



msa *news*

MSA Trust Members Magazine | Issue 60 | February 2021

Vaccine, Research and Services

*with a New Season
comes New Hope*



Welcome to Issue 60

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Welcome to your latest MSA News. As we enter a New Year, we are all hoping for a new beginning. By the time you read this, the Covid-19 vaccine programme will be well underway, so heralding what should be light at the end of a very long tunnel.

I want to emphasise however, that having the vaccine does not mean people should let their guard down. The guidelines for keeping safe will remain in place for a while yet, so please try to follow them closely and maintain the good habits we have all had to adopt.

On a lighter note, this issue has a reminder for you of ‘who is who’ at the MSA Trust, so you know who to contact. We are here to support you so please do not hesitate to give us a call or email and we will do our best to help.

Finally, you will also see an update on research on page nine which I hope will be a great mood booster as the recruitment for drug trials all begin to roll out again.

Do keep safe and I hope you enjoy reading this edition of MSA News.

Karen Walker, CEO

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NEWS ROUNDUP

Voice Banking

A reminder about our new voice banking partnership with Acapela, funded by the Trust for our members. It allows you to record a short list of phrases with your own voice whilst your speech is still reasonably good. Voice banking helps to preserve your identity and enables you to express yourself verbally, should your voice deteriorate.

The process is simple, requiring a PC or Laptop and a headset with USB connection. Your voice can then be downloaded onto a laptop, tablet or similar device. Liaise with your Speech and Language Therapist who can advise if this is right for you. See more information on our website www.msatrust.org.uk/support-for-you/for-people-affected-by-msa/voicebanking.

We fund the fees to activate the synthetic 'voice' and we were pleased to raise £9,827 through last year's Big Give Christmas Challenge, making voice banking accessible to our members. We are so grateful to donors, pledgers and funder Candis Club who contributed. *msa news*



Virtual Clinics

With pressure on hospitals, and continuing rules around travel and social distancing, we know that face-to-face consultations with your health and care professionals have been limited. Many consultations have been conducted by phone or virtually using digital platforms. These are likely to remain part of healthcare even after the pandemic has subsided. We are keen on hearing your views of how things have been for you in terms of accessing health and care support, both good and bad, and what you think the Trust should be doing to ensure the ongoing support you get is not compromised and hopefully improved. Please email support@msatrust.org.uk to let us know your views. *msa news*



Critical Illness Cover

We have had several issues in the past year where people had been unable to claim critical illness cover on their insurance policy on the basis of their MSA diagnosis, simply because it was not on a prescribed 'list' of conditions. The Trust initiated a discussion with the Association of British Insurers to get things changed. We are delighted that a major insurer - AIG Life - has accepted our recommendations and changed their policy terms.

The groups covered now focus on

the impact on daily life for customers, not the name of the illness. If the impact is the same, the customer will be covered – whatever the name of the condition.

Our CEO, Karen Walker, commented "Congratulations to AIG for leading the way and recognising a pressing need to simplify critical illness cover. More insurers should be thinking as AIG has." We hope other companies will soon follow suit. *msa news*

Applications for New Trustees

We will shortly be saying a sad farewell to two of our Trustees – Amy Couture and Helen Craik. In a later edition we will thank them properly, but in the meantime, we need to begin recruiting their replacements. We want to welcome people from a range of diverse backgrounds to make us even more inclusive. If you know anyone who might be interested in applying please get in touch by email at support@msatrust.org.uk or call 0333 323 4591. *msa news*

Keep an eye out for vaccine scams

Calls and messages asking you to provide personal and financial details to book your COVID-19 vaccination are becoming more common. But these are scams. **The vaccine is free and only available from the NHS.** You will NEVER be asked to give financial information to receive it.



Caring about the Carer

Here at the MSA Trust we recognise the fantastic role carers play in supporting those they love, and we are conscious of the support carers require.

Being a carer for someone with MSA is usually something that evolves over time because of the situation you find yourself in. For many, being a carer will be an unfamiliar role, often one you feel ill prepared for and may struggle to adjust to. Caring can be very rewarding but it may also be isolating and exhausting. For example, understanding how to get help and how the health and social care systems work can be confusing and we know many carers leave it a long time before asking for help.

Seeking support at an early stage can be key to making arrangements work well - for the person you are caring for and for yourself. At the Trust we can be a starting point for any questions you may have. Diane Ball, our Greater Manchester Support Group Leader, cared for her late husband Geoff who was living with



DIANE & GEOFF BALL



MSA. She says “Finding the places you can get advice from was the biggest thing. Very early on Geoff himself got in touch with the MSA Trust – he would email Katie (Rigg, MSA Nurse Specialist) his questions and we found this very helpful.”

As a carer it is important to value yourself and to take steps to maintain your own wellbeing. Doing so will help you in your caring role and will benefit the person you are caring for too. Everybody is, of course, different, and each situation is unique but it can be enormously helpful to build a ‘circle of support’ around you and the person you are caring for. Your circle may include a mixture of family, friends and professionals, all of whom will have a different, but supportive, role to play. We know carers often try to ‘cope alone’ and try not to ‘worry others’ while those around them would often love to know how best to help. Try to be open about your own needs with the person you are caring for, with your family and friends, and with the professionals involved.

