



# msa *news*

MSA Trust Members Magazine | Issue 70 | June 2024



*Your chain  
of support*

Finding  
help in *your*  
community



## Welcome to Issue 70

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**W**elcome to your Summer edition of MSA News.

This issue is packed full of articles to support you in living well with MSA. Our MSA Nurse Specialists have written three articles about symptoms that we know consistently affect people. On page 6 we have an article on saliva management and on page 13 we look at ways to help regulate your temperature.

Finally, on page 16, our MSA Nurse Specialist, Katie writes about catheters and when these may be needed.

We are very pleased to tell you we have welcomed another colleague to our Social Welfare Specialist Team, Louise Hardy joined us in March. Read more about Louise, and the community support you may be able to access, on the next three pages.

Our 2024 MSA Study Day for Health and Care Professionals (HCP's) will be taking place in Glasgow on the 19th September. Please encourage your HCP's to attend – they can book tickets via our website now.

We hope you find this edition of your magazine interesting and informative and as always if you have any feedback please get in touch.

Emma and Andy

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We have taken every care to ensure the accuracy of the information contained in this publication. However, the information should not be used as a substitute for the advice from your doctor or appropriate qualified professionals. Please note that personal views and opinions expressed are not necessarily endorsed by the Trust.





# Community Support

**Louise Hardy joined the Trust as our second Social Welfare Specialist in March 2024. Louise has many years of experience providing information and support on a wide range of issues, including welfare benefits and social care. Here, Louise highlights some of the additional help and support that may be available in your community.**

**W**hen considering community and non-medical support, the first point of contact is your local Adult Social Care Team. They can be accessed via your local council and anyone can self-refer to Adult Social Care.

The Adult Social Care Team will carry out an assessment of your needs, which includes any caring support that is needed, occupational therapy aids or equipment, or adaptations needed to your home. If you are providing care to somebody with MSA you can also separately ask for a carers needs assessment. Some services, e.g. provision by professional carers, are subject to a financial assessment.

**Local Hospices** provide support for people with a life-limiting condition. Hospice services can be accessed at any stage of a person's health condition and they offer a holistic approach which is centred on improving a person's wellbeing. Hospices can also support family members and carers.

Hospices may offer a wide range of services, including:

- **Physiotherapy** – help with exercises to keep people active and to help their mobility
- **Occupational therapy** – can assess home equipment or adaptations
- **Complementary therapies** – such as massage and reflexology to help with relaxation

- **Play specialists** – support children and young people if a family member is seriously ill
- **Counsellors and spiritual advisers**
- **Community Buddies or Befrienders** – support people at risk of social isolation, or people wanting support to socialise or attend activities
- **Day care or therapies** – such as art or gardening sessions
- **Short breaks** – support if a person with caring responsibilities needs a rest.

A GP or Consultant can refer people to hospice care, and some hospices accept self-referrals. You can find your local hospice and the services they offer here:

[www.hospiceuk.org/information-and-support/your-guide-hospice-and-end-life-care/im-looking-hospice-care/what-hospice](http://www.hospiceuk.org/information-and-support/your-guide-hospice-and-end-life-care/im-looking-hospice-care/what-hospice).

If you live in Ireland, speak to your MSA Health Care Specialist or your Occupational Therapist who can help you find similar services in your area.

As part of NHS services, **Social Prescribers** are link workers who connect people to community-based support, including activities and services to meet their needs. They support people with their health and wellbeing and use a “what matters to me” approach. They produce a person-centred action plan with each individual and using their local knowledge, they help people access local partners for practical,



social, physical and emotional support. This can be, for example, exercise classes, carers' groups, arts or gardening groups.

Social Prescribers are often attached to GP surgeries, a local Council for Voluntary Service (CVS) or a local authority. Sometimes they have different names to describe their role, such as Wellbeing Adviser or Community Connector. If you feel you would benefit from social prescribing, speak to your GP to check if this service is available in your area.

