to develop a fatigue management plan. msa *news*

# Getting a Good Nights Sleep

**Good sleep is vital to our mental and physical wellbeing. Samantha Pavey, MSA Nurse Specialist, looks at ways to help you get a better nights sleep…**

Experts tell us we should be getting between six and nine hours of sleep every night. Our sleep goes through different cycles, known as circadian rhythms, but people with MSA may have several sleep issues.

Sleep hygiene can help towards getting a good night's sleep. This includes:

- **Going to bed and getting up at the same time**
- **Avoid having lie-ins**
- **Prepare for night-time by winding down an hour before you go to bed**
- **Make a list of things that are worrying you or plan what you need to do tomorrow**
- **Have a routine that prepares your mind for relaxation such as a warm bath or shower or do some yoga or stretches, if you are able to**
- **Listening to some soothing music, a podcast or a relaxation CD can be helpful**
- **Lavender and chamomile essential oils are good for aiding sleep (avoid citrus oils as these are uplifting)**
- **You might wish to buy some ear plugs or a sleep mask, if noise or light are disturbing you**
- **Your bedroom should be at a temperature between 18-24 degrees Celsius, dark, quiet and tidy**
- **Your bedroom should be a relaxing environment. Avoid using electronic devices an hour before bedtime.**

## Sleep Diary

If you see your GP or a sleep expert, they may ask you to keep a sleep diary to help them diagnose your sleep problems. It can identify factors such as stress, sleep apnoea (where your breathing stops and starts when you sleep) or any medications that may be affecting your sleep. If you regularly wake in the morning with a headache, this could be an indication of low oxygen levels in the bloodstream. Talk to your Neurologist as you may need to have an overnight sleep assessment. Heavy snoring should not be ignored, it may be stridor which can indicate problems with the vocal cords, which needs addressing by your Specialist.

## Food and Drink

Cut down on caffeine in tea, coffee, energy drinks or colas after lunchtime. Caffeine interferes with the process of falling asleep and also prevents deep sleep. Instead, have a warm, milky drink or herbal tea. Alcohol may make you feel sleepy initially but is actually a stimulant and will disturb sleep later. Smoking will also disturb your sleep pattern.

## Addressing Pain and Anxiety

If you are experiencing pain, discuss this with your Neurologist, Parkinson's Nurse Specialist or MSA Nurse Specialist. Different types of pain can be managed with medication depending on the cause. Anxiety and depression are a common symptom in MSA and there are medications that can be helpful in treating these. Counselling can be helpful if you are able to access it via your GP or local hospice. Aromatherapy, acupuncture and reflexology can also help with sleep, pain and anxiety. We have a factsheet on complementary therapies on our website that you may find helpful.

## Equipment

You may find it difficult to turn over in bed or get into a comfortable position due to upper body rigidity. Talk to your Occupational Therapist (OT) about a slide sheet or similar that can help you to turn over. Satin pyjamas or satin sheets may enable you to turn more easily – but don't use both together. Also see the 'Snoozle' recommendation on page 16. The OT can also supply a grab rail that slides under the mattress and allows you to pull yourself into a different position. They can provide a wedge-shaped cushion if you have postural hypotension and need to sleep more upright or, depending on the type of bed, can raise the head of the bed for you (ideally 30 degree head up). They can advise you on the best type of mattress, especially if you are unable to move at night. You may require a special mattress and a hospital type bed to prevent pressure ulcers (sometimes referred to as pressure sores). Your Community Nurses can help advise you about where to obtain these.

If you are able to do some form of exercise each day this will aid sleep but avoid doing this in the evening. Walking and swimming are particularly good at relieving muscle tension as is hydrotherapy if you can access this locally. If you are a carer sleeping in another room, you might want to use a two-way monitor. If your pet sleeps in the room with you but wakes you often, you should consider moving their bed to another room.

## Medication

- **Pain relief, depending on the type of pain and cause, can be prescribed**
- **Sleeping tablets are only useful in the short term and can be addictive**
- **Sleep apnoea can be treated with a Continuous Pressure Airway Pressure machine (CPAP)**
- **Restless Leg Syndrome can be treated with some Parkinson's medications**
- **Melatonin is sometimes used to try to reset the sleep pattern**
- **Muscle relaxants can be helpful for rigidity and nightmares or Rapid Eye Movement sleep behaviour disorder.**

There are various apps that can help you with sleep such as Pzizz, Sleepstation and Sleepio.

