MSA NEWS | ISSUE 74 | OCTOBER 2025

MSA Trust

MSA News

Your Autumn Edition

Our MSA Children's Activity Book

Mouth Hygiene Tips

SCAN TO VIEW ONLINE

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Registered Charity Number 1137652. Scottish Charity Number SC044635. Company Number 7402036.
Designed by Base Media www.base-media.co.uk. Printed by INQ Design 020 7737 5775.
See our up to date policy statements here: www.msatrust.org.uk/privacy-notice.

Welcome

Hello and welcome to your autumn/winter 2025 edition of MSA News.

It's been a busy year for the MSA Trust, supporting more people than ever before, as we continue to expand our services. You can read about the work we have been doing on page 19. In November, there will be an opportunity to have your say on the impact the Trust makes to our MSA community and ways we can improve. Find out more on the next page.

Our MSA Health Care Specialists have extremely varied roles working at the MSA Trust. We receive no government or NHS funding, so all their work directly supporting people registered with us is funded by donations. You can read about their work on page 16.

On page 8 we have an article for people who are caring for a loved one living with MSA. Our Social Welfare Specialists share here information about carers assessments and entitlements.

Finally, please support our Christmas Appeal if you can (information on the back page). This Appeal is focussed on increased training and awareness of healthcare professionals. You will also find Christmas cards, wrapping paper and more on the insert inside your magazine or visit our online shop here – **www.msatrust.org.uk/christmas**. Happy holiday when it comes!

Emma and Andy

Welfare Benefits Changes

In March 2025 the UK government proposed changes to disability benefits.

One of the main proposals was to alter the eligibility criteria for the Daily Living part of Personal Independence Payment (PIP). The government announced that to receive PIP, claimants would need to be awarded 4 points in one of the single tasks, in addition to being awarded at least 8 points overall.

The MSA Trust believed that this would have a devastating impact on people living with MSA, their carers and families. Alongside many other health and disability charities, we launched a campaign to oppose the proposals. We asked the MSA community to support our campaign by signing an open letter to government, requesting that they rethink the changes and to fully consult and engage with people with disabilities.

Following pressure from health and disability charities, the government reversed its decision to bring in the 4-point rule for PIP. They announced that a review of PIP would instead take place, to be finalised by Autumn 2026. We continue to keep a watchful eye on the review and any future proposed changes.

Together with other charities, our Social Welfare Specialists have met with senior members of the Department for Work and Pensions and Sir Stephen Timms (Minister of State for Social Security and Disability), who is carrying out the PIP review.

We have been able to convey the financial and day-to-day experiences of people living with MSA and their carers, and how any changes will affect them. The MSA Trust will continue to strive to ensure that the views and experiences of our MSA community are represented in the review process.

Our letter was signed by 131 people, which was a fantastic response from our community. Thank you to all who supported our campaign.

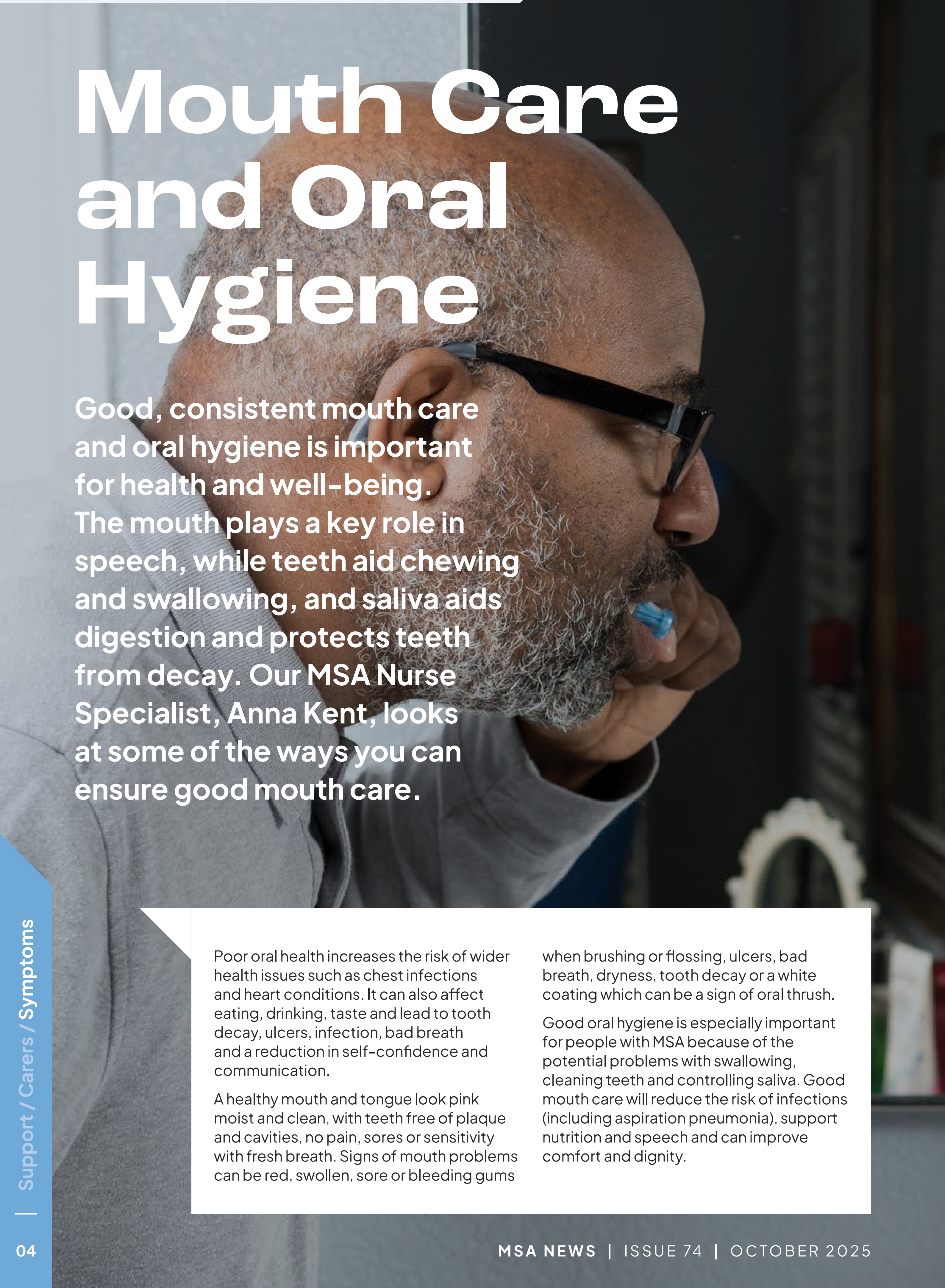
Your feedback on the MSA Trust

Over the last year we have been making improvements in the way we capture the impact of the MSA Trust.

