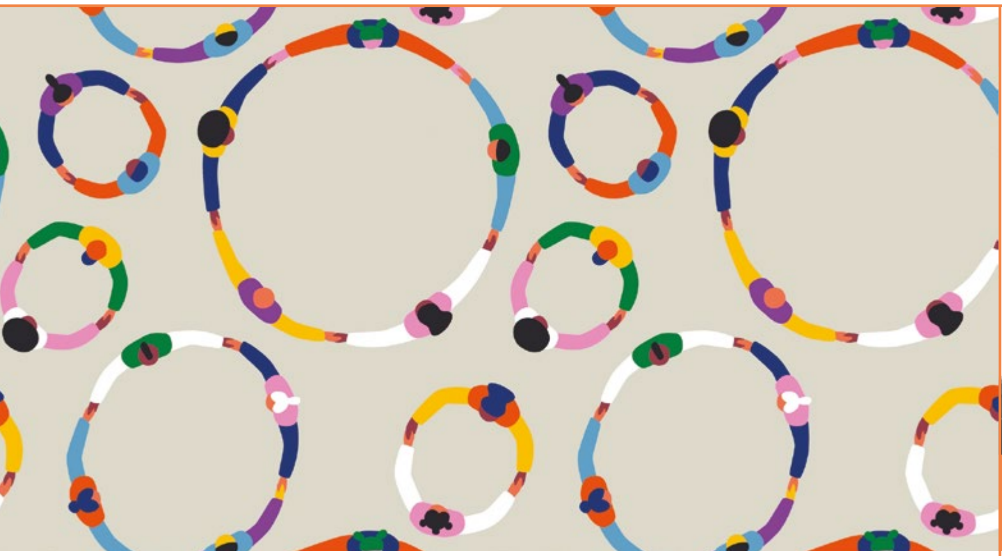
msa *news*

MSA Trust Members Magazine | Issue 72 | February 2025

Raising Awareness, Fighting Loneliness

and our 3,300 mile challenge



TACKLING LONELINESS - PAGE 12

Your Stories 03

Thank You Volunteers 04

News Roundup 05

Bowel Management in MSA 06

In Memory 08

Policy Work 09

Research Updates 10

Tackling Loneliness 12

Fundraising Roundup 14

Non-medical Practical Tips 16

Supporting and Helping Each Other 18

Raising Awareness of MSA 19

MSA Candlelight Event 20

CHIEF EXECUTIVE OFFICERS:
Karen Walker
Andy Barrick

MSA NEWS EDITORS:
Emma Rushton
Andy Barrick

ALL ENQUIRIES TO OUR NEW ADDRESS:
Multiple System Atrophy Trust
128 B Business Design Centre
52 Upper Street
London N1 0QH
Tel: 0333 323 4591
www.msatrust.org.uk

Registered Charity Number 1137652. Scottish Charity Number SC044635. Company Number 7302036.
Designed by Base Media www.base-media.co.uk. Printed by INQ Design 020 7737 5775.

Welcome to Issue 72

Hello and welcome to your first MSA News magazine of 2025. Whether this is your first time reading MSA News, or you have been receiving the magazine for many years, we hope you will find informative and interesting articles in the following pages.

It has been a hard winter for many and we know some people affected by MSA have been struggling during this time. Our Social Welfare Specialists share some practical tips on pages 16 and 17 on ways to ensure you are making the most of your entitlements. On page 12 one of our MSA Nurse Specialists looks at the impact of loneliness and ways that you can try to manage this.

We also wanted to highlight that over this year we will be looking at the impact the MSA Trust has on our MSA community. We will be asking you to help with some surveys and other activities. Please keep an eye on your inboxes, mailboxes and on social media for more throughout 2025.

March is MSA Awareness Month so in this edition we are highlighting some of the great ways our supporters raise awareness of MSA, and give details of our new grants programme on page 19.

We hope you enjoy reading this edition.

Emma and Andy

Your Stories

Jonny, a keen cyclist, is living with MSA. Here he describes how he continues with the sport he loves on his trusty tricycle.

"I had always been a keen cyclist. I was one of the first to get an electric bike in our local village, where we had lived on Lake Como for 26 years. Suddenly I could climb up steep hills and discover the remote mountain villages near our home. I could keep up with the Italian athletic cyclists dressed in colour-coordinated lycra, with their shaved legs and bulging calf muscles. Going up very steep hills, I would often overtake them. Much to their annoyance!

> **OK, so my wife needs to help me on and off it. But I still get that feeling of freedom with the wind blowing in my face as I pedal the pathways.**

Occasionally I would take a tumble, especially when looking behind me prior to making a turn. I put this down to my life-long clumsiness.

I also had a few balance issues but put this down to my ageing knees. In May 2023 I had a full knee replacement on my right knee and found myself using a walking stick for support. But I was concerned that my balance had not improved so went to see my GP. He sent me to see a neurologist.

I got a diagnosis of MSA-C on 1st September 2022. As the Consultant described the various stages I would encounter during the MSA journey, I heard myself gulp. I asked him if it would affect my cycling and he said there was no way I should be out on a bike. That hit me almost as hard as the diagnosis itself.

So, the very next day, I started researching tricycles and came across numerous different options. My goal was to not give up the sport I love.

There were many things to consider: Folding or rigid frame? Middle or front hub motor? Number of gears? Weight? Battery Life? It was all mind-boggling and involved many hours of research and asking lots of questions in the online forums.