The current restrictions related to Covid-19 may mean that their support has to be offered in different ways. Some of the suggestions given below may need to be seen as options for a later date but can be discussed now.

Family and friends might take on specific tasks such as dealing with paperwork or setting up technology you are unfamiliar with. They may offer to visit on specific days each week (Covid allowing) or to accompany you both on hospital visits. They may offer to phone you, as the carer, at a regular time just to ‘check in’. Some may offer care support, perhaps on a rota basis, to give you a break.

If there are specific things that your family or friends could do don’t be afraid to ask. As Diane Ball says “it is about finding ways of explaining the things you need. You are the expert because you see the difficulties throughout the day.” Diane’s comments are also relevant in respect of accessing help from professionals. MSA is a complex condition and you should have ongoing contact with doctors, nurses, therapists and others who should be alert to your needs too. Diane says of the professionals involved in Geoff’s care “it really felt like we were a team.”

Adult Social Care services have a role to play in supporting carers. You can refer yourself for a ‘Carers Assessment’ or you can ask your GP to do so. A Carers Assessment is a detailed look at what your needs are and how these needs can be met. For example, you might wish to continue working or you may wish to have

a regular break (respite) or the help of carers on a daily basis. Perhaps there are social activities that you wish to continue. Some of these needs may be met by family and friends, others by a service arranged through Adult Social Care. Diane recalls “Respite was so important. We had a carer every Thursday afternoon for a few hours. We also had an old friend who was very specific in what help he wanted to offer – he offered to read to Geoff once a week for 2 hours. Geoff was so pleased and it gave me a break.” Diane also says “I always went to church (even if I was quite late), as it was an important thing for me.” Care support was provided to relieve Diane “We had a carer to help me every morning – this really took the pressure off. I knew if I had ever been ill someone else knew how to care for Geoff. It was such a relief.” Having a ‘back up’ plan is vital in helping to prevent a crisis should you be unwell or injured. Having regular care support may also

prevent you being unable to carry on because you are totally exhausted.

Most areas have Carers Centres which you can refer yourself to. These offer advice and support, for example about local services, about your employment rights and about claiming benefits

such as Carers Allowance. They also arrange meetings for carers. We at the Trust run a range of Support Groups specifically for people living with MSA and their carers. Diane recalls “At the local Support Group meetings I enjoyed meeting others and Katie (Rigg) who spoke so knowledgeably...” Diane also recommends online support “HealthUnlocked, Facebook MSA UK and Ireland and other forums are a great place to ask questions with very supportive communities.” [msanews](#)

Your GP should be aware of your role as a carer. You may be entitled to a flu vaccination (and a Covid vaccination) at the same time as the person you care for and the surgery may offer specific services for carers.

Useful Resources:

MSA Trust Helpline:

0333 323 4591

Carers UK:

www.carersuk.org

0808 808 7777

Family Carers Ireland:

www.familycarers.ie

1800 24 07 24

HealthUnlocked MSA community:

www.healthunlocked.com/msa-trust



Bowel Management in MSA

What is constipation? Why is it common in MSA and how can you best manage it? Our MSA Nurse Specialist, Katie Rigg, explains...

What is constipation?

Constipation is when:

- At least 25% of the time you strain to open your bowels or pass only hard pellet stools
- You open your bowels less than three times a week

- Your bowel does not feel cleared at first attempt or you need to assist yourself to achieve this.

Once the digestive process has extracted nutrients from our food what is left moves into the large bowel (colon). This semi-liquid waste passes down the colon where

fluid is removed making a formed stool. The formed stool stretches the muscles in our rectum alerting us to go to the toilet to expel it.

The longer the stool sits in our colon the more solid and larger it becomes and more difficult to expel. If the whole of the colon gets filled with increasingly solid waste,





the semi-liquid waste following down can't get into the colon and firm up, so it leaks around the sides of the solid matter and is passed as loose stool or apparent diarrhoea. This is termed overflow due to severe chronic constipation, not true diarrhoea.

Why does constipation commonly occur in MSA?

In MSA we know the autonomic nervous system does not work as it should and this, alongside the lifestyle changes caused by MSA, increase the likelihood of developing constipation. Speed and coordination of bowel movements are regulated by the autonomic system, which senses when the rectum is full and regulates stool consistency.

Lifestyle changes associated with MSA include altered diet, drinking less, moving about less and not sitting correctly on the toilet. The optimum position is with the knees slightly higher than the hips with the feet flat on the floor. Poor balance and trunk control whilst sitting on the toilet, or incorrect toilet height, prevents proper alignment of the lower bowel and reduces effectiveness of the pelvic muscles to expel stools.

Getting to the toilet or needing to wait for assistance to get there, as well as the time needed once on the toilet, can all result in the person with MSA 'holding on' or not completely expelling the stool. Both situations over time reduce the stimulus to open the bowels, causing further constipation.