We want to be able to better capture your views, which will help us to plan and improve care for people living with MSA and their families, today and in the future.

You may receive requests for feedback from us if you have accessed certain services. In November we will be launching our first Impact Survey. We encourage you to complete this (it should take around 10-20 minutes). Your feedback on our services and support will help us better meet your needs. The survey will be sent to people living with MSA, carers and family members via email. If you need a postal copy, please get in touch. Your responses will be completely confidential and anonymous.

Please take a moment to read our 'At a Glance' 2024-2025 impact report on page 19 to give you a flavour of what we achieved in the last year.



Mouth Care and Oral Hygiene

Good, consistent mouth care and oral hygiene is important for health and well-being. The mouth plays a key role in speech, while teeth aid chewing and swallowing, and saliva aids digestion and protects teeth from decay. Our MSA Nurse Specialist, Anna Kent, looks at some of the ways you can ensure good mouth care.

Poor oral health increases the risk of wider health issues such as chest infections and heart conditions. It can also affect eating, drinking, taste and lead to tooth decay, ulcers, infection, bad breath and a reduction in self-confidence and communication.

A healthy mouth and tongue look pink moist and clean, with teeth free of plaque and cavities, no pain, sores or sensitivity with fresh breath. Signs of mouth problems can be red, swollen, sore or bleeding gums when brushing or flossing, ulcers, bad breath, dryness, tooth decay or a white coating which can be a sign of oral thrush.

Good oral hygiene is especially important for people with MSA because of the potential problems with swallowing, cleaning teeth and controlling saliva. Good mouth care will reduce the risk of infections (including aspiration pneumonia), support nutrition and speech and can improve comfort and dignity.

Swallowing problems can prevent proper saliva clearance, leading to build-up and dribbling. This may be moderated with swallowing exercises and medications to control saliva production. To prevent soreness, clean the skin around the mouth regularly. Use barrier creams to protect from moisture. Apply gentle moisturisers for any dryness or chapping.

A dry mouth can cause discomfort as saliva helps clean the mouth and neutralise acids. To manage this, increase water intake, use saliva substitutes like artificial sprays or gels and stimulate saliva production with sugar-free gum or sweets. Take care if swallowing problems are present.

Sugar in the diet causes tooth decay by fuelling bacteria in the mouth that produces acid, which erodes tooth enamel and forms cavities. After eating or drinking sugary foods, it takes up to an hour for your mouth to neutralise the acid they produce. Try to limit sugary foods and drinks just to mealtimes. If able, chewing sugar-free gum and drinking water after meals or snacks can help to neutralise the acid more quickly.

If plaque, a sticky layer of bacteria on teeth, is not removed by brushing it feeds on food residue, leading to decay or hardening into tartar, causing gum inflammation and irritation.

Some key tips:

- **Brush teeth, mouth and gumline for at least two minutes twice a day (or more often if there is difficulty clearing food from the mouth) – you may need help.**
- **Use a brush with a small head and medium bristles.**
- **Use a small pea size of toothpaste to reduce foam and excess fluid.**
- **Sit upright with chin tilted forward – this helps safer swallowing and reduces the risk of aspiration.**
- **If it is difficult to spit, wipe away excess with damp gauze - don't rinse with water.**
- **Use dental floss or an interdental brush daily.**
- **Oral foam sponges should not be used as they pose a choking risk if the foam comes off the stick.**

Talk to your dentist, speech and language therapist or occupational therapist for personalised advice.

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Teeth cleaning

Difficulty opening the mouth or holding a toothbrush affects the ability to move the toothbrush and clean all the mouth and teeth. Electric toothbrushes tend to clean teeth better and have a wider handle. There are also specialised toothbrushes which may help, including triple headed brushes, wide handled brushes and 360º Tooth and Mouth brushes.

Replace a toothbrush every two to three months or sooner if the bristles become splayed.

Where possible, use a high-fluoride, low or no- foam (Sodium Laureth Sulfate (SLS) free) toothpaste. Strong flavours, particularly mint, may trigger discomfort or gag reflexes.

Free or reduced cost NHS dental treatment is based on receiving certain benefits. A valid HC2 certificate is needed to prove eligibility and private dental treatment still incurs costs.

Visiting the dentist

Regular dental check-ups are important. To find an NHS dentist visit the NHS website and use the "Find a Dentist" tool or contact NHS 111. If you are unable to find an NHS dentist, contact your local Integrated Care Board (ICB). In the Republic of Ireland you may be able to access free or subsidised dental care through the medical card system, specialised HSE services or the PRSI-based Treatment Benefit Scheme.

Inform the dentist about your MSA diagnosis and provide details of any related issues such as speech, swallowing and blood pressure, along with any other medical conditions.

Specialised dental services, often part of local NHS community dental services, provide care for people with disabilities or medical conditions with facilities like hoists and wheelchair-accessible equipment. Referrals are made by your regular dentist if specialised care is needed, check NHS 111 or the NHS website for self-referral options.

Leaving a gift in your Will for the MSA Trust

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After prioritising your loved ones in your Will, it would be wonderful if you could consider leaving a gift for the MSA Trust. Your gift, large or small, will ensure we can support people affected by MSA in years to come, and that, one day, we fulfil our vision of a world free of MSA through research.

Your gift would be exempt from Inheritance Tax so that more of your gift goes towards advancing the vital work of the MSA Trust.

We recognise how expensive will-writing can be, so we have partnered with the National Free Wills Network to offer a free will-writing or updating service provided by qualified local solicitors. The MSA Trust pays for this service and although you are under no obligation to leave a gift to us, we would be incredibly grateful if you think of the Trust when creating it.