Eventually, I found a trike ideal for my needs. It took some getting used to. It requires both patience and caution. It's very different from riding a 2-wheel bike. Although three wheels give you more stability, great care is needed when riding on uneven surfaces. A camber taken wrongly can tip you off. But if you remember to lean away from the camber, you will be fine.

It's now over two years since my initial diagnosis and although my walking is now bad enough to require a walking frame inside the house and a wheelchair outside, I can still ride my trike. OK, so my wife needs to help me on and off it. But I still get that feeling of freedom with the wind blowing in my face as I pedal the pathways".

msa *news*

Celebrating Our Long-Serving Volunteers

Our in-person Support Groups couldn't run without a network of wonderful volunteers. But few have been with us as long as Brenda, Dennis and Betty from the Devon Support Group. They've been volunteering for an incredible 16 years!

We asked them what volunteering means to them.

How did you start volunteering with the MSA Trust?

Dennis: I was initially diagnosed with MSA around 2005. After more tests I discovered that I had a hereditary condition that is controlled by medication. At that time the MSA Trust was looking for volunteers to run a Support Group in Devon so I took up the challenge.

Brenda: I started volunteering with the MSA Trust as my husband was living with MSA. We didn't know of any support groups in our area or anyone else with the condition.

Dennis: On my first support group meeting in Barnstaple I met Brenda and her husband. Brenda kindly decided to help me in a volunteer role.

What do you do as a volunteer?

Brenda: I always chat to people and make them welcome at our meetings. Being a member of Cullompton Baptist church means I can book the room at no cost to the Trust.

Dennis: Brenda brings a home-made cake for us, and my wife Betty and I bring extra refreshments. Brenda and Betty organise the tea and coffee. We have our MSA Nurse Specialist at these meetings for advice and support. After discussions it turns into a lovely social afternoon which everyone enjoys.

You've been volunteering for a long time. What keeps you involved?

Dennis: What keeps me volunteering is the thought of it helping everyone and their partners or carers who also come along.

What is the best thing about volunteering with the MSA Trust?

Brenda: The best thing about volunteering is working with Dennis and Betty to provide a place where people with MSA and their carers can meet and spend an afternoon in a different environment, and discuss openly the circumstances they find themselves in.

Dennis: I love seeing everyone leave happy. I enjoy working as a team with Brenda and Betty.

DENNIS AND BETTY

Thank you to Brenda, Dennis and Betty from everyone at the MSA Trust. Their dedication and support has made a huge difference to so many people over the years.

If their story has inspired you to become a Support Group volunteer, email us at **volunteer@msatrust.org.uk**. We can help you use your skills and experience to help others.

msa news

NEWS ROUNDUP

Supporting us Through Gift Aid

giftaid it

If you are thinking of donating to the Trust you could increase the value of your donation, or regular donations, at no extra cost through the government's Gift Aid scheme. The Trust can claim 25p for every £1 donation, but you must be a UK taxpayer and pay more, or at least equal to, the amount we reclaim. We can claim Gift Aid on your current donation as well as any you have made to the Trust in the past four years.

You need to let us know your gift is eligible by completing the enclosed declaration form and returning it to us, or ticking the Gift Aid box when donating online. If your tax paying status changes you need to let us know so that we can stop claiming. Please give our office a call if you are not sure if you are eligible and we will assist you. msa *news*

Thank you for Completing the Neuro Alliance Survey 2024

A huge thank you to all of our members who took part in the Neurological Alliance's 'My Neuro Survey 2024'. Over 9,500 people affected by neurological conditions took part, including those from all four UK nations and Ireland.

They will now analyse the responses, and we should get the first findings in mid-2025, which will include specific information about the particular issues for people affected by MSA. We will report back on these in MSA News and will use them to improve our services and those of others.

We really appreciate our members taking the time to help with this and our other engagement events, it really does help our wider MSA community. msa *news*

Sarah's Wood Tree Planting

In November, we welcomed over 80 of our members to Sarah's Wood in Nottinghamshire for our annual tree-planting day. Together, we planted 250 oak saplings in honour and in memory of loved ones affected by MSA. To date, we have planted over 1,000 saplings in Sarah's Wood. Find out more here - **www.msatrust.org.uk/sarahswood**. msa *news*

2024 Christmas Appeal

Thank you to everyone who donated to our 2024 Christmas Appeal. All raised funds will go towards continuing the Support Group services we provide. Your support has made a huge difference, enabling anyone affected by MSA to access the help they need.

We exceeded our target and reached an incredible £8,000. Thank you for your marvellous generosity and support! msa *news*


OUR ESSEX SUPPORT GROUP

Coming Soon…

We are delighted to announce we will soon have an additional partnership with ElevenLabs, a pioneer in AI audio and voice technology, to provide a free voice banking service for people diagnosed with MSA. We will be providing free access to ElevenLab's voice cloning service and text-to-speech App for our MSA Trust members. Voice Cloning is the same as Voice Banking. By preserving your unique voice, the initiative aims to maintain a crucial aspect of your identity. Your voice can be used on a smart phone, tablet or laptop.

Look out for more information on our website soon. msa *news*

BOWEL MANAGEMENT

What is *Constipation* and *How to Manage it*

Our MSA Nurse Specialist, Debra Vincent-Scott, looks at the difficulties that people living with MSA can experience with constipation and how this might be managed.

A person is considered to be constipated when bowel movements result in the passage of small amounts of hard, dry stool, usually fewer than three times a week.

Hard, dry stools are the result of the colon absorbing too much water. Normally, as food moves through the colon (also known as the large intestine) the colon absorbs water while forming stool (waste products). Muscle contractions then push the stool towards the rectum and by the time the stool reaches the rectum, most of the water has been absorbed, making the stool solid.