Often part of the GP surgery team, **Community Matrons** work with people with long-term or complex health conditions. They can act as a single point of contact for care or advice. Community Matrons are experienced senior nurses and their role includes assessing and treating patients, which can help to reduce the need for hospital admissions. If your GP surgery does not have a Community Matron, you can check if this service is available in your area by contacting:

- **England** - local integrated care board  
[www.nhs.uk/nhs-services/find-your-local-integrated-care-board](http://www.nhs.uk/nhs-services/find-your-local-integrated-care-board)
- **Wales** - local health board or hospital trust  
[www.gov.wales/nhs-wales-health-boards-and-trusts](http://www.gov.wales/nhs-wales-health-boards-and-trusts)
- **Scotland** - local health and social care partnership  
[www.hscscotland.scot/hscps](http://www.hscscotland.scot/hscps)
- **Northern Ireland** - local health and social care trust  
[www.nidirect.gov.uk/contacts/health-and-social-care-trusts](http://www.nidirect.gov.uk/contacts/health-and-social-care-trusts)
- **Republic of Ireland** - HSE local health office  
[www.hse.ie/eng/services/list/1/lho](http://www.hse.ie/eng/services/list/1/lho).

Some charitable organisations have **Volunteer Companions** who can offer free emotional and practical support. This can be in a person's home or a hospital setting. Companions are matched after finding out about the person's interests and needs. They can spend a few hours a week with the individual being a "listening ear", having a chat or accompanying someone to an appointment. Companions do not assist with medical issues, personal care or act as counsellors.

Organisations which offer companions are below. Some offer a telephone befriending service only.

- [www.mariecurie.org.uk/help/companions](http://www.mariecurie.org.uk/help/companions)
- [www.royalvoluntaryservice.org.uk/our-services/supporting-people](http://www.royalvoluntaryservice.org.uk/our-services/supporting-people)
- [www.ageuk.org.uk/services/befriending-services](http://www.ageuk.org.uk/services/befriending-services)
- [www.reengage.org.uk/join-a-group/get-a-call-companion](http://www.reengage.org.uk/join-a-group/get-a-call-companion)
- [www.alone.ie/our-work/#Coordinated-Support](http://www.alone.ie/our-work/#Coordinated-Support)

If you live in Ireland, speak to your MSA Health Care Specialist or your Occupational Therapist who can help you find similar services in your area.

The **British Red Cross** offers support to people after a stay in hospital. Their 'help at home' service includes transport to and from hospital, help with everyday tasks such as picking up shopping or prescriptions, and companionship. The package of support lasts for up to 12 weeks. A referral from a GP or healthcare professional is usually needed. Details of their UK-wide services can be found here:

[www.redcross.org.uk/get-help/get-support-at-home](http://www.redcross.org.uk/get-help/get-support-at-home)

In addition, the British Red Cross hires out toilet aid equipment, such as toilet seats, toilet frames and commodes for a small charge. Aids can be provided for free in some geographical areas - [www.redcross.org.uk/get-help/hire-a-toilet-aid](http://www.redcross.org.uk/get-help/hire-a-toilet-aid).

Across England, Wales and Northern Ireland, the British Red Cross also offers wheelchair hire (the minimum hire period is one week) - [www.redcross.org.uk/get-help/hire-a-wheelchair](http://www.redcross.org.uk/get-help/hire-a-wheelchair).

Please note that in England and Wales, the NHS provides wheelchairs to people with mobility and posture needs who require a wheelchair for long-term use. A GP or Physiotherapist can make a referral to your





local wheelchair service for an assessment.

In Scotland, wheelchairs are provided via the needs assessment carried out by Health and Social Care Partnerships (HSCP) - [www.hscscotland.scot/hscps](http://www.hscscotland.scot/hscps).

In Ireland, wheelchairs are provided by the Health Service Executive (HSE) via an Occupational Therapist - [www.hse.ie/eng/services/list/4/disability](http://www.hse.ie/eng/services/list/4/disability).

The MSA Trust runs both digital and in-person **Support Groups**, which are a great way of meeting others living with MSA. Our Support Groups are open to anyone affected by MSA including carers, family members and health or social care professionals. Support groups are usually attended by one of our MSA Health Care Specialists and provide an opportunity for people to ask questions or find out more information. One of our Social Welfare Specialists also regularly attend our digital Support Groups. If you would like to receive invites please contact us at [support@msatrust.org.uk](mailto:support@msatrust.org.uk) or call 0333 323 4591.