Solicitors registered with the Network are available throughout the UK to write or update a Will. They are flexible and can offer in-person or online appointments, and in certain circumstances, offer home visits as well.

To find out more visit: www.msatrust.org.uk/free-will. Alternatively, call 0333 323 4591 or email fundraising@msatrust.org.uk and we will refer you to the Network.

Once registered, you will receive a Free Wills pack with a list of solicitors to choose from.

We are so grateful to those who have already generously thought of us in their Will. Myra Morris was diagnosed with MSA in 2021 and kindly left a generous gift in her Will which allowed us to fund a third MSA Research Fellowship (see page 12).

Her husband, Philip Morris says:

NATIONAL FREE WILLS NETWORK

"From the start they (MSA Trust) were far more pro-active than other charities we had been working with, giving help and advice in all areas of concern from health to welfare. We attended meetings which we both found very beneficial. They were always on hand to discuss medical issues and offer help on how to improve Myra's quality of life. They have also helped me cope with understanding the challenges that carers like me have to deal with.

It therefore came as no surprise that when Myra was in the final stages of her life, she decided to include a legacy in her Will in the hope that it will benefit others in the search for the cause and cure for MSA."

NEWS

2025 Great North Run

We were so pleased to be at the 2025 Great North Run on the 7th September, cheering on our incredible MSA community. 15 runners took part in aid of the MSA Trust, proudly wearing orange on the course and helping to raise both awareness and vital funds.

We were joined by staff, volunteers and the families and friends of our runners. It was a fantastic day of cheering and we are delighted to share that our runners collectively raised over £9,000 in support of the MSA Trust.

Privacy Notice

At the MSA Trust we are committed to keeping your personal data safe and secure.

We have recently updated our Privacy Notice to ensure clarity about the way we process your data. It sets out in detail the purposes for which we process information about you, who we share it with, what rights you have in relation to that information and everything else we think it's important for you to know.

You can view our Privacy Notice on our website - **www.msatrust.org.uk/privacy-notice**.

Fundraiser of the Year Awards

Our Fundraiser of the Year awards are returning! These awards celebrate and recognise the incredible fundraising efforts undertaken by our MSA community during 2025.

We invite you to nominate friends, family or colleagues who have fundraised for us during 2025. If you believe they have been particularly successful, impactful or innovative, we encourage you to submit a nomination.

Applications will open on the 2nd January 2026 so please keep your eyes on our social media channels and website for more information on how to apply.

Updating your Details

It is really important that we have the correct contact details for you so that we can provide you with the best support and information.

If you have moved house recently, changed email addresses or phone numbers, please do let us know so we can update this. Just call us on 0333 323 4591 or email **support@msatrust.org.uk**. If you are in contact with our MSA Health Care Specialists, it is also a good idea to ensure they have your up-to-date GP and Specialist contact details too.

MSA Trust Research Grant Call

Our Research Grant Round for 2025-2026 has launched and will shortly close for pre-proposals. We are seeking innovative basic, translational or clinical neuroscience research projects to improve our knowledge of the cause and cure of MSA. We are open to working collaboratively where there is a demonstrable connection to a UK-based Principal Investigator or Institution. Our Scientific Advisory Panel will make a decision on the studies we will fund in early 2026.

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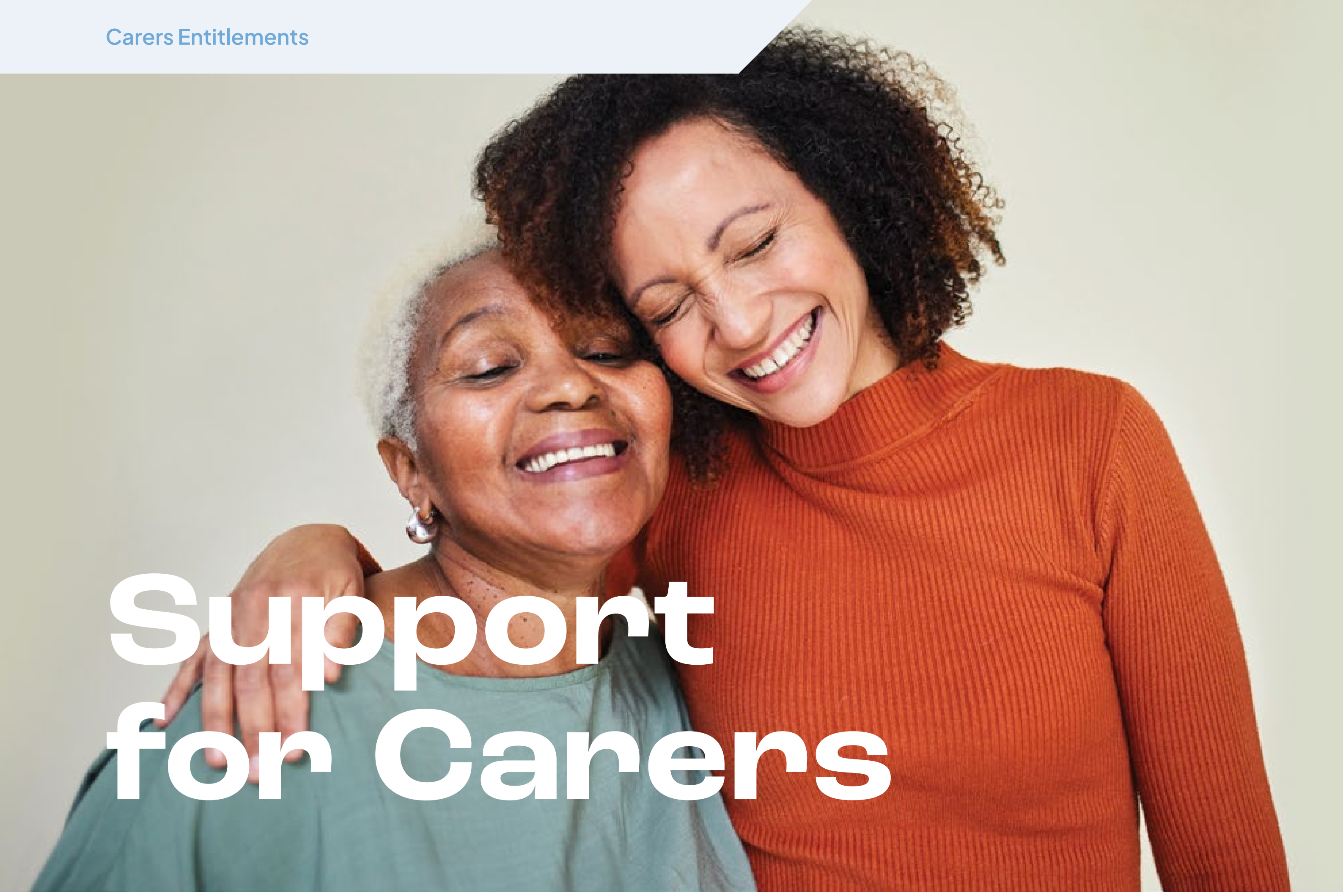