Movement of food through the digestive system is controlled mainly by the autonomic nervous system. The autonomic nerves act to keep food moving steadily through the bowel to the rectum. Normally you are unaware of this process. These nerves also send messages to the bowel to enable us to eliminate faeces on a regular basis. In conditions where the autonomic nerves are impaired, such as in MSA, the movement of food through the digestive system becomes disrupted. The whole process becomes slower and can be uncomfortable and unpredictable. This slowing down results in more water than usual being reabsorbed by the colon.

Constipation in MSA

Constipation is common in people with MSA. Some people don't recognise it as a problem because it has become 'normal' for them. Constipation in MSA can be caused by some of the following:

- **Not going to the toilet in time or not going to the toilet when you need to.** The longer the stool remains in the body, the more fluid is reabsorbed through the bowel wall, making it dry. This can make it harder to push out stools.
- **A lack of physical activity.** If you find it difficult to move around or exercise, this can also mean your bowel isn't stimulated to work properly.
- **Eating problems.** If you find it difficult to chew and swallow food, it's harder to have a diet with plenty of fibre, which helps to keep stools soft and easy to pass.
- **Not drinking enough fluids.** This can cause stools to be harder and more difficult to pass. This can get worse during hot weather.
- **MSA can affect the muscles in different parts of the body.** It might become more difficult for you to contract your abdominal muscles, and the anal sphincter may not relax at the right time to allow you to pass the stool easily. Sometimes the sphincter tightens when it should relax, which can make emptying the bowels difficult.

If you have severe constipation, you may feel unwell, tired and nauseous. You might experience abdominal pain, acid reflux and bloating. You may also experience weight loss or weight gain.

You may feel you have to strain to pass a stool, or that your bowel is not empty even after you've passed one. If you strain a lot, you are at greater risk of getting haemorrhoids (piles).

If you are constipated, the bowel can become loaded with hard stools and you might find it difficult to pass anything. This is called 'impaction'. If you experience impaction, your bowel may overflow, and there can be accidental leakage of lumps of stool or a brownish mucus that looks like diarrhoea. If this happens, you'll need urgent medical attention and should contact your GP or call 111.

Here are some things you can do to help with constipation issues:

- Be aware of your bowel movements and aim to keep these as they were before you had MSA – amount, frequency, consistency
- Using a regular daily laxative to keep your bowel moving steadily is better than waiting until you can't go and then trying to resolve the problem
- Drink plenty – laxatives will not work if you do not have enough fluid in your system.

There are several medications that can be helpful for constipation. Below are some commonly used examples; however, there are many others available. They all work in a similar way so do not worry if you have a medication for your bowel of a different name to those mentioned.

Make sure to speak to your GP or Specialist about these possible medications.

Stool softeners such as Liquid Paraffin, Movicol, Laxido, Lactulose or Docusate work by helping to keep fluid in the stool, thus keeping it soft. It is important to drink plenty to help these work effectively and reduce the risk of getting dehydrated, as more fluid is lost through the bowel when using these medications.

Stimulants such as Senna, Bisacodyl or Dulcola. These medications increase the bowel muscle contractions and speed of movement through the bowel. They are sometimes used together with softeners. All can cause cramping discomfort.

It is important to treat and manage constipation. Please speak to your GP, Specialist or MSA Health Care Specialist if you are having difficulties. msa *news*

In Memory

Caroline Witts
Anne Baitey
Stephen Anscombe
Jo Quinn
Heather Hembrough
Marie Richardson
Emer Morgan
Michaela Park
David Franklin
Paul Brackley
Philip Senior
Ian Walker
Michael Pritchard
Jason Denbow-Arnold
Lynda Paterson
Christopher Harris
Paschalis Mouscos
Karen Day
Valerie Higginbotham
Des Thompson
Michael Spafford
Aileen Hunter
Martin Welburn
Gwen Jimmieson
Susan Laming
Perry Wilsher
Jill Howell
John Cann
Shirley Farquhar
Ernest McGeorge
Phillip Cullum
Steve Oatway
David Knight
Tina Fitzpatrick
Graham Wills
Sandra Bell
Susan Phillips-Waring
Irving Goldman
Susan Blackwell
Susan Atkins
Ian Williamson
Michael Davis
Luisa Bracco
Avril McGarry
Stephen Richardson
Stephen Davis
Elizabeth Conway
John Ripley
Fridrik Thorsteinsson
Sheila Hill
Bertie Hunter
Mark Pepperday
Peter Cunningham
Michael Sayer
Christopher Vowles
Hugh Clark
Paul Wheeler
Diane Goddard
Richard White
Penny Blanch

SUSIE'S LEGACY

WRITTEN BY HER FAMILY

Susan (Susie) Lackie's artistic journey began in the 1980s with a City & Guilds course in Needlework, which ignited her passion for embroidery. Her use of texture and colour was seen in every piece she created. She transitioned into teaching adult classes and organised exhibitions of her student's work, many of which were displayed in the Millennium Embroidery in Sunbury-upon-Thames.

Sadly, her career was ended when MSA robbed her of the dexterity needed for needlework. Susie and her family then had to deal with significant challenges with her MSA diagnosis, her husband's sudden passing and her own subsequent additional separate diagnosis of advanced dementia. Her daughters prepared for the worsening journey, and with the help of carers had to navigate everything from incontinence (exacerbated by Susie's inability to navigate a catheter due to her advanced dementia), to frequent falls, memory loss and the inability to swallow. Susie's condition worsened rapidly, and as Social Services could not keep up with the deteriorating situation, it culminated in her being placed in a care home and then eventually her peaceful passing in July 2024.