## Additional support for carers

In addition to the support outlined above for people living with MSA, help and support is available to carers. As previously mentioned, carers can request their own needs assessment from their local authority. There are also national organisations which provide information and support to carers and many have local support groups and activities for members to join. The main two organisations are Carers UK and Carers Trust, their details can be found here:

**Carers UK** - [www.carersuk.org](http://www.carersuk.org)

**Carers Trust** - [www.carers.org](http://www.carers.org)

The MSA Trust runs a Carer's Online Support Group. This virtual Support Group provides an opportunity for carers to come together and share tips and experiences or simply have a chat. If you would like to receive invites please contact us at [support@msatrust.org.uk](mailto:support@msatrust.org.uk) or call 0333 323 4591. [msa news](#)



## A brief introduction from Louise...

I joined the MSA Trust in March 2024 as a Social Welfare Specialist and I work three days per week (Tuesday - Thursday) alongside Sam Fitzgerald. I have worked for several voluntary and public sector organisations, including the past ten years with Citizens Advice providing advice in GP Surgeries. I have provided support with and helped people to claim welfare benefits; with income maximisation and grants and have helped people to access care assessments.

I enjoy working alongside people, helping with information and support on a range of non-medical issues. I appreciate the difficulties and challenges people living with MSA can face and I'm happy to help and support people to navigate both the benefits and social care systems.







# Management *of* Saliva Needs

**In this article, Samantha Pavey, MSA Nurse Specialist, looks at the difficulties people living with MSA may have with saliva and ways to help support the management of this.**





We need a certain amount of saliva to be able to swallow and digest our food and to prevent bad breath, tooth decay and gum disease. We all produce about a litre and a half of saliva every day and we swallow around every two minutes to manage this. People with MSA often have a reduced swallow, or swallow less often, meaning the saliva can build up at the back of the throat. If the head is pushed forward (called antecollis), which can happen in MSA, the saliva can drool from the mouth causing soreness and for some, embarrassment. It doesn't take much saliva (or food or fluid) to "go down the wrong way" into the lungs instead of the stomach. This puts people at risk of developing a chest infection. Any infection someone with MSA experiences will suddenly make all of their MSA symptoms much worse.

## How to manage excess saliva:

Posture is really important, especially when eating and drinking. Your head should be upright and facing forward. Your Occupational Therapist can advise you on your posture and suggest a suitable chair, cushions or equipment to support your head and neck if needed. You may notice the saliva is worse when you are concentrating on other things, such as watching television. Your Physiotherapist can provide exercises to improve posture. They can also educate carers on how to use a suction machine if necessary or suggest steam inhalations to loosen secretions.

Try to remember to swallow often as this can help to prevent the saliva pooling in your mouth. Chewing gum can be helpful, as can frequently sipping water. Sugar free gum can help to prevent tooth decay. Ginger tea or sucking dry ginger may help. Dark grape juice can help reduce thin runny saliva, whereas fresh pineapple juice can be helpful for breaking down thick saliva.

Your Speech and Language Therapist can show you some techniques to help strengthen your facial muscles, which can help with lip seal. They can refer you for botox treatments (injections into the salivary glands) if they feel that may be beneficial. Humming can help to keep your lips together. You might like to use a timer on your phone as a reminder to swallow frequently or a swallow prompt app.

Our saliva factsheet has examples of exercises that can also help with lip seal - [www.msatrust.org.uk/support-for-you/factsheets](http://www.msatrust.org.uk/support-for-you/factsheets).

Drooling of saliva can make the skin around the mouth sore, which can lead to cracks or infections. This can impact on speech and swallowing. Try to use lip balm or Vaseline to prevent soreness. Try to keep your mouth as clean as possible to reduce bacteria. Using an electric toothbrush if able, can be helpful or a child's toothbrush with a smaller head is softer to help clean the tongue and gums. Dabbing saliva with a tissue, rather than wiping it away causes less skin irritation.

## Treatment of excess saliva:

There are several medications that can be helpful to dry up saliva and these are listed in our saliva factsheet (see above). GPs are guided by clinical guidelines to try all non-pharmaceutical options before prescribing medications. They should refer you to a Speech and Language Therapist in the first instance.

## Dry Mouth:

A dry mouth can also be an issue in MSA. This may be caused by certain medications, drinking alcohol and caffeine and smoking can also exacerbate this. Try to increase your fluid intake and suck on crushed ice if you are able. Ask your GP or dentist (available on prescription) if your mouth is very dry.