The impact of constipation

Constipation significantly impacts on a person's quality of life. The time and effort of getting to the toilet and then not being able to open the bowel effectively; or coming away uncomfortable and needing to repeatedly go back to the toilet is debilitating. Incomplete clearance

of stools may cause bloating, abdominal pains, haemorrhoids, anal fissures, soiling and leakage. As a result, many people avoid going out and worry where the nearest toilet is all the time. You can find locations of accessible toilets at www.accessable.co.uk.

A full lower bowel can compress the bladder, increasing the need to pass urine, but outflow may be obstructed by the full bowel and this can increase risk of urine infections.

Constipation and bloating can impair diaphragm movement and breathing. Often people feel sluggish and fatigued when constipated and some medications, particularly Parkinson's medications, may not get absorbed properly.

What can be done to improve bowel movements?

- Timing and habit - Developing a habitual time to move our bowels can help. Often the most natural time to open our bowels is in the morning. Getting up and having something to eat and drink acts like a 'wake-up call' to the bowel – known as the gastro-colic reflex - that triggers the urge to empty the bowel
- Diet and fluids – Increasing fibre from fresh fruit, vegetables, whole grain bread and pasta will help. Soluble fibre in these foods bulks up the stool volume by absorbing water, so needing increased fluid intake; insoluble fibre from fruit skins and seed husks speed the bowel up
- Drinking plenty, particularly water and fresh fruit juices, keep bowel movements softer
- Moving around as much as possible. Even just standing up several times an hour, doing stretching exercises and chair exercises – anything that increases circulation will help the gut work better

Medications - laxatives taken with plenty of fluids and ideally daily, such as;

- Bulk forming – e.g. Fybogel (isphagula husk) – must be taken with plenty of fluid. Takes 2-3 days to work
- Osmotic laxatives – Lactulose; Laxido / Movicol – softens the stool by retaining fluid in the colon. Takes 2-3 days to work
- Stimulant laxatives – Senna; bisocodyl; sodium picosulphate – speeds the bowels up, usually works within 12 hours
- Stimulant and softener – Docusate – takes 2-3 days to work
- Rectal laxatives e.g. suppositories usually work within 30 minutes:
 - Glycerol - lubricates so may help clear any stool not completely expelled
 - Bisacodyl - helpful for incomplete passing of soft stool
 - Sodium phosphate / carbonate suppositories - have effervescent effect
 - Enemas – Mostly work within 5 – 15 minutes:
 - Microlax / Relaxit (Sodium citrate enemas) 5ml volume that may help clear hard impacted stool
 - Phosphate is a larger volume to clear significant hard impacted stool
- Colonic irrigations – may take 20-40 minutes to administer, 3 times a week e.g. Persiteen; Navina; Qufora; Aquaflush. These clear the lower bowel if other options have not resolved the problem.

msa.nhs.uk

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



In Memory

Earl Allen
 Mary Holt
 Stephen Ashworth
 David Walters
 Cheryl Wade
 Raymond Hendren
 Brian Lawson
 Hugh Harrison
 Robert Tucker

Linda Hewitt
 Reiko Wada-Hughes
 Dennis Smith
 John Withers
 Isabella Macfarlane
 Christine Roberts
 Kim Williams
 Brent Smith
 Anthony Welsh

Jonathon Green
 David Lee
 Peter Sheerin
 Alan Payne
 Colin Ashbridge
 Geoffrey Goodwin
 Peter Smallbone
 Janette Howarth
 Michelle Belinis

Alison Nicolle
 Patricia O'Connor
 Carole Clement
 Andrew Wagner
 John Bell
 Hilary Brimacombe
 Simon Coulby
 Majella Freeman

NEW YEAR, NEW SERVICES TO SUPPORT...

While we kept our core services going throughout the pandemic last year, this year we want to focus on new services that address other challenges we know our members struggle with.

Many members, especially those newly diagnosed, turn to the Trust for our information resources specific to MSA. We will soon launch the first of our webinar series to provide information in a more accessible format. In the coming months also look out for our new resource on Planning for the Future, which will feature on our website and for Emotional Support information which will be in a booklet format and on our website. We also hope to provide more information on the symptoms of MSA and will add four new factsheets this year that cover topics such as respiratory

support and issues with sleep.

The pandemic has sadly exacerbated feelings of isolation that comes with an MSA diagnosis, and we hope to combat this with our new befriending service. People with MSA will be put in contact via phone or online, with volunteers who have faced similar challenges and who can provide support and friendship.

Additional staff time and resources will be needed to deliver these new projects and we will be so grateful if you can help us towards this with a regular contribution. You can set this up online by visiting www.msatrust.org.uk/regular-giving or through your bank using a Standing Order mandate (email Tanya at fundraising@msatrust.org.uk for a form).

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Research Update

Open and Recruiting Studies

MSA can cause dizziness, light-headedness and fainting, due to a drop in blood pressure called Orthostatic Hypotension (OH). Theravance Biopharma are investigating a new drug called Ampreloxetine, to learn whether it can reduce symptoms of OH and assess its safety. Research sites in Birmingham, London, Guildford and Plymouth are currently able to see participants in a Covid-secure environment. Help can be given with transportation if needed.