"The MSA Trust was a guardian angel we could access and feel they understood us and the journey we were on. However, with both diseases we had a very hard, long and difficult road both physically and mentally for six long years." – Susie's daughter, Caroline Laspas.

The family has kindly donated many of Susie's fantastic embroidery pieces to the MSA Trust. These are available for purchase from our online shop **www.msatrust.org.uk/shop/handmade-art**.

We are grateful that Susie's work and legacy can be used to raise vital funds for the MSA community, thank you. msa *news*

Our Policy Engagement

In recent years we have conducted two MSA Needs Surveys which have been the largest ever surveys of people affected by MSA. These have proved to be invaluable to us in terms of improving our services. They also provide an evidence base so that we can press for better overall services and support in wider society.

Although our support services and research will always be our priorities, we also engage with policymakers where we can see that issues are of key importance to you, our members.

As well as health issues (including mental health) these include social care, benefits and education of health and care professionals. We regularly respond to NICE guideline consultations, and we are currently involved with looking at how palliative care (and hospice support) can be improved for people with neurological conditions, such as MSA.

Where possible we also engage with the devolved nations and Ireland, and as a general rule we try to join in with other organisations who represent people with similar issues, such as the Neurological Alliance and the Specialist Health Care Alliance, so our voice can be amplified.

As always, we are guided by the needs of you, our members, so if you feel that there are issues we should pick up, please let us know. msa *news*

Terminally Ill Adults (End of Life) Bill

Over the last few months there has been substantial focus on the issue of Assisted Dying for terminally ill adults. Legislation has recently been proposed in Scotland, Ireland, the Isle of Man and in the UK House of Commons.

The MSA Trust has a neutral policy on the issue. From our Needs Surveys we know that our members have differing views on this subject.

The latest discussion took place in the House of Commons in late November where the Terminally Ill Adults (End of Life) Bill passed its second reading. The bill aims to "allow adults who are terminally ill, subject to safeguards and protections, to request and be provided with assistance to end their own life."

This now means that a committee of MPs will look at the Bill in more detail and suggest amendments. It will then come back to the House of Commons for a third reading to be voted on again, where MP's may still decide to vote for or against this. If the vote is in favour, then the Bill would go to the House of Lords for further discussion. It will become law only if both Houses of Parliament agree.

If passed, this law would apply only to England and Wales but as mentioned there is legislative activity in other parts of the UK and Ireland.

The MSA Trust exists to support people affected by MSA and we respect the differing views of our members. Where we see opportunities to improve support provided, such as in care co-ordination, improved palliative care services and end of life choices, we will continue to highlight the views and needs of our members. msa *news*

Research Roundup

Movement Disorder International Congress

In autumn 2024 two team members represented the MSA Trust at the International Congress of Parkinson's Disease and Movement Disorders, in Philadelphia. Emma Rushton, Head of Operations and Emma Saunders, MSA Nurse Specialist, had the opportunity to find out about the latest clinical and research information and met with MSA colleagues from all over the world. They were able to promote the work of the Trust and identify opportunities for collaboration and research moving forward.

OUR TWO EMMA'S

MSA Trust Research Strategy Update

We are committed to supporting MSA research and are the main UK funder of research into the condition. Research activities are directed by our Research Strategy which is compliant with the criteria for research standards of the Association of Medical Research Charities (AMRC).

The development and implementation of the Research Strategy is led by an independent Scientific Advisory Panel (SAP). Membership includes experts in clinical, scientific and research aspects of MSA, and people whose lives have been affected by MSA. SAP members draw on their experience and knowledge in the field of MSA to determine research priorities that are pertinent to finding the cause and cure of MSA.

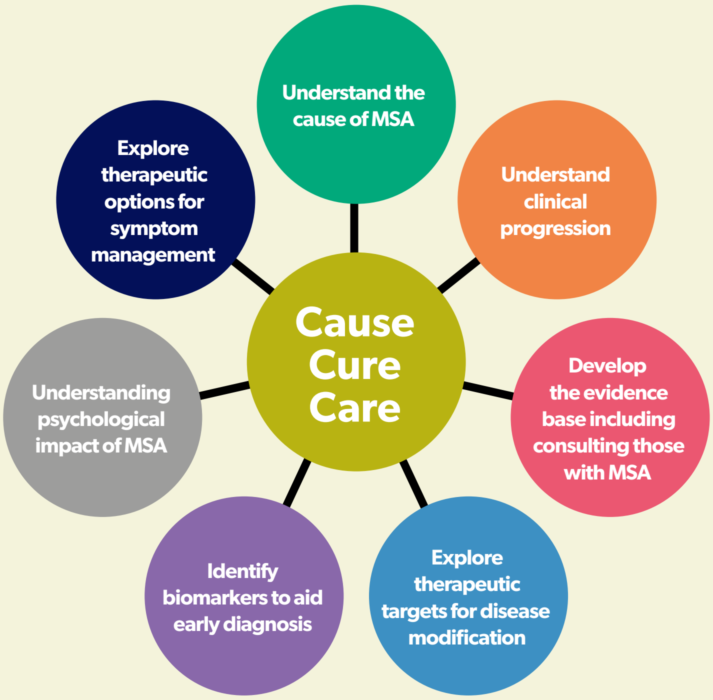
Over recent months, the SAP have reviewed and updated the MSA Trust Research Strategy. The updated strategy will be published soon and will detail in full the MSA Trust Research Priorities. These are:

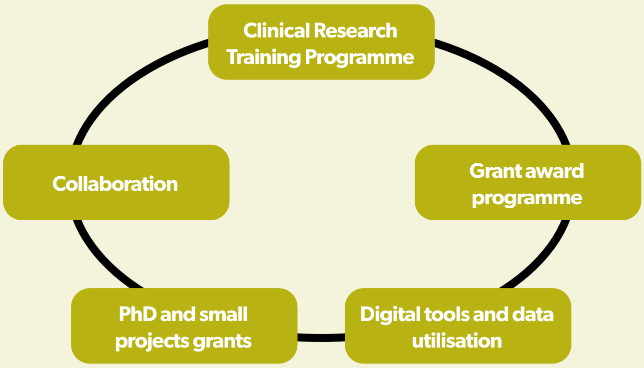
- **Understanding the cause of MSA**
- **Understanding the clinical progression of MSA**
- **Developing an evidence base to inform and improve clinical care for people with MSA.**

It aims to do this through a focus on research that furthers understanding in the following areas:

- **Biomarker identification – finding a test e.g. a blood sample or skin sample that can accurately and objectively diagnose MSA**
- **Disease modification and symptom management – finding treatments for MSA and for the symptoms that MSA causes**
- **Mental health and quality of life.**

Our research priorities and the methods to facilitate these include:





More details can be found in the Strategy, which will be available on our MSA Trust website.

Don't forget to regularly check the online research hub for research news, updates and opportunities.

Research Symposium

On the 25th April the MSA Trust will be holding our third annual MSA Research Symposium in collaboration with University College London (UCL). The symposium is a chance for researchers to present their findings to the MSA research community and provides an opportunity for MSA researchers to meet, network and collaborate. Registration is open so please encourage your Healthcare Professionals to visit the MSA Trust website for more information - **www.msatrust.org.uk/event/msa-research-symposium**.

Research Results

Professor Anja Lowit summarises the results of a recent MSA Trust-funded study about Speech Therapy for people with MSA-C.

"Speech difficulties are an early symptom of MSA and can have significant impact on people's quality of life. Although a few studies have recently shown that speech can improve after therapy, they used intensive treatment models that are not always possible to deliver under the NHS. Our study compared two alternative types of therapy. The first modelled the therapy often provided by the NHS, i.e. one individual session a week over six weeks. The second type, ClearSpeechTogether, consisted of a novel approach which combines individual with group therapy. Patients received four individual sessions over two weeks followed by four weeks of daily, patient led group practice resulting in 24 sessions in total. Our study aimed to establish whether either of the two therapy types could have communication benefits for people with MSA-C, how acceptable the therapies would be to individuals and how feasible it would be to compare the two therapy types with each other in a larger trial to test their effectiveness.

We recruited 24 people, of whom 20 completed all treatments and assessments. Nine took part in the NHS type therapy, and 11 in ClearSpeechTogether. The study was delivered entirely online. A number of participants required additional support with using the technology for the online meetings, but everybody managed to join the sessions. Attendance was good in both therapy groups, and nobody in the ClearSpeechTogether group reported any negative impact from the intensive therapy on their energy levels, although some felt the meetings could have been a little less frequent. Both therapies resulted in some participants showing improved voice quality, breath support, and how well they were understood by others. The biggest improvements were observed for people's confidence and how much their MSA affected their participation in communication. Our study therefore suggests that there is value in providing speech therapy to people with MSA-C to improve their ability to communicate effectively.

Based on the outcomes of this study, we will now apply for further funds to run a larger trial to provide therapists with the necessary information on how to best support people with MSA-C".

Full results of this study will be available soon. msa *news*

Find out more about Speech and Language therapy here - **www.rcslt.org/speech-and-language-therapy** or speak to your MSA Health Care Specialist who will explain how you can access speech therapy.

Staying connected

In 2022 a government survey indicated that half of all adults in the UK felt lonely occasionally, sometimes, often or always. Katie Rigg, MSA Nurse Specialist writes about how people living with MSA may experience loneliness and suggest some tips on how to ease this.

Most people at some point in their lives will experience loneliness. For some it is situational and triggered by something. For example a common trigger for many people is to feel lonely at Christmas time.

It is a feeling that is particular to the person and their circumstances. Loneliness occurs when the quantity and quality of the social relationships we have at that time are less than we want.

Our vulnerability to feeling lonely can be increased by factors that constrain our access to the social relationships we want. For example, if we have to move to a new area further away from family and established friendships; when children move away from home; or at times of bereavement of a significant person.

People with a significant health condition will often be more susceptible to feeling lonely as the condition may impact on their independence to get out and about to engage with activities and meet people. Not only does a significant health condition impact on physical access to maintaining and developing relationships, but also how we feel about ourselves and our desire to socialise.

Our self-esteem can be undermined by changes to our appearance, posture, ability to move swiftly and communicate fluently. When physical function is impaired by a condition there is increased anxiety and loss of self-confidence to manage situations we may find ourselves in. Previously we may not have given a second thought to doing something or going somewhere but that can now feel overwhelming and put us off from continuing to do things that gave us positive social interactions.

> ***Linking in to MSA Support Groups can be a good way to start trying to overcome the anxiety about being with other people.***

A diagnosis of MSA can compound the vulnerability to loneliness as anxiety, fatigue and poor sleep can be significant symptoms of MSA and the effort to socialise can feel too much. MSA being a rare condition means there is limited awareness and understanding of MSA amongst many professionals, and the general public. A person with MSA may perceive this as a lack of empathy for their situation and this can increase the feeling of isolation.