It is important to visit your dentist for regular check-ups. A dry mouth and pooling of saliva and food in the mouth can cause problems with the health of your mouth and gums. If you aren't registered with a local dentist, you can find a dentist here:

- [www.nhs.uk/service-search/find-a-dentist](http://www.nhs.uk/service-search/find-a-dentist)
- [www.mygov.scot/register-with-dentist](http://www.mygov.scot/register-with-dentist)
- [www.northerntrust.hscni.net](http://www.northerntrust.hscni.net)

Some dentists will offer home visits so ask about this at your dental surgery.

**Do check with your Speech and Language Therapist first before trying any suggestions given here.**

*msa news*

Do contact the MSA Health Care Specialists for further information on saliva issues or if you wish to discuss anything in this article - [www.msatrust.org.uk/support-for-you/hcps](http://www.msatrust.org.uk/support-for-you/hcps).





# In Memory

Penelope Snape  
Annie Moldram  
Jane Bridges  
Hazel Taylor  
Paul Cross  
Mary Newton  
Barbara Coombs  
Annie Pratt  
Margaret McGarry  
Paul Walton  
Robert Gavin  
Robert Bate  
Margaret Jones  
Geoffrey Manser

Mitzi Cooper  
Brian Sowerby  
Yvonne Andee  
Linda McCulloch  
Alexa Peach  
Laurence Jay  
Justin Macadam  
Christopher Duncan  
Debbie Browne  
John Gosling  
Roy Ball  
Dave Jardin  
Michael Thompson  
Susan Kershaw

John Youngman  
Mary Meagher  
Robert Sims  
Vivien Rose  
Eric Coates  
David Fitzgerald  
Geoff Hayward  
Susanna Rice  
Sally Cottrell  
Stephen O'Neill  
John Costigan  
Vera Young  
David Morton  
Neal Williamson

Marian Johnson  
Alan Mitchell  
Jackie Pickford  
Josephine Taylor  
Peter Winter  
Margaret Tyhurst  
Alan Rooke  
Andrew Hensley  
Michael Verburg  
Birthe Jennings  
Albert Kane  
Carvar Noon  
Dilys Palmer  
Roy Mitchell

## IN MEMORIAM EVENTS

The Trust continues to receive incredible fundraising support from families who take on activities in honour of their loved ones. It's a lovely way to pay tribute and ensure a legacy of supporting others affected by MSA continues and helps towards funding MSA research.

**Charles Nelis** got his local running club, Stopsley Striders involved in raising funds in memory of his dear sister, Lisa Marshall. The Club's sponsored runs, raffles and collections have raised a fantastic £2,747 so far.

Sisters **Leanne Wellington** and **Vicky Tonkin** (pictured) take on the Dartmoor Tors this year, trekking 64 of these to mark each year of their beloved mother, Vanda Wellington's, life. They said:

*"Growing up we would often go for walks on the Moors so this feels like a fitting challenge and tribute, and hope that family and friends will come and join us along the way. Mum was very keen that we go on to raise awareness about this rare disease so hopefully less people suffer in the future."*

Leanne and Vicky provide regular updates on their treks so far and are pleased that they have reached almost half their fundraising target.

Thank you so much to Charles, Leanne and Vicky. If you would like to complete an event in memory of your loved one please contact our fundraising team at

[fundraising@msatrust.org.uk](mailto:fundraising@msatrust.org.uk). msa news





# When Urgent Antibiotics are Needed

People with MSA often don't show the typical signs when they have an infection and need quick access to antibiotics when one is present. We have received feedback from members that it is a struggle to get medication urgently when their GP Surgery is closed. We spoke to the team at NHS England about what you can do to help prevent this from happening.

Recently, we met with members of NHS England who are responsible for running the digital services provided by the NHS, including the NHS 111 service. NHS 111 is an online and telephone service that can give you immediate healthcare advice and direct you to the best place to get help. That could be A&E, an out-of-hours doctor, an urgent care centre or walk-in centre or a late-opening chemist. Trained advisors work at NHS 111 and are supported by a team of clinicians and nurses.

When people contact NHS 111, they are assessed based on their presenting symptom and asked questions to determine if anything is life threatening and needs ambulance intervention. If you are calling about MSA symptoms, it is very important that you tell the call handler that you have Multiple System Atrophy. Make sure you say the full name and not just MSA. Anything deemed as a complex call will be referred to a clinician for a call back, but this may not be for a number of hours.