A new study of Exenatide in MSA is now also open and recruiting. Exenatide is a drug used to treat diabetes and has shown potential benefit to people with Parkinson's Disease in previous studies. The open label, randomised controlled trial will be carried out at The National Hospital for Neurology in London, but people from any location can be considered for the trial if they meet the inclusion criteria and are able to travel.

The Trust continues to fund the PROSPECT-M study, which will follow people over time. PROSPECT-M is a study that will track disease progression and the aim is to inform earlier diagnosis of MSA in the future. This may enable future clinical trials to start at an early stage of MSA.

Please contact your MSA Nurse Specialist if you would like to find out more about any of these studies.

[msa news](#)

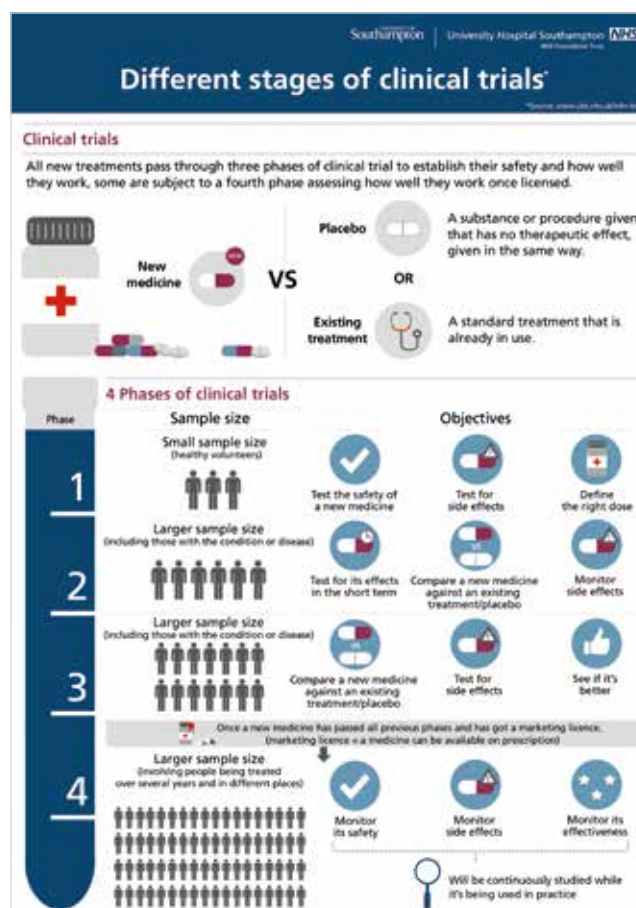
The Research Process

People often ask how long it takes to complete a clinical trial and have results that make a difference to clinical practice. This varies, but for a new compound it can take between 10-15 years. In recent years a method called 'translational research' aims to reduce the time taken for treatments to get from 'bench to bedside' and improve health outcomes. The infographic here explains the different phases a new treatment must go through;

after the discovery and pre-clinical phases there are three clinical trial phases to be completed prior to approval. In the UK new treatments must be approved by the Medicines for Healthcare Regulatory Agency (MHRA) and National Institute for Health and Care Excellence (NICE) before being available for use in the NHS. Once available, post-licensing or phase four clinical trials measure safety and effectiveness in the general population.

Recently, the time taken to gather data and approve a new vaccine for Covid-19 was reduced during the coronavirus pandemic by running the phases of trials concurrently, with the MHRA assessing data as it became available, to reduce time for approval.

[msa news](#)



Used with kind permission from Southampton National Institute for Health Research Clinical Research Facility



The MSA Trust – *Here to Support You*

The Trust continues to be here for everybody affected by MSA and we pride ourselves on our personal contact with members (which has been hit by recent Covid-19 rules). Here we outline who currently works at the Trust as a handy guide so that you know who to ask for...

Our aim is to support every person affected by MSA in the UK and Ireland. This includes people living with MSA, their family members and friends, carers and the health and care professionals that support them.

Our Helpline is open Monday to Friday, 9am to 5pm, except on Bank Holidays. This is the best way to contact us for general enquiries or for Fundraising queries. Call the office number on **0333 323 4591** and one of our team will be happy to help or point you in the right direction. We also have our email service at support@msatrust.org.uk or message us on social media – we're

on Facebook, Twitter and Instagram.

We run regular Support Groups which are currently being held virtually but we will eventually return to physical meetings as well. Contact us for details and invitations to these.

On page 19 you will find a summary of information materials including factsheets, guides and resources we are currently producing.

We hope you can use these pages as a directory if you need to contact any one of us. We are all here to support you.

MSA Nurse Specialist Team

Our four MSA Nurse Specialists – **Katie Rigg**, **Samantha Pavey**, **Jill Lyons** and **Emma Saunders** - each cover a different area of the UK and Ireland. For a map of who covers where, see www.msatrust.org.uk/support-for-you/nurses. They support people affected by MSA with any medical queries such as questions about MSA symptoms, medication and treatments. They can also help with referrals to health and care professionals, may attend clinics with your Neurologist and run training sessions.