Linking in to MSA Support Groups can be a good way to start trying to overcome the anxiety about being with other people. Everyone attending the groups understands MSA and the impact is has, so it can feel a safe environment knowing no-one judges if posture is not great or speech is tricky. Often initially attending groups online can feel really safe, as you are in the comfort of your own home and can leave if it feels too much.

Attending a face-to-face meeting can lift the spirits by getting you out of the house and having a purpose and goal. Although it may feel daunting attending a group for the first time some good support and friendships have been forged at the meetings. Often people will share their contact details and keep in touch between meetings as mutual support.

Allowing friends to keep in contact and come alongside as things change for you enables them to continue to be the friends they want to be. If the roles were reversed you would want to support your friend if they had MSA.

You might want to think about where you meet up if you need a quieter environment if your speech is less clear or need somewhere you can easily get in with a wheelchair. Having friends visit you at home can allow a partner or carer to do other things whilst they are visiting. Also, being in your own space may help you feel more relaxed and able to manage any needs you may have over the time someone is visiting.

Having two or three friends visit together means you can still be part of the conversation even when your speech may be less spontaneous or difficult. It will help to not feel pressured to interject but still hear all the chat about things you would share together.

Some people find it easier to go out and join in things if there is purpose for doing so. Seated exercise classes or singing groups can be a great way to have time with other people. Brain chemicals released by being with other people, doing exercise and singing have a positive impact on mood. You will not be alone hitting a 'bum' note or unable to do an exercise. Being able to laugh about that with others is the main thing! Opportunities to reduce loneliness can be missed if we become too self-conscious.

Our '**Living with MSA: The Emotional Impact**' resource has a section on building your support network, which you may find helpful. You can access it here, or contact our office for a hard copy booklet - **www.msatrust.org.uk/living-with-msa-the-emotional-impact**. msa *news*

Fundraising Stars

LEANNE AND VICKY WELLINGTON

Throughout 2024 Leanne and Vicky have been walking 64 Dartmoor Tors in honour of their mum, Vanda, who sadly passed away in October 2023 at the age of 64.

"Growing up, we would often go for walks on the Moors, so this feels like a fitting challenge and tribute to raise money for the MSA Trust. We hope that family and friends will join us along the way."

They completed Tors 62, 63, and 64 at the end of December and raised over £1,000 in aid of the MSA Trust. Thank you so much for your generosity and support taking on this huge challenge! msa *news*

Celebrating Special Occasions with the MSA Trust

ANDY AND LOZ

Andy and Loz Jackson have been supporting the Trust throughout 2024 following Andy's MSA diagnosis. They have been fundraising and have helped raise awareness during their recent "Season of Blessings" ceremony.

Loz "commandeered" Andy's bucket list, which included a wedding blessing and a visit to a French chateau with friends and family. Their fundraising efforts were rounded off at the Newick Bonfire Society's annual bonfire collection during the spectacular parade.

Andy's diagnosis of MSA is devastating. But as they say in the Jackson tribe, ***"We refuse to be devastated."*** The total raised was £3,020 and T-shirts have been worn across the globe to raise awareness in orange! msa *news*

If you have an upcoming celebration, such as a wedding or birthday, contact fundraising@msatrust.org.uk for more information on how you can help raise awareness and funds on your special day.

3,300 Mile Challenge

March is MSA Awareness Month, and we will be launching our annual 3,300-mile challenge to help raise awareness and funds during this time. We invite all our members to join this upcoming walking challenge to support the 3,300 individuals in the UK and Ireland living with MSA.

Simply sign up and connect your Strava or other fitness devices to monitor your progress throughout March. Whether it's a casual stroll to the shops, a lap around the garden in your wheelchair, or a family walk, every mile adds up. Together, we aim to cover 3,300 miles, representing one mile for each individual living with MSA in the UK and Ireland.

Join us and let's support the Trust and raise awareness with every step we take - **https://register.enthuse.com/ps/event/3300MilesinMarch2025**. msa *news*

SCAN ME

Raising Awareness in your Communities

We know that MSA is not widely understood and our MSA community often spend considerable time explaining it to their loved ones and healthcare professionals. When our members take it upon themselves to give talks in their communities, sharing their journeys and raising awareness of MSA, it has a big impact.

Stephen Rose, who has undertaken numerous fundraising efforts in memory of his wife, Vivien, recently gave a community talk to help raise awareness of MSA.

"My talk about MSA and Vivien's journey was given to an audience of around 250 people at a community meeting of The West London Synagogue on 3rd November 2024. The talk was unscripted and totally off the top of my head. I didn't need a script for something so close to my heart."

Together, the Rose family has raised over £20,000, while The West London Synagogue has contributed more than £35,000 in memory of Vivien. msa *news*

Maybe there is a raising awareness project, such as a community talk, that you'd like to organise but feel financial barriers are holding you back. If so, look at page 19 for information on how to apply for one of our new raising awareness grants.

Social Welfare Practical Tips

Our Social Welfare Specialist, Louise Hardy, outlines some tips she would like people affected by MSA to know about. Our service can also support with reviewing general benefits entitlements.

VAT-free Works and Equipment

In the UK, goods for people with a health condition or disability are VAT-free. This also applies to some building works. Eligible types of work include a ramp into your home; the widening of existing doorways or passages; a new bathroom or toilet, or adaptations to your existing bathroom or toilet; installation or maintenance of a lift. Building materials used as part of the works are supplied VAT-free.