One thing you can do if antibiotics may be needed urgently, is ensure that your GP includes a 'Special



Patient Note' on your patient record. It is visible to NHS 111 call handlers nationally. Ask that your GP writes that you need prompt antibiotics and may not show the usual signs of infection.

Another action you can take is making sure your GP creates a 'Pre-determined Management Plan' for you. This should specify that you need antibiotics urgently if an infection is suspected and the signs of how the infection might present e.g. a sudden deterioration of neurological symptoms. If you tell call handlers that you have a 'Pre-determined Management Plan' you will be triaged to speak to a clinician. This should only be used in urgent situations.

Alongside these ideas, you can access the 'Emergency Prescription Supply Service' using the NHS 111 online service. This is to get repeat prescriptions needed urgently sent to a pharmacy near you. GPs can set up a 'variable repeat prescription' as an alternative to putting antibiotics on a regular repeat. You can access the service here - [www.111.nhs.uk/emergency-prescription](https://www.111.nhs.uk/emergency-prescription).

NHS 111 also suggested that it is pre-arranged with your GP or Consultants to keep a 'rescue pack' of antibiotics at home, in case of emergency. [msa news](#)

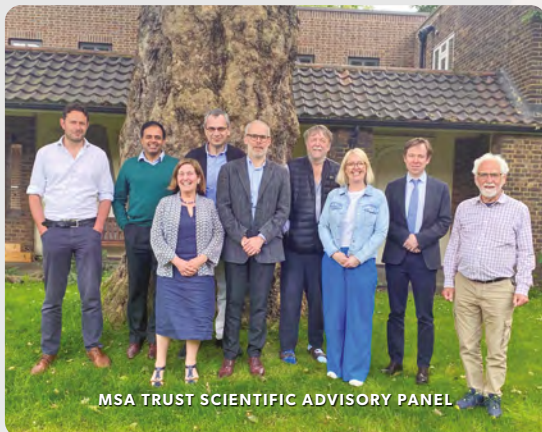
If you have any questions about infections in MSA please speak to your MSA Health Care Specialist - [www.msatrust.org.uk/support-for-you/hcps](https://www.msatrust.org.uk/support-for-you/hcps).



# Research Roundup

## MSA Trust Research Funding Update

In Autumn last year the MSA Trust put out a call for research grant proposals and we were delighted to receive 13 initial summary applications. These were reviewed by our Scientific Advisory Panel (SAP), with a number invited to proceed to full application stage. Six full applications were finalised and in May our SAP met to review these. More information on the successful applications will follow in our blogs and on our website when they begin in Autumn this year, and we will keep you updated on their progress in future editions of MSA News.



MSA TRUST SCIENTIFIC ADVISORY PANEL

## MSA Research Symposium

In February we held the second annual MSA Research Symposium alongside the University College London. It was a fantastic event that brought together MSA researchers from all over the world. They were able to meet and hear updates and results from MSA research that is already happening. The event provided researchers with the opportunity to network and collaborate with colleagues with a shared interest in MSA. The morning sessions focussed on genetics and biomarkers of MSA and the afternoon sessions focussed on diagnosis and clinical management of MSA, ending with a session on clinical trials. The sessions are summarised in a blog on our website. The event was a great success and planning for next year's symposium is already underway.





## Research programme - Feeding Tubes

An ongoing MSA Trust funded research project looking at the use of feeding tubes for people with MSA continues. The team published an article recently that looked at frequency and outcomes of insertion of a feeding tube (also called a Percutaneous Endoscopic Gastrostomy, or PEG) in people with MSA. The research team are asking people with MSA to complete a short online survey about their experience of having a PEG. You can read more here -

[www.bit.ly/3wfw4st](http://www.bit.ly/3wfw4st). The link to the survey is [www.de.surveymonkey.com/r/F6X29N6](http://www.de.surveymonkey.com/r/F6X29N6).

The next steps will involve a focus group with people who have a PEG inserted and are willing to contribute their time and experience to help further the research project. If you have a PEG tube and would like to take part, please complete the survey linked above.

## Current trials

The Horizon study is looking for a small number of people very early in their MSA journey, who may be suitable to take part in testing whether a new treatment, which is injected into the spinal area, has any effect in MSA.