Do discuss these options with your GP or Neurologist. Don't put up with lack of sleep as it can affect your wellbeing and if you are a carer it means you aren't able to cope as well. You should contact your GP if your lack of sleep is affecting your daily life and lasts for more than four weeks.

Further information can also be found at **www.sleepfoundation.org/sleep-topics/sleep-related-breathing-disorders** and **www.nhs.uk/live-well/sleep-and-tiredness/10-tips-to-beat-insomnia**.

We are in the process of producing a sleep factsheet which will give you further information about sleep issues in MSA. msa *news*

If you have any questions about something you have read in this article or want to discuss any sleep issues you may be having, please email us at **support@msatrust.org.uk** and an MSA Nurse Specialist will get in touch with you.

# Young Voices for the Trust

**Aoife McGrath** (17) from Warrenpoint, Northern Ireland was nominated for the Michaela Foundation Wings Award which recognises the achievements of young people between 11 – 24 years.

Aoife was nominated for her dedication towards a range of community volunteering she does whilst also being a young carer, helping her mother in the care of her father who has been diagnosed with MSA. As part of the Award, Aoife received a bursary of £250 to spend as she wished. As a wonderfully kind gesture, she donated this to us in the hopes of helping her father and others with MSA.

Aoife has also used her insight and personal experience of MSA to help us develop resources for the Trust's web hub for 11-17 year olds - **www.msatrust.org.uk/support-for-you/young-people**. We, and her parents are so proud of the support she gives them and others in the local community. Well done!

**Emilie Wathan**, (11) decided to courageously go for a 'big hair chop' for her grandmother, Ann (her 'Mamgu'), who is currently living with MSA. She raised £1,613 for bravely cutting nine inches off her locks! Thank you, Emilie!

# 100K for MSA

**Clare Flood** and **Alice Orr** organised a team fundraising challenge '100k for MSA' at the beginning of the year in memory of Clare's sister, Eileen Anderson. The family reached their 100km target each in the month of January through runs, walks and cycle rides, raising over £3,665. A great team effort!

# A delicious challenge!

**Tom Barnes** (left), whose father has recently passed away from MSA, is the Executive Chef for Simon Rogan's Michelin starred restaurants. He looks after Simon's North/West restaurants including Rogan & Co. in the Lake District and faced off against the Executive Chef in London in a culinary challenge. Guests attended a ticketed event at the restaurant and decided whose menu they preferred, and the winning chef would donate £5 from each ticket to their chosen charity. Tom won the culinary battle and donated £925 on behalf of Simon Rogan restaurants.

# Richard's "Wheelchair to 5K"

## Richard Whitfield, currently living with MSA and now using a wheelchair, did not let this come in the way of his efforts to raise vital funds for the Trust.

Following in the footsteps of the late Captain Sir Tom, Richard used a rollator walker for support as he completed laps around the courtyard of his family home, a difficult but rewarding challenge. His target was to walk 5km between 1st January and his 59th birthday in April. He was delighted to complete the challenge two days before his actual birthday with his family cheering him home.

This is Richard's first fundraising challenge for the Trust. From this he has already raised more than £35,000 and the total keeps on rising. He feels overwhelmed by the support he has been given.

> ***"The sum raised far exceeds my wildest expectations. I have received support from so many people including former colleagues I was last in contact with over twenty years ago".***

A big well done and a huge thank you to Richard and all his supporters! msa *news*

# Miles for MSAT challenge

## If you are inspired by Richard then our 'Miles for MSAT' challenge is a fantastic opportunity.

Last year was a difficult one as many of the Trust's coveted Marathon events like the London Marathon were cancelled. **This year you can do your very own Marathon challenge and raise vital funds to help the Trust's work at a time when the MSA community needs it the most.**

Many of our supporters, like **Kym Stubbins** have done short walks throughout a fixed period to reach their target. Kym recently completed her walking challenge in the month of May and managed to raise £1,195 in support of her father, Derek. Amazing work, Kym!

This doesn't necessarily have to be a solo effort, it's a great chance for someone with MSA to link up with family and friends to do a joint Miles for MSAT walking challenge this summer or autumn. You can also link your fundraising page to a fitness app and share the miles completed with supporters. They get to easily see your effort and sponsor your challenge.