You do not have to be in receipt of any government benefit to qualify. You will need to complete a standard HMRC Declaration Form which states that the works are for someone who is 'chronically sick or disabled'. Your supplier or contractor should not charge VAT, and you do not need to claim VAT back from HMRC.

The Declaration Form and further information is here: www.gov.uk/guidance/vat-relief-on-certain-building-work-if-you-have-a-disability#building-work-vat-free.

In the Republic of Ireland, VAT paid on certain aids and appliances for use by someone with a disability can be reclaimed. Further information is here: www.revenue.ie/en/vat/repayments-to-unregistered-persons/disabled-persons/reclaim-vat-aids-appliances.aspx.

Council Tax

In England, Wales and Scotland a Council Tax Disability Reduction Scheme applies. To qualify, the property must have either:

- **an extra bathroom, kitchen or other room needed for a disabled person, or**
- **extra space inside the property for using a wheelchair.**

Your Council Tax bill is then reduced by one band, for example if your home is Band D it is reduced to Band C. To apply, contact the local authority to whom you pay your bill.

In Northern Ireland a Disabled Person's Allowance can reduce your Rates bill by 25% and the same criteria as above applies. The application form and details of where to send it are here: www.nidirect.gov.uk/articles/disabled-persons-allowance.

In the Republic of Ireland if you pay Local Property Tax, a disability reduction may apply. Details are here: www.revenue.ie/en/property/local-property-tax/lpt-exemptions/incapacitated-persons.aspx.

Energy

Energy prices increased again in January 2025. It is good to shop around to make sure you are not over-paying. Many people stick with their same energy provider and if you are on a Standard Variable Rate that may not be the best rate. If you have a fixed rate and decide to switch, check if early exit fees apply. You can check your tariff and annual consumption on your latest bill or via your online account.

For England, Scotland and Wales, two useful price comparison websites are: https://energy.which.co.uk and www.moneysavingexpert.com/energy.

For Northern Ireland, a useful website is here: www.consumercouncil.org.uk/consumers/help-consumers/electricity-oil-and-gas/electricity-price-comparison-tool.

For the Republic of Ireland, price comparison websites are here: www.cru.ie/consumer-information/switch-supplier/price-comparison-websites.

The eligibility criteria for the Winter Fuel Payment (WFP) for people over pension age has changed. In England, Wales and Northern Ireland, people in receipt of means-tested benefits, such as Pension Credit or Universal Credit, are eligible. WFP should be paid automatically. Details are here: www.gov.uk/winter-fuel-payment/eligibility.

In Scotland, the Winter Heating Payment and Pension Age Winter Heating Payment is payable to people in receipt of means-tested benefits. The Payment should be paid automatically. Details are here: www.gov.scot/policies/social-security/help-with-heating-costs.

In the Republic of Ireland, the Fuel Allowance is payable for people in receipt of certain benefits and satisfy a means test. Information and application are here: https://services.mywelfare.ie/en/topics/pensions-and-older-people/fuel-allowance.

Water Rates

In England, many water companies have Social Tariffs for their customers who use more water than an average household. To qualify, you must have a water meter and be in receipt of specific benefits. Each water company has their own financial eligibility rules, which are here: www.ccw.org.uk/save-money-and-water/help-with-bills/#social-tariffs.

In Wales, a similar scheme applies: www.dwrcymru.com/en/support-with-bills/watersure-tariff.

Social tariffs do not exist in Northern Ireland and the Republic of Ireland. In Scotland discounts are related to Council Tax Reduction.

Prescription charges

Prescriptions are free in Scotland, Wales and Northern Ireland.

In England, the current prescription charge is £9.90* per item. Some items are free. Prescriptions are free for some groups of people, such as those aged 60 years or over; or who receive means-tested benefits.

If you do not qualify for free prescriptions, it may be cheaper to buy a Prescription Prepayment Certificate. A 3-month certificate costs £32.05* and a 1-year certificate costs £114.50*. You may be eligible for help towards prescriptions and other NHS costs based on your income. Details are here: www.nhsbsa.nhs.uk/help-nhs-prescription-costs.

In the Republic of Ireland, prescriptions are free if someone has a Medical Card (based on a financial assessment). For other people, charges apply. If you do not qualify for free prescriptions, it may be cheaper to buy a Drugs Payment Scheme card if you pay more than Euros 80 per month. Details are here: www2.hse.ie/services/schemes-allowances/drugs-payment-scheme/card.

Driving

A new or changing medical condition which affects someone's ability to drive safely should be reported to the relevant driving standards agency. You should also inform your insurance company of any medical condition.

In England, Wales and Scotland you should inform the DVLA. It is best to do this by telephone, email or post as we have found that using the online service causes delays. Contact details are here: www.gov.uk/contact-the-dvla/y/driving-and-medical-issues.

In Northern Ireland, you should inform DVA about a medical condition. Contact details are here: www.nidirect.gov.uk/articles/how-tell-dva-about-medical-condition.

In the Republic of Ireland, you should inform NDLS. Contact details are here: www.rsa.ie/help-support/online-support-centre/details/learner-permits-driving-licences/medical-fitness-to-drive/i-ve-been-diagnosed-with-a-medical-condition.-do-i-need-to-inform-the-ndls.

* All figures correct at time of writing. msa *news*

If you have any questions about information given here, or you would like support with a non-medical enquiry, contact our office and we will connect you with our Social Welfare Specialists.