Social Welfare Specialist

Jane Stein offers information and support about a range of non-medical issues. For example, she can advise on benefit entitlements and on how to access various forms of care support and carers services. She can help link people to local services and agencies and act as an advocate where necessary. Jane also runs our Grant Service and Lightwriter communication aid loan scheme.



Chief Executive Officer

Karen Walker's role is to support the team to achieve the goals set through our strategies, liaise with Trustees to ensure we are meeting our objectives and to drive the charity forward. She also takes responsibility for keeping the charity solvent and financially secure and ensures we invest in ground-breaking, innovative research.

Deputy CEO

Andy Barrick manages our Information and Support Services. He is also responsible for the wider policy and campaigning work that the Trust takes on. He works alongside Emma to edit and produce MSA News and complete projects such as the National MSA Needs Survey.

Information and Services Manager

Emma Rushton coordinates our Patient Information Forum accredited information provision including factsheets, MSA News, website content and new initiatives such as our webinar series. She manages many of the projects and information events the Trust holds, and you may well speak to her on the phone or by email when contacting us.

Services and Volunteer Officer

Nicole Adam is the main person who will help you if you contact the office by phone or email. She also coordinates all of our Support Groups, manages our volunteer network and works on a range of projects.

Services Administrative Assistant

Mandy Byrne makes sure that everyone who registers as a member is on our database system and gets the information they need. She also coordinates our Voice Banking service.

Senior Fundraising Manager

Tanya Mitra helps supporters donate in memory of their loved ones and can answer queries related to funeral collections, opening a tribute page or our memorial event, MSA Candlelight. She also oversees other aspects of fundraising such as donating regularly to the Trust, Gift Aid and Fundraising Appeals.

Events and Community Fundraising Officer

Bunmi Akinwale provides support to individuals who would like to raise funds for the MSA Trust, whether it's a solo, community or challenge event. She also deals with fundraising queries including donations, so please get in touch if you have an inspiring idea that will encourage any sponsorship.

Trust and Corporate Fundraising Officer

As well as making grant applications to charitable organisations, **Jennifer Ebrey** also liaises with companies that have the potential to offer us donations or fundraise on our behalf. If a business in your area is asking for nominations of charities to support and you would like to suggest us, Jennifer can help.



Managing Daily Living

Debra Gallant is a Parkinson's Occupational Therapist working at James Cook University Hospital in Middlesbrough. Here she explains about her role as an Occupational Therapist (OT) and how OT's support people with MSA...





What training do Occupational Therapists undertake?

Up to very recently an Occupational Therapist (often referred to as an OT as its easier to say!) has taken a three year degree programme to qualify as an OT. Apprenticeships have recently been agreed via the Royal College of Occupational Therapy so we will now have two routes for qualification. I have been qualified as an OT for over 20 years.

Where do OTs work?

OTs work in a variety of settings which often leads to some confusion, however, basically we either work in an NHS or Social Care setting. We are dual trained to work with both physical and mental health conditions. This is what really led to my special interest in Parkinson's and Parkinson's Plus conditions, and the ability to utilise all of an OT's skills.

Where do I work?

I am very fortunate to have worked for the Parkinson's Team at James Cook University Hospital, South Tees Trust in Middlesbrough for the last five years. Previous to this I have worked in mental health, an acute hospital setting and a Community Therapy service. Unfortunately, OTs who specialise in Parkinson's and Parkinson's Plus conditions such as MSA are in the minority. I know of only a handful of OTs across the UK who are lucky enough to have gained a specialist post.

Personally, I feel that this needs to change as people who live with conditions such as MSA require support and consistency from a familiar OT throughout their journey with MSA. People have often taken a rocky road before diagnosis and once this has been made, access to the full Multi-Disciplinary Team to guide you through any difficulties you experience is essential. This is best provided by an OT who has the specialist knowledge about MSA, experience and the skills to support you.

How can an OT help you? How can you get a referral to an OT?

If people are experiencing any difficulties in managing their daily life - be it carrying out a daily task such as dressing, eating, bathing, walking or participating in social or leisure activities then a referral to an OT would help. Often a GP will make that referral to either a Social Care OT or an NHS Community Health OT, and if you're lucky to have a Parkinson's Multi-Disciplinary Team then

it will be to the Parkinson's OT.

In the early stages of a diagnosis, a referral to an NHS Health OT would be advised to help you manage your difficulties by learning a new way of approaching tasks. OTs are often known as 'problem solvers' but we like to solve problems together with you - always focusing on 'what matters' to you. Equipment is sometimes needed to make your life easier and this is introduced only when necessary. I often make contact with my Social Care colleagues early on to support this. We can help you decide what options are available and acceptable to you, for example if ground floor living is required.

My adage is always 'plan for the worst and hope for the best'. Really that is the ultimate goal to help you live your life with MSA having the least possible impact.

There is a comprehensive professional guide produced by the MSA Trust 'A Guide to Multiple System Atrophy for: Occupational Therapists'.