Email the Fundraising Team to sign up for the Miles for MSAT challenge - **fundraising@msatrust.org.uk**. msa *news*

NICOLE ADAM PRESENTS A REGULAR ROUNDUP OF YOUR TOP SUPPORT GROUP TIPS

# Supporting & Helping Each Other

## *The Future of Our Support Groups*

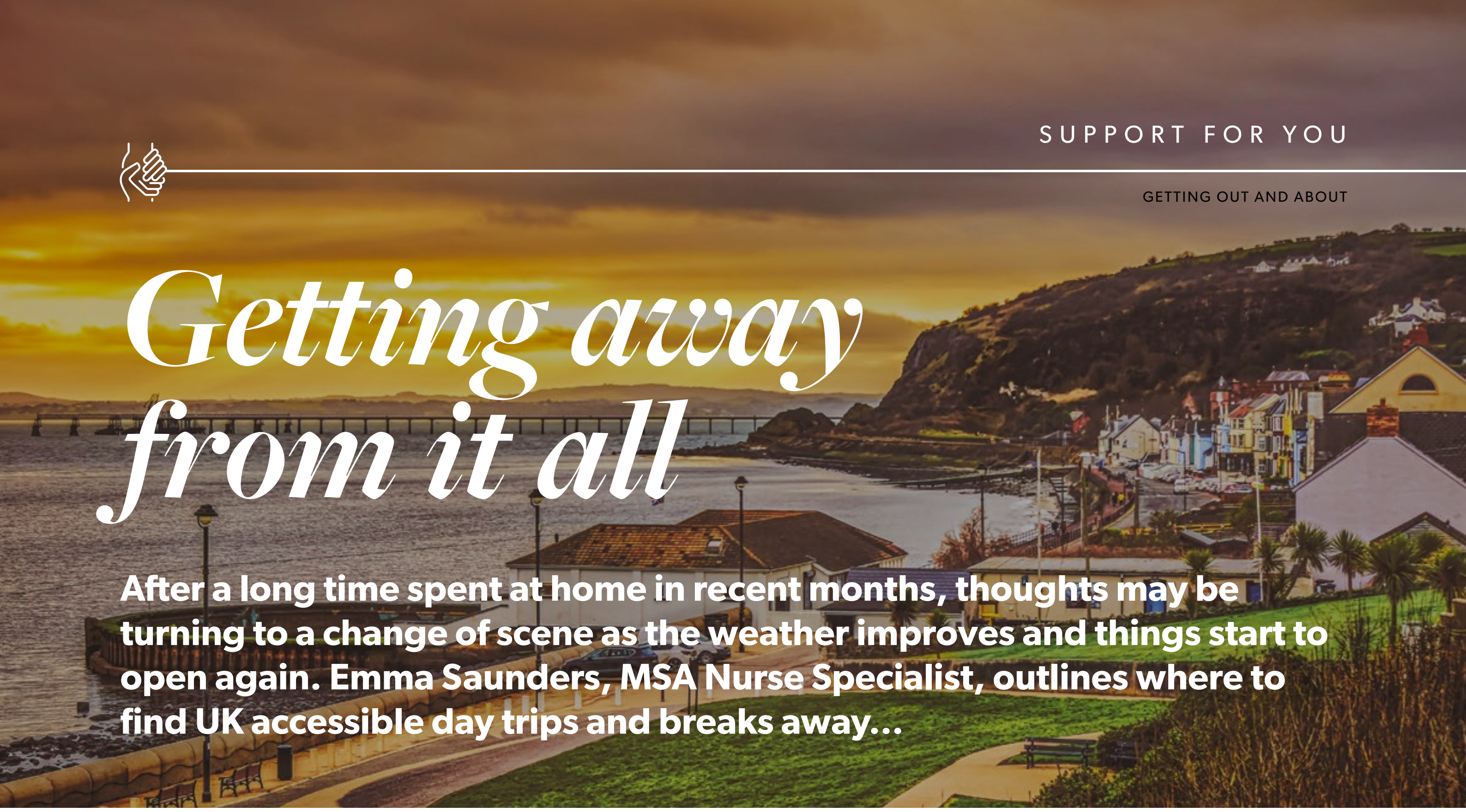
*A big thank you to all who have continued to participate in our Digital Support Groups over the last year. As restrictions ease, we hope to cautiously bring back our in-person Support Groups as well. Some locations will be changing from previous meetings, please see our Support Group Calendar online or give us a call to find out if an in-person Support Group will be meeting near you. We send out regular information about Support Groups by e-mail, if you are not hearing about groups but would like to, please get in touch to update your details. Our Digital Support Groups will continue alongside our in-person meetings so you will have access to the option that works best for you.*