Support for Carers

Carers UK estimates that there are 5.8 million unpaid carers in UK (at March 2025). Are you one of these? People who care for those living with MSA carry out a significant role in supporting their partner, family member or friend. Here Louise Hardy, one of our Social Welfare Specialists, outlines how carers can access resources and support in their caring role.

Accessing Social Care

As an unpaid carer, you are entitled to a Carer's Assessment (Adult Carer Support Plan in Scotland). This is carried out by the Adult Social Care team at the Council where the person you care for lives. The person that you care for does not need to give their consent to the assessment, and it is your choice whether you want them to be present. Alternatively, you can request a carer's assessment while Adult Social Care carries out an assessment for the person you care for.

You can request the assessment by calling the Council or using their online self-assessment form. The assessment focuses on your needs and the practical support you may want, taking into account how your caring role affects your life and work. It may be completed in-person in your home or over the telephone. You may be given a questionnaire to complete before the assessment.

During the assessment, you will be given the opportunity to discuss things like:

- the number of hours you spend caring
- what sort of care you provide, such as help with washing, dressing and eating
- whether any particular care tasks are causing you concern, for example helping the person you care for to get out of bed safely
- whether you have enough time for work, family and leisure
- how your caring role is affecting your own physical and mental health.

If, following the assessment, you are eligible for practical support, the Council should explain how it will meet your needs. This may be by referring you to local organisations for support. If you are not eligible for support, the Council should still give you information and advice about other local sources of support.

Paying for Care

England and Wales

If the Council provides practical support such as, paid carers to give you a break from your caring responsibilities, it may charge you for those services. The Council will then carry out a financial assessment. This is based on **your** finances, not the person you care for. Some Councils do not charge for certain services, for example they may fund some respite care for free, so it is always worth checking your specific Council's policy.

If the Council decides to provide more social care support for the person you care for, for example increasing their care package hours, then the Council will carry out an assessment of their finances to see if they should contribute.

Scotland

Practical support services for carers are usually free in Scotland. You can ask the Council to arrange the services for you or request a personal budget so you can arrange them yourself.

Northern Ireland

Carer's assessments are carried out by your local Health and Social Care Trust. Support services arranged by the Trust are not usually free so they will carry out a financial assessment. For more information visit – **www.ageni.org/information-advice/care/helping-a-loved-one/can-carers-get-help-from-social-services.**

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Republic of Ireland

The Health Service Executive (HSE) is responsible for health and social care services for carers. Local HSEs can arrange respite care, which are sometimes called 'Breakaway' or 'Friendship' schemes. You can find more information here – https://msamag.link/4mfGXi8.

Hospice Support and Respite Care

Hospices provide support to people living with a long-term and life-limiting health condition, and not just to people at the end of their lives. Many hospices provide services for carers, such as complementary therapy and support groups. They may also offer in-patient respite care, providing a break for the carer. You can find your local hospice and the services they offer here – https://msamag.link/48iLaym.

Some local carer organisations offer respite breaks. Crossroads Care are a network of care agencies who provide weekly respite care. Further information may be available from your local Adult Social Care Team.

Carer's Allowance (UK only)

Carer's Allowance or Carer's Support Payment in Scotland, are benefits you can claim if you provide at least 35 hours of care per week. The person you care for must be in receipt of a disability benefit, for example Attendance Allowance or Pension Age Disability Payment (Scotland), or the Daily Living component of Personal Independence Payment or Adult Disability Payment (Scotland).

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There are additional eligibility rules to Carer's Allowance:

- if you work, you can claim Carer's Allowance if your earnings are less than £196 a week net (that is after deductions for tax, national insurance, 50% of any pension contributions, and some other expenses)
- occupational or personal pensions are not classed as earnings for Carer's Allowance
- if you receive State Pension, you cannot claim Carer's Allowance if your State Pension is more than the amount of Carer's Allowance benefit (currently £83.30 a week)
- even if your State Pension is more than Carer's Allowance, your caring role may give eligibility to means-tested benefits such as Pension Credit or Universal Credit, and you may want to get a full benefit check for this.

In the Republic of Ireland, you qualify for Carer's Allowance if the person you care for needs full-time care for at least 12 months; you provide at least 35 hours per week of care; you are not working more than 18.5 hours a week; and your income is below a certain amount. A means-test is carried out.

Employment
(England, Scotland and Wales only)

If you work in addition to caring for someone, you have certain legal rights. Further employment information can be found here – www.acas.org.uk/advice.

Emergency Plan and Carers Card

Many carers are worried about what would happen in case of emergency or if they were unexpectedly not able to care for the person they look after. An Emergency Plan is a way of bringing together all the important information that may be needed in this situation.

This plan could include:

- contact details of who should be contacted
- medication and any allergies
- GP and Pharmacist details
- care or support services the person receives
- any ongoing treatment that is needed
- equipment or aids needed, such as mobility or continence aids.

It is useful to discuss the plan with the person you care for and share it with family, friends and healthcare professionals, such as your GP Practice. Further information and help to create an Emergency Plan can be found here – https://msamag.link/46hiSSd.

It is a good idea to lodge an Emergency Plan with your local Council's Adult Social Care team, who can then be contacted if your nominated contacts are unavailable. Some Councils and some local carers organisations will help you to put together an Emergency Plan and may also provide you with a free Carer's Card, which can include details of your nominated contacts.

National carers organisations also have information and support services. Their details are here -

www.carersuk.org
www.carers.org
www.familycarers.ie

And finally....