What do you like best about your job?

I have always enjoyed my role as an OT but the last five years have been the most rewarding, being a part of the Parkinson's Team. I attend MSA clinics and I am introduced to people from the point of diagnosis not just late in the condition when problems start having a more significant impact on their lives. This is important as I feel OTs can offer so much more to people living with MSA throughout all stages of their condition by helping them to adjust their lifestyles. It may be as simple as helping people rekindle previously enjoyed hobbies, and being able to put you in touch with people who can help. I loved reading about the gentleman who was able to fly a plane again with the help of 'Aerobility' in a previous MSA News!

We have established some groups locally to enable people to participate in activities that may help their wellbeing; A Nordic walking group and choir and dance classes enabling people to keep doing the things that give them joy.

Sometimes it is just one small piece of advice that makes a big difference or something more major, such as provision of a Rotoflex turning bed for a lady who was going to bed before her children as she needed the help of a carer. This lady can now get herself in and out of bed whenever she wants.

Knowing that I have made a difference big or small - that's what gives me job satisfaction.

If you have questions about anything covered in this article please contact your Occupational Therapist or our MSA Nurse Specialists at support@msatrust.org.uk.

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Virtual and actual fundraisers across the world!

Lindsay Vernon, Chris Coleman and Tracey Forbes (based in Australia) and **Heather and Tim Magson** (in the UK), 'joined' forces and ran or cycled, to complete 13.1 miles in their respective countries on the same day. They together raised £2,283 – what a fantastic global effort! This was done in support of Lindsay and Heather's dad, David Perkins and Tracey's father who has MSA.



Trust member, **Julie Payne** (on horse) with friend **Janet Bayley** (right) did an exciting Halloween Trail Ride at the Naphill Riding Club and helped raise an amazing £670 while thoroughly enjoying the trail.

Mark Potter took part in a 26.2 mile walk in memory of his dear friend Earl Allen to mark the one-year anniversary of Earl's passing. Mark, his friends from the Ormson family and his four-legged companion, Lemmy, joined Earl's family to cover many Thames bridges on one cold December day. They raised over £3,000 for the Trust – well done everyone!



In the community

Jane Lightfoot made it as far as the 'Education Secretary' taking part in the 'Can you get to No.10?' quiz show hosted on Times Radio. She got her family and friends to donate for each question she got right, raising an amazing £505 in memory of her dear husband Chris Lightfoot. Well done, Jane!



Denise Wells hand knitted some amazing Victorian Christmas dolls during lockdown in support of her neighbour, David who has MSA. She sold them in her local area in aid of MSA Trust and raised a wonderful £150.

Partners during challenging times...

Our committed supporter Josephine Burnett did not allow injury setbacks to get in the way of her '10k per day for 10 days' challenge.

Josephine's resilience to carry on 'paid off' as she raised an incredible amount of more than £26,000 for the Trust in support of her father who has MSA. The timing could not have been more appropriate with many of the Trust's regular fundraising opportunities and events suspended due to the pandemic. We are ever so grateful to Josephine and her father's community of friends and family for their help when it was needed the most.

Josephine reflects on her experience:

"After four months of training, injury, rest, physio appointments, and a lot of mental anguish, on Saturday 26 September I finally finished my challenge. The original timetable was to do this as a running challenge back in June, but unfortunately a knee injury prevented me from going ahead as planned. Determined not to be defeated and to cover the distance somehow, I decided to walk it instead. The challenge involved walking 10km every day for 10 consecutive days, up and down the beautiful (but very hilly) North Devon coast path and around our local area. I am so pleased to have done this for such a worthy cause."

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JOSEPHINE AND HER FATHER



Veramed is a biostatistics consulting service and their employee, Nia Williams nominated the Trust for support in memory of her father, Gareth. Given the lockdown restrictions in November last year, 32 members of staff undertook an incredible virtual (local to their areas) walking challenge surpassing their initial target of one million steps to clock 6.5 million steps in total! They were able to double the £1,340 raised in sponsorship through match funding during the Big Give Christmas challenge, with all funds supporting the Trust's voice banking service. *msa news*



Our member, and Marks and Spencer employee Sheila Angus, nominated the Trust as charity of the year for their Inverurie branch. They kept the support going through numerous fundraising activities, the most popular of which were donations to the Trust in exchange for bags being packed for customers. We are exceptionally grateful for the £4,307 raised and especially thankful to store manager, Anette Gauld and local Trust volunteer, Yvonne Webster for their hard work and efforts.

If you work for or know of any company – be it local, national or international – who might be willing to support the Trust, please get in touch with our new Trust and Corporate Fundraising Officer, Jennifer Ebrey, via email at jennifer.ebrey@msatrust.org.uk. *msa news*



ANETTE GAULD, SHEILA ANGUS & ANGIE DAVIS



Supporting & Helping Each Other

By the time this magazine hits your doorsteps and inboxes it will be just under one year since we had to suspend our in-person Support Groups due to Covid-19. We have missed being able to meet each other and to share stories and tips over tea and coffee, but we are very grateful to all the members who have been able to join our Digital Support Groups over Zoom. Our members have continued to share support and advice and we have included some of their tips below.