Fantastic ideas have continued to be shared at our Digital Support Groups. Snoozle slide sheets have become the unexpected hit of our Four Counties Support Group. After a recommendation from within the group, other members purchased it and found it a great product to help with limited mobility. These comfortable slide sheets help you move and turn in bed with minimal effort. It was also highlighted that it has a stylish design which can be a refreshing change for members used to paraphernalia which is solely functional. It can be found on **www.thesnoozle.com** and our Support Group Leader, Ian has even arranged a discount code, use **MSAFRIENDS** at the checkout for **£5.00 off**.

Hopefully, the coming months will see many people able to enjoy more fresh air, but some of our members shared the new indoor hobbies they have enjoyed. Online Jigsaws seemed to be very popular at our Digital Coffee Morning. Doing them online meant less fiddly hand work, but with all the satisfaction of a job well done. This website even allows you to play with friends and family, **www.jigsawexplorer.com** and is available to anyone on a laptop or desktop. The Magic Jigsaw Puzzle app was recommended as well. If a traditional mouse is too tricky, chunkier, ergonomic options might be an alternative. AbilityNet have some helpful advice on possible options - **www.abilitynet.org.uk/factsheets/keyboard-and-mouse-alternatives-and-adaptations**.

One member discussed some of the difficulties around dressing and clothing being too restrictive for a carer to assist with. It was helpfully pointed out that a number of organisations make clothing that is adaptable. Clothing that opens at the front and back or uses magnetic fastenings can make dressing easier. There are many different adaptable clothing brands, some can be found here - **www.adaptawear.com**.

To round things off, chocolate was a big topic of discussion in one of our South East Support Groups. One member had always enjoyed chocolate bars but was now finding chewing and swallowing them difficult. Alternative suggestions included chocolate mousse and chocolate pudding, both of which have a variety of options available at most supermarkets. If it simply must be chocolate, our MSA Nurse Specialist, Samantha Pavey suggested chocolate buttons; they are thinner so melt quickly in the mouth, making them easier to enjoy. Time to get sampling! msa *news*



# *Getting away from it all*

**After a long time spent at home in recent months, thoughts may be turning to a change of scene as the weather improves and things start to open again. Emma Saunders, MSA Nurse Specialist, outlines where to find UK accessible day trips and breaks away…**

Our members often share with us, at Support Groups and on our MSA HealthUnlocked online forum, their favourite holiday and day trip destinations that they find accommodating and accessible. Here are some recommended resources and things to consider when planning a trip.

The 'Rough Guide to Accessible Britain' contains ideas and information about days out all over the UK and can be viewed for free online at **www.motability.co.uk/news/rough-guide-to-accessible-britain**. It contains details of places to visit, along with practical advice and useful symbols to show what facilities are available at which place.

**www.euansguide.com** is a disabled access review site where disabled people, their family, friends and carers can find and share reviews on the accessibility of venues around the UK and beyond. The site is an invaluable tool for everything from planning a day out, to picking a last-minute place for coffee or lunch. The site includes a forum for people to ask questions and share ideas. Similarly, **www.accessable.co.uk** is a website where you can input any location and it will list access information for places in that area.

For longer trips or holidays, many places offer accessible accommodation and varying levels of additional support. Revitalise (**www.revitalise.org.uk**) provide respite holidays for people and their carers and can supply equipment, care and nursing support if needed. Their Sandpipers resort overlooks the Marine Lake at Southport and has an indoor heated hydrotherapy pool, bar and entertainment area, hair and therapy salon, sun terrace and gardens.

Cofton holidays offer disabled access caravans and day visits at their site in Devon - **www.coftonholidays.co.uk/accommodation/static-caravan-holidays/disabled-access-caravan-holidays**.

For family-centred holidays, there is accessible lodge accommodation at Bluestone Wales resort **www.bluestonewales.com/accommodation/caldey-adapted-lodge** and Centre Parcs offer adapted accommodation with hoist access to hot tubs **www.centerparcs.co.uk/discover-center-parcs/lodge-holidays/accommodation-type/adapted-lodges.html**.

The Ceiling Hoist User Community website has a function where you can search by accommodation type at **www.chuc.org.uk/index.php** and read user reviews.