To look after yourself as well as the person you care for, please consider six things:

- Create a network of helpers.
- If you work, explore whether flexible working is an option for you.
- Get a full benefits check.
- Request a carer's assessment.
- Register as a carer with your GP.
- Seek out respite care.

It is important that carers recognise their own amazing work. It is only natural to want to put the needs of the person with MSA first, but your needs are important too. Caring is often physically and emotionally demanding and if you don't look after yourself, you won't be able to provide the best possible care and support. Hopefully you can find the time and space to do something you enjoy and to keep you happy.

Giving the gift of your time

SCAN ME TO GET INVOLVED

Lots of people want to help the MSA Trust by volunteering but aren't sure if they have the time. We understand that signing up to volunteer can seem like a big commitment, especially when life with MSA feels uncertain. However, even a small donation of time can make a big difference.

There are lots of actions you can take that help us but don't take a lot of time or energy. **Micro Support Actions can include:**

- sharing your story on our website
- letting us know about a useful local resource
- sharing your views as part of a focus group
- sharing information on fundraising events
- signing a petition
- sharing campaigns
- filling in a survey
- showing support on social media
- encouraging friends to buy our Christmas cards.

If you find you have some time or skills you would like to share, our new Ambassador Volunteer role might be for you. Ambassadors give their time when they can to raise awareness of MSA and to connect with supporters and the MSA community. There is no minimum time commitment. The role is flexible and depends on the opportunities that come up in your local area. **You might be asked to:**

- Deliver leaflets to local hospitals, GP surgeries or community groups.
- Give a talk about MSA and our work to community groups and potential donors.
- Attend a cheque presentation with a group that has raised funds for the Trust.
- Talk to fundraisers or at healthcare conferences about your personal experience of MSA.
- Help with local fundraising events, such as a bucket collection.

This isn't an exhaustive list. We're always interested to hear your ideas for raising awareness, so if you're feeling inspired then let us know. If you'd like to find out more about the Ambassador role or Micro Support Actions, there is a lot of information on the volunteering pages of our website. Or get in touch with us at **volunteering@msatrust.org.uk** and we can chat about how you can gift your time.

Research Update

Welcoming our new Research Fellow, Linda Lei

I am delighted to introduce myself to the MSA Trust community. My name is Linda Lei and I am currently a neurology trainee with a special interest in movement disorders, particularly MSA.

This year, I have been fortunate to be the recipient of the Myra Morris Clinical Research Training Fellowship programme in collaboration with the Association of British Neurologists (ABN). This has given me the unique opportunity to dedicate focussed time to MSA research and clinical work.

Through this Fellowship, I am actively involved in ongoing MSA clinical trials and am working to identify potential clinical and biological markers that could help us diagnose MSA earlier and more accurately. Just as importantly, I am exploring how these markers might relate to disease severity. It is hoped that they will not only improve diagnosis but also provide meaningful ways to monitor progression and, ultimately, measure the impact of future treatments.

I feel very privileged to be supported by the MSA Trust, whose dedication to patients, families and research is truly inspiring. My goal is to contribute to the growing understanding of MSA while keeping patient needs at the heart of my work. I look forward to sharing updates as this journey continues.

Research Trials Update

Theravance

Theravance pharmaceuticals have recently completed recruitment to the CYPRESS clinical trial. CYPRESS is a phase 3 study of a new medication called ampreloxetine. This trial will test whether ampreloxetine can help with the symptoms of blood pressure that drops on standing in people with MSA. This symptom is called neurogenic orthostatic hypotension, or postural hypotension and can occur when someone stands up or changes position. In MSA, the autonomic system doesn't always recognise a change in position and the blood pressure doesn't adjust automatically. This can cause symptoms of feeling faint or lightheaded. Ampreloxetine aims to help with these symptoms by reducing this drop in blood pressure and the CYPRESS trial is testing how effective the medication is.

Next steps - Results are expected to be reported in 2026 and we will update you as soon as they are available.

Further information - **www.theravance.com/our-study**.

Alterity

Earlier this year Alterity Therapeutics announced that the phase 2 trial of their compound ATH434 showed 'positive' results. The phase two trial recruited 77 people with MSA, who were randomly assigned to receive either a placebo (a tablet with no active ingredients) or ATH434. ATH434 aims to redistribute excess iron in the brain, to assess whether reducing excess iron inhibits the aggregation of alpha-synuclein, the protein that builds up in the brains of people with MSA. Participants were scanned to measure iron levels in the brain and completed a scale that measured how MSA impacts activities of daily living. The results showed that people who received ATH434 had improved scores on their rating scale compared to those that received a placebo. They also showed reduced accumulation of iron on brain scans.

Next steps – further testing of ATH434 in larger numbers of people with MSA will be needed and Alterity is currently exploring this.

Further information - **https://msamag.link/4n6ZLBN**.

MASCOT trial

A new trial of an antibody that binds to alpha-synuclein, with the aim of reducing aggregation of the protein in the brains of people with MSA, has opened in the UK. This trial is being run by Lundbeck and will open at several sites in the UK over the coming months.

More information can be found on our website **https://msamag.link/mascot-trial** or speak to your MSA Nurse Specialist or Consultant for more information.

SCAN ME TO LEARN MORE

Research Webinar – 6th November

Join us for the next MSA Trust Research Webinar on 6th November 2025, introduced by Dr Chris Kobylecki, Chair of our Scientific Advisory Panel. The theme is 'Imaging in MSA – Tracking Disease Progression.'

We'll hear from two leading MSA researchers:

Professor Hoggard (University of Sheffield), presenting on physiological imaging for faster treatment trials. While regular scans like MRIs show the structure of the brain, physiological imaging shows how the brain is working. For example, it can show how much blood is flowing to a certain area, brain activity in different areas or how cells are using energy.

Professor Pavese (Newcastle University) will discuss multimodal imaging. This uses more than one type of scan at the same time, to get a fuller picture of what's happening inside the body. It is hoped that this technique may improve early diagnosis.

The presentations will be followed by a 20-minute Q&A.

To register, please email **support@msatrust.org.uk**.