One such piece of advice shared at our Northern England Digital Support Group was using very light wrist weights to help with severe hand tremors. This will not be suitable for everyone but might help stabilise the hand.

As winter really takes hold, staying cosy can be more of a challenge for people with MSA. One of our members recommended an Electric Footwarmer to keep feet warm. This is normally plugged in and has adjustable settings, some even have a foot massager built in. They can be found in many places including at www.completecareshop.co.uk. Another member found wearing compression socks helped them stay warm at night. They said they noticed a difference when they switched from normal woolly socks and that the new compression socks seemed to help more.

A carer at a Support Group raised the importance of carrying an 'emergency plan' on their person if leaving the house, 'just in case' something happened. This should include details stating that you care for someone, their name and address, any relevant medical information and an emergency contact.

Unsurprisingly Covid-19 queries have come up at almost all of our Digital Support Groups so we wanted to briefly discuss it here too. Government advice is frequently updated but at the time of publication the following advice is correct. You can get the most up to date advice from the MSA Trust on our website

www.msatrust.org.uk/covid-19 or by contacting us at the office.

Is the vaccine safe?

We recommend people with MSA have the vaccine when offered. There is no current evidence that the vaccines pose any greater risk to people with MSA. Any vaccine available through the NHS has been through the full safety assessment and approval process. If you normally have other concerns with vaccinations (such as allergies) discuss these with your GP in advance of any appointment.

Will I get to choose my vaccine?

You cannot choose which vaccine is offered.

When will I get the vaccine?

We would expect people with MSA to be vaccinated as someone with an 'underlying health condition'. Some members may be called upon earlier based on their age.

Contact your MSA Trust Nurse Specialist if you have any further concerns. msanews

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



Out and About, Come Rain or Shine

We were delighted to hear from some of our members about how they have been continuing to get their fresh air even during these difficult times. Coronavirus has disrupted life on every level for people with MSA and their loved ones, so it is wonderful to see people still able to enjoy getting outside.



Our member Hilary Brimacombe was also kind enough to share her experiences of biking in the great outdoors. Hilary's bike is a standard model Jorvik Tricycle. The bikes were originally manufactured for the designer's father who has Parkinson's Disease.

"I love it! It's great...it's also 'really cool' and I know this because my 15-year-old grandson told me so. It makes me feel like everybody else but someone who is really lucky because I've got "Nellie" my bike." Hilary's photos also show off her bike's very special feature, a basket that is the perfect size for a furry companion. Hilary's dog's enjoy the bike almost as much as she does.

You can find more information about Trike Bikes at www.icetrikes.co and Jorvik Tricycle's at www.orviktricycles.com. *msa news*

"We have a fabulous promenade here in Morecambe and it's absolutely ideal for Jenny to get out and about while we can walk Queenie, our little Lancashire Heeler, at the same time.

The photos show Jenny with Queenie on the trike and another with myself, Sarah (our daughter) and one of the carers enjoying the ramble.

Jenny has had the Trike for a few years now and it has been fabulous. As it is a recumbent bike, she is in an ideal position and although she can't mobilise herself anymore, she can pedal the trike, so it's great exercise for her. She loves getting out every day. Even in bad weather, she'll ask for her waterproofs and still go out. The weather has to be really bad to prevent her from an expedition.

The trike is an 'Ice Trike' made in Cornwall by a specialist cycle & trike company. It has about 18 gears, disc brakes, full suspension, lighting, double panniers and even folds for transportation. They are more or less made to order for each individual with the correct measurements for comfort and ease of use. We are usually out for at least an hour every day, so the dog gets exercised, but so do we." – David and Jenny Willan



Very sadly Hilary passed away just before publication of this magazine. Our thoughts are with her family and friends and thanks to them for wanting her story to still be told.



Why you should give MSA HealthUnlocked a try!

Four years ago this January, I became aware of some excellent forums on a social media site for medical conditions called HealthUnlocked. I subsequently encouraged the MSA Trust to support one for MSA. We could hardly have hoped for more success than we have achieved with now over 700 members who share one thing in common...an interest in MSA.

What is HealthUnlocked?

HealthUnlocked is a free to use social media site, based in the UK that has communities for specific health issues.

Where do I find HealthUnlocked for MSA? It couldn't be easier, just go to www.healthunlocked.com/msa-trust on any

web browser or download the app for your smartphone. There is also a link to it on the MSA Trust homepage and if you have any issues finding it you can always get in touch with the MSA Trust office at support@msatrust.org.uk.

Do I have to 'join' or pay a fee? You'll be able to see most of the posts without joining however, if you're a member, you will be able to write your own posts and see private postings. It's very easy to join and it's free. You can use your own name or a pseudonym – I use Yanno simply because that's a nickname of mine. You have to give your email address however, that's never shown on the screen or given to anyone else.