In Ireland, the Irish Wheelchair Association partner with hotels that offer specialised equipment and offer tailored advice so that you can plan a holiday that meets your individual needs - **www.iwa.ie/services/holidays**. The Accessible Ireland website (**www.accessibleireland.com**) lets you search for accessible facilities throughout Ireland, including places to stay, eat and drink, tourist attractions, venues and transport.

For holidays that are further afield, **www.disabledholidays.com** are an accessible holiday specialist that can offer tailored advice. If you are thinking about travelling abroad, do make sure your travel insurance covers you for MSA and that any previous insurance is still valid, particularly in light of changes due to COVID-19. See our Travelling and MSA Factsheet on our website for further tips.

**Before booking a holiday, do make sure accommodation and equipment meets your personal needs and requirements, so that you can plan accordingly. We recommend calling and confirming over the phone where possible.** msa *news*

# Voice Banking – *Making it Personal...*

***We're offering free voice banking to all of our members. Our Social Welfare Specialist, Jane Stein, speaks to Therapists and members about the potential benefits...***

"Take a moment to think about your voice, its qualities, the expressions you use, and the accents and dialect that reflect your heritage and life experiences" says Laura Van Nijkerk, a Speech and Language Therapist (SaLT) from Stafford.

> ***"As you will be realising, your voice is closely linked to your sense of identity and how people recognise and relate to you. So, when communication becomes difficult, electronic devices may be needed to support you to get your ideas and comments across. Thanks to technological advancements you can now record and capture the essence of your voice so it can be your words that are spoken using your voice."***

As we mentioned in the October 2020 issue of MSA News, we can now offer our members free access to a service (Acapela) which creates and banks a synthesised version of your own voice.

Laura explains ***"You can also 'Message Bank' which allows you to record and store phrases in their entirety, meaning that personal expressions such as 'I love you', the chant for your favourite sports team, or the lullaby you sing your child/grandchild, can be captured exactly as you say them, making them so much more meaningful and powerful."***

Laura says ***"You may be thinking 'there's nothing wrong with my voice at the moment, so I don't need to worry about that yet', but actually we would recommend that the earlier you can think about the personal phrases you want preserving, and complete the voice/message banking process, the better. Completing it early is quicker, less fatiguing and gets a better quality end result. So, don't delay, capture your voice and protect your sense of identity."***

Richard Cave is the SaLT project manager at the Motor Neurone Disease Association. He explains that it is really important to think about the device, app or software that a voice bank will be used with. ***"What kind of device or app works best for the person themselves? How this is answered will be different for many people, after all we all communicate in varying and unique ways, we choose our own words, we decide what we want to share. We also may have difficulties with movement, or additional requirements. The equipment must be easy to access and use and quick to get the message across. It should support (and not hide) our individuality as far as possible. It may be that a communication app could be installed on a device we already use and are familiar with, like a tablet or a phone. It is helpful to work with a SaLT to discuss options and try out different apps or equipment. The rule of thumb is to choose the communication app or device that helps you communicate what you want, as quickly as possible."***

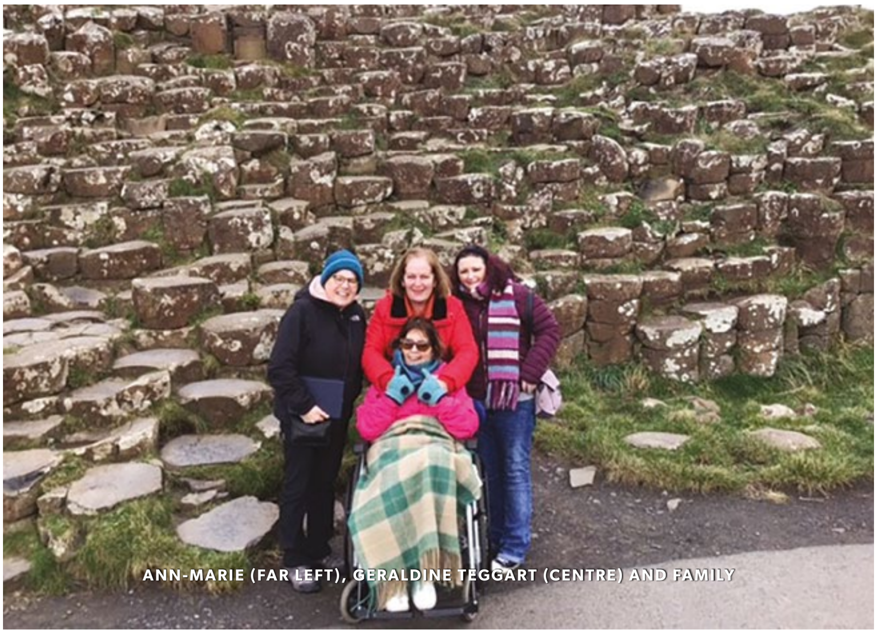
Ann Wathan has banked her voice using the Acapela service and found the process quite straight forward. She recorded the required 50 phrases in two sessions and used the option of listening back to each phrase before accepting it for banking. Headphones with a built-in microphone are needed for this stage (which the Trust can lend). Ann uses the system on a 7" tablet which works well for her because it's portable. She did some research into apps and settled on Predictable because Ann found it user friendly allowing her to build up a library of phrases she can use with just one tap on her tablet. For Ann one of the best things about using voice banking is that ***"it sounds like me and has a bit of a Welsh accent"***.