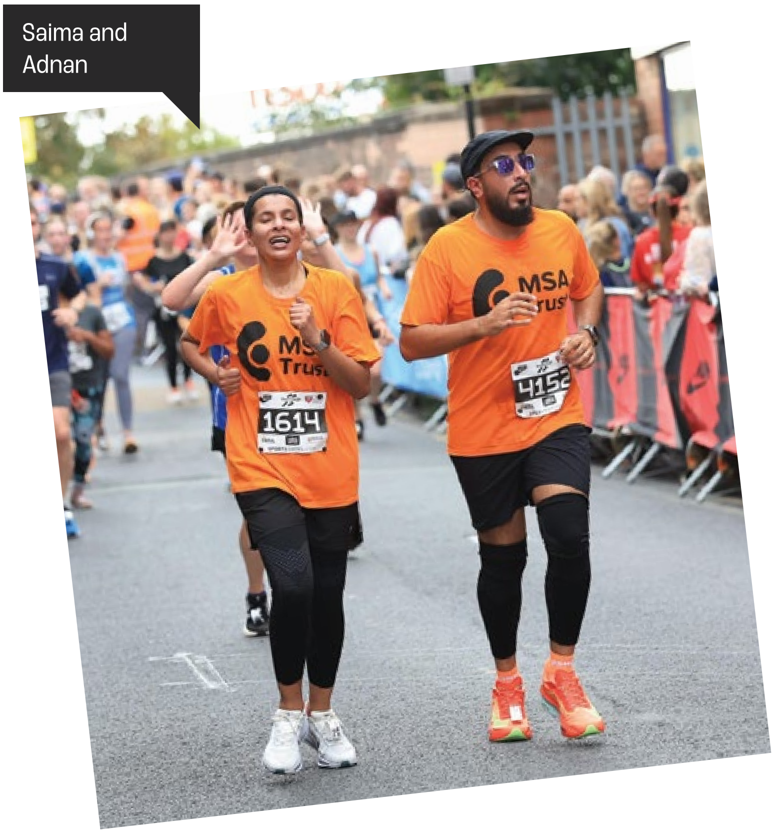
Fundraising Stars

Thank you to every single person who has fundraised for us. Whether you organised a walk, hosted a bake sale or ran a half marathon - we are so grateful to you and to everyone who has supported and donated to the MSA Trust.

We receive no government funding and rely entirely on voluntary donations, so your support truly makes a difference.

Siblings United

Saima and Adnan



Brother and sister, Saima and Adnan, raised a staggering **£3,500** by taking on a 10k run in support of their brother-in-law, who has recently been diagnosed with MSA.

> "We're heartbroken by his diagnosis. But we're not giving up. This run is our tribute to him. MSA is so unknown, so misunderstood, and so cruel. That's why we are running — to raise money, yes, but also to raise awareness. Families like ours need support. Research needs funding, and people like my brother-in-law deserve to be seen, heard, and helped."

Helen Hunt Golf Day

Gail & Andy Ventress, Chris & Mike Foley

"As a long-standing member of Moseley Golf Club, I've had great support from many golfers in the Birmingham area, as well as from our many friends in The Round Table Family. Now in its second year of celebrating Helen's memory, we were able to donate **£1,733** to the MSA Trust. This wonderful total came from the Tombola, Auction, and donations on the day. We also had fantastic support from local businesses in Kings Heath, who kindly provided prizes including restaurant vouchers, a £100 whisky tasting voucher, and a family photo-shoot worth £250. I am especially grateful for the support of our close friends Gail & Andy Ventress, Chris & Mike Foley (pictured), and Lesley & Fred Titley (not pictured). Our thanks also go to mine and Helen's children, Natalie & Stephen, and my brother John, for their help and encouragement. It was very much a team effort. The plan is for this day to go from strength to strength each year and become a regular event in the MSA Trust calendar". **Helen's husband, Peter.**

SCAN ME TO GET INVOLVED

6K Fun Run

Carrie (right) and friend at 6k fun run

Winners of the 6k Fun Run

"It was a beautiful day for our 3rd annual 6k Fun Run in memory of our amazing wife, mam, and Gran, Valerie Stainthorpe, who passed away in July 2022. This year we had 55 runners, joined by family and friends who came along to support. There was a post-run raffle, cakes, and even an ice cream van! A local DJ kept the atmosphere lively with music and cheers for the runners. It was a truly lovely day, made possible by the wonderful family and friends who came out to help. Together, we raised £937 and we hope to grow and do even better each year".

Painting Nails for the Trust

Nicola

A huge thank you to Nicola, whose husband was recently diagnosed with MSA. She works at an independent living scheme for people over 55 and wanted to raise awareness and funds for the MSA Trust. Nicola organised a community event, setting up a salon and painting residents' nails. She raised **£300** while also helping to increase awareness of MSA by giving out information leaflets.

Getting the most from our MSA Health Care Specialist (HCP) Team

One of the key aims of the MSA Trust is to provide information and support to our MSA community across the UK and Ireland. Our MSA Health Care Specialists play an integral role in this. This article explains the support they offer to enable you to make the most of them.

Three of our HCP Team - Jill, Emma and Anna

Telephone and Email Support

Our team are available to respond to your telephone calls and emails about all aspects of living with MSA. For other health issues, or in an emergency, you need to access your GP or the emergency services. We will always try to have one of our team available to cover calls and emails when the others are out and about at clinics, meetings, teaching sessions or Support Groups. It will not always be possible to get back to you instantly, but we respond as soon as we can.

We also often have calls from other health and care professional colleagues who may not be so familiar with MSA and want some information so they can better support you. We are not part of the NHS or HSE systems or funded by them, but we are able to contact NHS or HSE colleagues confidentially if needed.

Support Groups

We have over 40 different locations where our face-to-face Support Groups run. Many of these will have one of our HCP team attending and facilitating informal friendly meetings. These groups are to help you and your family and friends, meet others to share experiences and share information about resources that are available in your local area. There is also the opportunity to have an individual chat with your MSA Health Care Specialist.

During Covid we developed digital access Support Groups. These proved popular and are now a core part of the Trust's work. As with the in-person groups there is usually one of the HCP team and one of our Social Welfare Specialists in attendance.