Why should I try HealthUnlocked? Have you ever wanted to chat to someone who understands what you're going through? Perhaps you have concerns over new symptoms; maybe you don't know what your medication is for; or maybe you just need to get something off your chest. HealthUnlocked has members who understand the MSA journey and use their time to share with others all that knowledge and understanding.



I'm nervous about joining something new?

We all feel a little apprehensive about joining something new however, with HealthUnlocked you can just observe from the side-lines to begin with. You will soon see some of the regular friends who you will get to know. I am there as Yanno; Freda, Jane, Paul, Helen, Diane, Chester (just to

name a few) have some great contributions. Once you get to know us, it's simple to ask your question, add your comment, have a rant or maybe shed a tear with others... just press 'Post' and away you go.

Who runs the MSA community? Every condition on HealthUnlocked must have a sponsor organisation and in our case it's the MSA Trust. The Trust Nurses monitor activity, occasionally commenting themselves, and this community has now completely replaced the previous forums which were on the Trust website. However, predominantly we run it ourselves and so should you wish to add something, just join in.

You must try HealthUnlocked and I'm sure you will enjoy and benefit from the conversations there. I look forward to seeing you in the forum and in the meantime hope you have as good a 2021 as possible.

Take care,
Ian Pickford (Yanno)
msa news

HealthUnlocked



Giving you the information you need...

The Trust provides a range of information to help you. The summary below is a useful list to keep handy...

We know that accurate, reliable and accredited information on all aspects of life with MSA can be hard to find. One of the Trust's key aims is to provide our members with the information they need at the time they need it. We send all new members an information pack, but we have a wide range of other useful information resources to follow this up.

Below is a summary of our factsheets which are available for you to download and read on our website here – www.msatrust.org.uk/support-for-you/factsheets. You can also contact the office and we will be happy to post them out to you.

This year we are also hoping to launch some new initiatives, most of which will be digital resources on our website. One of these is a webinar series presented by our MSA Nurse Specialists and Social Welfare Specialist. They will cover a range of topics including an Introduction



to MSA, Fatigue and Benefits Advice. You will be able to view these on our website in the coming months.

Results from our MSA Needs Survey indicated that people would value information tailored to address the emotional impact of living with MSA. To try and help with this we will be launching two new factsheets/ website resources this year written by a counsellor. These will focus on how people might be feeling following a diagnosis of MSA and the emotional impact of your journey with MSA, including how to access support.

Finally, we will shortly be adding to our website a section about Planning for the Future. Many members have said that they wish they had been able to be more proactive in terms of making plans and thinking about what they want to be organised in the future. This resource will aim to support with this and get people thinking. *msa news*

Symptoms and Management of MSA

A Guide to MSA	Diagnosis Of MSA
Carers Guide	PEG Feeding
An Introduction to MSA leaflet	MSA and Parkinson's Medication
Bowel Management and MSA	Eye Health and MSA
Continence in MSA	Sex and Relationships
Postural Hypotension	Complementary Therapies
Monitoring Blood Pressure	Saliva Control

Living with MSA

Driving and MSA	Going into Hospital
Travelling and MSA	Hospital Information Folder
Equipment - Communication, Eating and Drinking	Children's Activity Book
Equipment - Posture and Mobility	Understanding Palliative Care
Equipment - Personal Hygiene	Brain and Tissue Donation

I Wish I'd Known That a Year Ago - Finalised versions for: England and Wales, Scotland, Northern Ireland with Republic of Ireland in production

Our special place for the MSA community, *Sarah's Wood*

Located in Sherwood Forest, Nottinghamshire, the Wood continues to thrive. Launched in 2017 in honour of our founder Sarah Matheson, the Oak trees serve as a symbol of hope and resilience to all those living with MSA and inspire memories of those lost to it. There are various ways through which we hope you and others will get involved with Sarah's Wood...

By purchasing an engraved brick to help build a path to the centre of the Wood, you can symbolise the steps we are taking to fight, and eventually defeat MSA - our 'Path to a Cure'. For a donation, you can have a brick engraved with your name or a loved one's. We will ensure it is fixed in the ground to extend the Path and make it part of Sarah's Wood.

Please see below for how to place an order for a brick to be engraved.

Great opportunities during the year to visit the Wood and view the Path in person:

July - Afternoon Tea at our Sarah's Wood Summer Social with children's activities so families are welcome. Tickets go on sale soon!

November - Free tree planting sessions for those who wish to plant their own Oak saplings.

Please email fundraising@msatrust.org.uk to register your interest for these events. We will send you an invitation as soon as we have confirmed our plans. Do keep in mind we may have to postpone or cancel depending on Covid-19 restrictions.

Please call the office on 0333 323 4591 or visit our website - www.msatrust.org.uk/engraved-brick to make the donation of £60* and provide the name you would like engraved on a brick.

Alternatively, please raise a cheque payable to 'MSA Trust' and send to MSA Trust, 51 St Olav's Court, Lower Road, London SE16 2XB.

* Minimum donation.

The brick can be in support of someone living with MSA, or in memory of a loved one, but due to space constraints please ensure it is only the name you provide as we cannot inscribe any additional information. [msa news](#)