Another of our members, Geraldine Teggart, has significant difficulties with her speech so took the option of asking her cousin, Anne Marie McKigney to do the recording for her.

**Anne Marie said that she "found it very daunting" because she "wanted to get it right – I didn't want to disappoint Geraldine" but also felt it was a bonding experience and she felt privileged to have been asked.**

***"I found it helpful to have the support of my husband who is very IT literate throughout. I downloaded the Acapela app and got used to wearing the headset. I thought very carefully about reading the set 50 phrases, my tone, volume, and my speed, not speaking too slowly. The set phrases generate the synthesised voice and the additional messages are "handy hit on" stock phrases and sound as recorded. My primary piece of advice is Persistence and Practice!"***

Anne Marie says voice banking ***"has given Geraldine a voice and the fact that it's a synthesised version of my voice, means it's not overwhelmingly like my voice. I tried to say things in the way Geraldine would say them."*** Geraldine reports that she would be ***"lost without it"*** but it does seem ***"a little strange on family zoom calls to hear Anne Marie's voice come from me."***


ANN-MARIE (FAR LEFT), GERALDINE TEGGART (CENTRE) AND FAMILY

**Geraldine is delighted that the voice is one from South Armagh and that she doesn't "*have to sound like Joanna Lumley!"***

***If a person's voice has become too indistinct to use Acapela we can support them through another organisation called Speak Unique that uses a 'voice repair' system to aid communication.***

For more information about voice banking contact your SaLT or see: **www.msatrust.org.uk/voicebanking**. Alternatively, contact us at: **support@msatrust.org.uk** or call 0333 323 4591.

# Raise a cup for our *MSA Nurse Specialists*

We would be so grateful if you could help us raise vital awareness and funds to support the work of our MSA Nurse Specialists. They continue to be a lifeline for members affected by MSA. Holding a Tea Party on or around **World MSA Day, 3rd October** would be a great way to celebrate their commitment and expertise.

## *A Special Milk Sugar And Tea Party*

**WHEN:** ***Saturday 9th October - afternoon***

**WHERE:** ***Online - Zoom***

With so many of us now familiar with the world of Zoom, we ourselves want to host a special online Tea Party that anyone is welcome to attend. Join us for a Tea Party quiz, a talk from one of our MSA Nurse Specialists and find out ways to get involved with the special place for the MSA community, Sarah's Wood. For a minimum donation you will receive a pack ahead of the event which includes some goodies and complimentary tea. This will be a great way to stay in touch with the MSA community while raising vital funds for us. To register your interest, please email **fundraising@msatrust.org.uk**.

## *Your own Tea Party*

With restrictions easing up, you can have a small Tea Party gathering in your home, garden or a venue of your choice. Email **fundraising@msatrust.org.uk** or call the office on 0333 323 4591 to order your do-it-yourself pack filled with great ideas and complimentary tea. Alternatively, fill out the slip below and return to MSA Trust, 51 St Olav's Court, Lower Road, London, SE16 2XB.

Name:...........................................................................................................

Address:........................................................................................................

Telephone:.........................................   Email:.......................................................................

When will you hold your Tea Party? World MSA Day, 3rd Oct or Other ..........................................................

How many people are you expecting? ........................

Please tick any additional items you will need:

○ Collection tins   ○ MSA handheld flags   ○ Awareness raising leaflets