MSA HealthUnlocked

Many of our MSA community participate in the MSA HealthUnlocked Forum. People share their stories and help each other out from their lived experiences. One of the HCP team keeps a guiding eye and may add contributions to topics and threads on the site when helpful or necessary, but it is essentially a space for vital peer support.

MSA Awareness and Education

We know from our MSA needs surveys that raising awareness and educating other health and care professionals is important to our community. Most weeks one of the HCP team will run teaching sessions about MSA to health and care colleagues in whatever setting they work in. A couple of the HCP team will support our MSA Study days and Research Symposium.

Attending NHS or HSE Clinics

Currently across 24 locations in the UK and Ireland there are NHS or HSE clinics attended by the team. These clinics give us the opportunity to share learning and best practice and offer support to people living with MSA at diagnosis and on their journey with MSA. Many of the clinics support trainee doctors and health professionals so our presence helps raise awareness of MSA.

Information Materials

The HCP team members write many of our information resources including our factsheets, webinars and professional specific information. This information may be symptom-specific or about equipment, planning for the future, resources for children and young people, how to access care provision and benefits, to name a few. We update and add to this information regularly so it is worth having a look at what is available that may answer some of your questions or concerns.

Webinar Production

Recently we have developed a range of webinars. Current topics include an overview of MSA, Blood Pressure management and Palliative Care. These can all be viewed at your leisure on our website.

Every couple of months we invite people to attend a supported session of our Introduction to MSA webinar. At these sessions one of the HCP team is available to answer any questions.

Additional Support

The HCP team value the opportunity to meet with our community at our social and fundraising events. There is always one of the team at the Summer Social at Sarah's Wood and also the Candlelight remembrance event.

Each HCP will, where possible, also attend meetings in their area to represent the needs of people with MSA in regional and national planning, strategy and lobbying groups for example the Neurological Alliance and Palliative Care organisations.

Each HCP has a mix of all these activities to fit into any week so some time is needed to book and plan.

SCAN ME TO LEARN MORE

As you can see the work of our HCP team is full of interest and variety. To find out who the MSA Health Care Specialist is for your area visit our website for their contact details – www.msatrust.org.uk/support-for-you/hcps.

Supporting and Helping Each Other

We have an MSA HealthUnlocked community which features many different conversations and themes. James Grogan, our Support Services Co-ordinator, looks at a recent post which stood out where the writer asked how to support a friend with MSA.

It is not uncommon for MSA to put a strain on friendships and for social circles to shrink. But there are ways for friends to care and support their loved one. We reached out to our MSA community online and at Support Groups for their thoughts about how best to help a friend with MSA, these are summarised below.

Lend an ear

Offering a friendly, listening ear can help someone offload the struggles that can come with MSA. Remember, you don't need to have the solution, you just need to be there for your friend. Arranging regular visits or calls is a great starting point.

Learn about MSA

Do your best to learn about MSA. It can make a big difference if your friend knows you understand what's involved in living with MSA, some of the common symptoms and how best to support them.

This was echoed multiple times in our Support Groups. One person said "*Everyone will need to adapt and this will take patience and understanding*".

Offer a helping hand

Small gestures can make a big difference. If you live nearby, maybe you can pick up prescriptions or do a food shop?

Social events should not be off the table, you just need to understand that your friend may need more help to communicate and get around. Offering to help with travel can help reduce the stress for the person with MSA and their carer. Show you understand the need to adapt plans.

"*Understand that it will take me longer to do most things, I may not be able to do what I once did*".

Carers can be under stress for sustained periods. Offering to spend some time with your friend to allow their carer some respite may be greatly appreciated. If your offer isn't accepted, don't be afraid to ask again.

Be the friend you always were

Things will be different and that's OK. A coffee morning attendee said "*Some friends will struggle to cope, but I'm still here, I haven't changed. Treat me like you always have*".

Whatever brought you together as friends still remains, so do what you always did for as long as you can. Search for new ways to share time together.

Watching TV was a common suggestion as it isn't impacted by someone's voice being weaker. To quote a Support Group attendee "*Just because I can't speak straight, doesn't mean I can't think straight!*" So, if communication becomes difficult still engage as you always have, just be patient and adapt.

SCAN ME TO LEARN MORE

Alongside our HealthUnlocked community, our coffee mornings and Support Groups are a great way to make new connections. To find out more, email support@msatrust.org.uk.

How we supported our MSA Community in 2024-25

More people affected by MSA supported than ever before…

136 MSA clinics attended by our Healthcare Specialists who also dealt with 22,500 enquiries

900 Healthcare Professionals attended our training sessions

Our **2025 MSA Trust Research Symposium** attracted world renowned researchers with 150 attendees

170 people attended our MSA Study Day with 100% positive feedback

We are the 1st organisation to hold the independent **PIF TICK Information accreditation** for five consecutive years

Our **Social Welfare Service supported 1,151 people** with families being awarded nearly **£400,000** in benefit entitlements

In conjunction with Rare Minds, our **pilot counselling interventions** were proven to be of great benefit to those accessing them

Research funding supported vital MSA research projects totalling nearly **£610,000**

Over 50 families in exceptional hardship assisted through our limited welfare grants support.

1,453
people living with MSA supported

2,777
Carers, Family and Friends supported

"Thank you for inviting us to the meeting yesterday. We both thoroughly enjoyed it. Was good to realise that we're all on the same journey, all be it with different symptoms."

165
Support Groups held

"Your deep knowledge of my condition gives me confidence in my desire to live the best life I can for as long as possible. Thank-you for bringing light to the darkness."

"This pack was so helpful when my husband was in hospital. I put it in the same folder as his hospital notes. It helped the staff to understand what MSA is and make allowances for it."

"Thank you for completing my PIP review for me. At times I have struggled with providing information over the phone, but you have always been so very patient and efficient it really is incredible."

As ever we are very grateful to all of you who have helped us during this time, be it through your fundraising, volunteering or general support to our MSA community.

Supporting Children and Young People

MSA is a condition that develops in adults. However, we know that children and young people can be greatly impacted by the effects of MSA if a family member is living with the condition. Here, Emma Rushton, Head of Operations: Information and Services, looks at some top tips for talking to children about MSA and the resources we have available.

Research suggests that when faced with difficult situations, children cope better if they are given information to help them understand what is happening, are included in discussions and are allowed to talk about their concerns. To help when having conversations with children about MSA we have two resources.