Supporting and Helping Each Other

Our wonderful members consistently share their valuable tips and insights on living with MSA. Here, Kirsten Olufsen and James Grogan, our Support Group facilitators, round up some of the learning from the last few months...

What do you think of when someone mentions a hospice? Many of us only think of palliative care. But our Support Group members often tell us that their local hospice offers so much more. We thought it would be helpful to share some of the services and support that local hospices can provide.

Several of our in-person Support Groups meet at hospices, including our Berkshire, Dublin, Norfolk and West Yorkshire Groups. The Hertfordshire group meets in the Spring Centre at St Francis Hospice. This is a free wellbeing centre that offers physiotherapy, occupational therapy and complementary massage therapy. One session recommended by our group members was creative therapy. Attendees can try different creative activities, which can promote wellbeing and relaxation. Priscilla Bacon Lodge in Norfolk offers music therapy, which can be especially helpful if talking is a challenge. If that sounds interesting, it's worth seeing if your local hospice runs something similar.

Keeping active also benefits your health and wellbeing. Many hospices offer tailored exercise classes and guidance on exercising safely at home. St Christophers Hospice in London has information on lying and seated exercises: **www.stchristophers.org.uk/videos/exercises**. Take a look but remember to always consult your Physiotherapist before trying any new exercise.

Group members highlighted the emotional support that hospices can provide to people with MSA and family members. Hospices often offer special support for children too. Some also have a carer's peer coaching service, provided by trained volunteers, for example - **www.stchristophers.org.uk/supporting-you/your-support/carer-support**.

Our Support Group members said that the greatest benefit to them is the personal interaction they've found through their hospice. Chatting in the café or sitting with others in the garden can build important social connections and help you feel less isolated.

If you're not sure what your local hospice can offer, the first step is to take a look at their website. They might have a useful knowledge hub or offer webinars on different topics.

You can search for your local hospice at **www.hospiceuk.org/hospice-care-finder**.

Services differ, but it's worth looking into what could be available to you. If you discover something helpful, why not share it at your next Support Group? msa news

If you are not receiving Support Group invitations, and would like to, please get in touch with us at **support@msatrust.org.uk** or 0333 323 4591 and we will look at where your nearest group is meeting.

Raising Awareness of MSA

Our Events, Community and Digital Fundraising Officer, Eleanor Jarvis, explains more about our recently launched grants programme for people aiming to raise awareness of MSA.

Are you living with or supporting someone with MSA? Has a loved one or colleague been impacted by MSA? Do you have a project that could help raise awareness of this little-known, rare neurological condition and could benefit from a grant to support its completion?

We recognise the financial pressures that living with a condition like MSA can create. Additionally, we know that MSA is not widely understood, and our members often spend considerable time explaining it to friends, family, and even healthcare providers.

To help raise awareness, we're launching a pilot programme offering small grants to support people in developing MSA awareness raising resources. This could be short films, blogs, literature, or covering travel and accommodation costs for community talks, that may otherwise be difficult due to financial barriers.

We also recognise the challenge of collecting content (photos, stories, videos) from people living with MSA.

We hope that these grants will help us share members' experiences more broadly, helping to raise awareness and understanding of MSA.

We encourage any member to apply for an Awareness Grant (up to £200) if they have a project that will fall into one of three categories.
Raising awareness of:

- **Living with or supporting someone with MSA**
- **The work of the MSA Trust**
- **How to fundraise or get involved.**

Our goal is to improve how we communicate about MSA, ensuring that our members' stories and experiences are represented authentically, making our communications more impactful and effectively highlighting the challenges of MSA. msa *news*

Please visit our website: www.msatrust.org.uk/get-involved/raising-awareness-grant or scan the QR code to complete the application form and find more information.

SCAN ME

MSA CANDLELIGHT

We are pleased to bring back our memorial event, MSA Candlelight, for those remembering loved ones lost to multiple system atrophy.

We will have an afternoon of music, candle lighting, an update on MSA research and ending with Afternoon Tea. We will enter your loved one's name in our Book of Remembrance which becomes part of the programme and will be presented to you on the day.

To fund research into MSA and cover expenses, we are asking for a minimum donation of £15 per attendee. If you cannot attend, for a minimum donation of £12, we will include your loved one's name in the Book of Remembrance and post it to you after the event.

To make the donation, please complete and return the form below with a cheque, call the office on 0333 323 4591, visit the link below or scan the QR code.

www.msatrust.org.uk/msacandlelight

SCAN ME

Date:
Saturday 17th May 2025

Time:
2 – 4pm

Venue:
St Columba's by the Castle
14 Johnston Terrace,
Edinburgh EH1 2PW

Please note that parking is limited at this venue. We recommend attendees come via train to Edinburgh Waverley Train Station.

Name:..

Address:..

Telephone:.. Email:..

I would like to attend the MSA Candlelight event in Edinburgh and enclose a donation for tickets:

Number of guests (tickets)...

Donation for tickets £...

Please let us know if anyone in your party has specific dietary requirements:

....

....

I cannot attend MSA Candlelight and enclose a donation to include my loved one's name in the Book of Remembrance:

Donation for dedication

£...

Additional donation for MSA research £......................... **Total payment enclosed £................................**

Dedication (your loved one's name as you want it to appear in the Book of Remembrance)

....

Due to data requirements, please let us know how you want us to keep in touch for fundraising news and events. Please fill out your contact preferences below:

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

Please make all cheques payable to 'MSA Trust' & return slip by ***Friday 11th April 2025*** *to:*
MSA Trust, 128 B Business Design Centre, 52 Upper Street, London N1 0QH