First, we have a Children's Activity Book which is aimed at children aged between 4–11 years old. With friends Monty, Sandy, Ali and Toni the book works through interactive activities to help with understanding the different elements of MSA. Topics covered within the book include 'What does MSA mean?', the most common symptoms of MSA, 'How you're feeling' and how to explain MSA to other people. The books comes with stickers and there are activities that the child and person with MSA can complete together.

You can order a copy of the children's book here - **https://msamag.link/children-book**.

Second, we have a Young Peoples Hub on our website for those aged 11–17 years old. This resource is split into different sections covering topics such as how MSA can affect family life, managing feelings and emotions and where to get further support. It is set up so young people can dip in and out of the hub, depending on what they might want to read at that particular time.

The Young Peoples Hub can be accessed via our website here - **https://msamag.link/young-people**.

If you are supporting a child through your MSA diagnosis, or a loved one's, here are some initial suggestions of ways to handle conversations, alongside the resources mentioned above.

- Answer questions honestly. If you don't know the answer say so and that you will try to find out and let them know when you do. If you are not honest they may not come back to you in the future when they need to.
- Check what they are really asking before you try to answer! They may not be asking what you first think so reflect back to them "So you are asking me if……?".

> "Me and my sister have these [books] for our children, they have been so helpful. We actually show carers and other family members and it's helped everyone understand my mum and what's happening a lot better. So grateful for them. Thank you"

- Ensure the child knows that getting MSA is no-one's fault and it is nothing to do with something they, or anyone else may have said or done to the person.
- Allow opportunities to talk about MSA and the person living with MSA, but don't push them to talk if they don't want to.

> "The activity book for kids is so brilliantly put together and I think will give us lots of starting points for working through the confusing aspects of MSA…"

SCAN ME TO LEARN MORE

- Try not to impose your emotions or beliefs on to them – their feelings and ways of dealing with the situation may be very different to what you think they 'should' be, but there is no right or wrong.
- Reassure them they will always be loved and cared for whatever else is going on.

A Diary of Love and Purpose:

Stephen and Alison's Story

Stephen met Alison in 1978, beginning a journey of love that has spanned 39 years of marriage, two children and three grandchildren. Their life together has been rich with adventure but it has also brought profound challenges – most recently, Alison's MSA diagnosis.

MSA changed everything for them, stripping away plans and independence. "You don't cope with the diagnosis," Stephen shares, "but with support, you learn to live a little." Determined to help others, Stephen used his background in print to create 2026 pocket diaries for the MSA Trust. "Rather than donate money, this promotes awareness," he says. "The more people who know about MSA, the better."

The diaries are more than tools – they're symbols of solidarity and visibility. Stephen hopes they'll raise awareness of MSA and gain recognition. Stephen's message to others is simple but powerful: "There will be people out there who have similar skills, and I would ask them to think if they can help as we have done."

We are incredibly grateful to Stephen and Alison for their generosity and courage in sharing their story.

Stephen and Alison's 2026 pocket diaries are now available from our shop – www.msatrust.org.uk/christmas.

Sarah's Wood

Our MSA community has been planting Oak saplings and growing Sarah's Wood since 2017. Situated within Sherwood Forest, Sarah's Wood, is a space dedicated to honouring our founder, Sarah Matheson. It provides a symbol of community and hope for all those affected by MSA.

We have been developing the space over the years through our annual tree planting event, where community members can come and plant saplings in support or memory of loved ones. Our Path to a Cure leads directly to Sarah's Tree and is made of engraved bricks bearing the names of members of our MSA community.

We warmly invite you to participate in our next tree planting event to help us further develop the woods. This will take place this year on the **29th November**.

If you would like to attend, please email **fundraising@msatrust.org.uk**. If you are unable to attend in person, we can still plant a tree on your behalf.

IN MEMORY

Our tribute to those loved ones recently lost to MSA.

Jasvir Kaur
Mary Gleeson
Ian Clabburn
Tim Harrison
Barry Robinson
Richard Pepper
David Whitney
Grenville Mitchell
Kevin da Silva Fernandes
Simon Buckley
Irene Martin
Mark Benson
Kathryn Fowler
Terence McCaw
Richard Etches
Marianne Jones
Kenneth Marchant
Robert Valentine
Margaret Middleton
Anne Cameron
Sheila Houldsworth
Tracy Smith
Stuart Marnoch
Jackie Robinson
David Backhouse
Nick Ewings
Linda Farmer
Claire Randle
Paul Ord
Janet Briggs
Sue Whittaker
Garry Murray
Susan Von Dinther
Andrew Robinson
Susan Barton
Ted Walsby
Diane Willis
Winston Thomas
Mandy Tye
Jane Smith
Monique Warham
Fiona Owens
Carol Cherrington
Michael Gilbert
Anthony Price
Dhiraj Jethwa
Maureen Slinn
Catherine McMullen
Sean Ockwell
Katie MacNeill
Meg Laird
John Aspin

Christmas APPEAL

Advancing Training and Awareness

This Christmas, your gift can help improve the lives of people with MSA by funding our vital external Health Care Professionals (HCP's) training and awareness initiatives.

Why we need your support

Our most recent Needs Survey revealed alarming gaps in the support and understanding of MSA, highlighting an urgent need for improved training for HCP's to better support people with MSA and their carers.

56% of people said their GP did not understand MSA

41% felt that on the day they were diagnosed they were not given information about what to expect when living with MSA

34% of people had never been referred to any specialist palliative care support

These figures show a pressing need: Health Care Professionals must receive better training to boost their awareness to effectively support people with MSA and their carers.

What we are doing

Last year the Trust provided **53** education and training sessions for **900** HCP's.
Next year, we will launch a new online training module alongside the Neurology Academy.

Please support our Christmas Appeal (or call 0333 323 4591) to help fund HCP training.

www.msamag.link/xmas-appeal

You can also support us this Christmas by making a donation to our **Virtual Christmas Tree** and helping us light it up.

Add a golden star in support or memory of someone.
Hang a bauble with a personal message and photo.
Light a candle of hope for those affected by MSA.

Visit our online page to share your dedication

www.msamag.link/visufund

FR FUNDRAISING REGULATOR