The CYPRESS study is recruiting people with MSA who have orthostatic hypotension – blood pressure that drops on standing and causes dizziness – into a trial to examine whether a new medication improves these symptoms in people with MSA.

Information about both of these trials can be found in the 'Open Trials' section of our website - [www.bit.ly/44ZBN36](http://www.bit.ly/44ZBN36).

Please talk to your MSA Health Care Specialist if you would like further information about research opportunities. The NIHR's 'Be Part of Research' and Scotland's 'Scottish Health Research Register' offer the opportunity for people to register their interest in taking part in clinical research.

## MSA Trust Members Research Group

Our second online members research group was held in May. It was chaired by Dr Viorica Chelban and attended by members of the MSA Trust. Dr Goh presented her research on Biomarkers for MSA and whether these could be used to predict the course of MSA in the future. Riona Fumi provided an overview of The Early Assessment, Diagnosis and Treatment of Parkinson's Plus Related Syndromes (ExPRESS) study. The ExPRESS study team are asking people with MSA their thoughts on being diagnosed with MSA, and whether earlier diagnosis would be useful. Please follow this link to complete the survey if you would like to contribute: [www.bit.ly/4dRwoir](http://www.bit.ly/4dRwoir).

Finally, Dr Iodice spoke about the autonomic system and how this is affected in MSA and presented information on current and upcoming research projects for management of these symptoms. People with MSA who experience low blood pressure can help by completing an online survey about this, more details are in the 'Research' section on our website.

**All of the researchers spoke about how invaluable the contribution of people with MSA is to research teams and research projects and how grateful they are for the participation of people with MSA in research projects.**

The MSA Trust online research meeting is held online twice a year, if you would like to receive invitations to these meetings, please email [support@msatrust.org.uk](mailto:support@msatrust.org.uk).

**Reminder!** The 'Research' section of our website contains information about current research, results and our research strategy. We will be updating our research strategy later this year and hope to build on previous work and expand future research opportunities.



# NEWS ROUNDUP

## 3,300 Mile Challenge

We want to say a huge thank you to everyone who participated in our recent 3,300-mile challenge. The goal was to walk 3,300 miles, a mile for each person living with MSA in the UK and Ireland. We exceeded our target by walking 4,409 miles! Not only did we surpass our goal, but we also raised an incredible £5,575 in the process with 94 of our members, along with staff at the Trust, getting involved. [msa news](#)



## HCP MSA Study Day – Scotland, 19th September 2024

We are excited to announce that our MSA Study Day for Health and Care professionals is taking place in Glasgow this September. This is an event which brings together professionals such as Parkinson's Nurses, Speech and Language Therapists, Physiotherapists, and many more, to share knowledge about MSA so they can better support people with MSA.

To help spread the word, we would like to ask you to share this information with any of the Health and Care professionals you are in

contact with, who you think may be interested in attending. Tickets are available via our website –

[www.msatrust.org.uk](http://www.msatrust.org.uk). [msa news](#)



## Sarahs Wood Events

We would like to invite all our members to our annual tree planting event at Sarah's Wood on Saturday 30th November. This is a free event and an opportunity to contribute to our growing copse of oak trees at Thoresby Park, in Sherwood Forest. The event is intended to commemorate our founder and serve as a symbol of hope for all those living with MSA, as well as a place of remembrance for those lost to it. We will continue to grow the Wood for years to



come, planting more saplings and watching it develop, leaving a permanent mark of hope for those affected by MSA. We have also rescheduled our Summer Social at Sarahs Wood to Saturday 21st September. At this event you will be able to view the Path to a Cure, enjoy afternoon tea and meet other members of the MSA community. For more information, please contact

[fundraising@msatrust.org.uk](mailto:fundraising@msatrust.org.uk).

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## A Heartfelt Thank You

The Trust sends its heartfelt thanks to our Trustee, John Shinton, who stood down at the end of our financial year in March 2024. John had been a Trustee for five years. He sat on the Finance Subcommittee during this time and made a significant contribution to establish and maintain good governance of the finances at the Trust. He was a great help during the pandemic in ensuring the Trust managed their resources carefully and came through that difficult time with resilience. The staff and Trustees send their gratitude and wish him well. [msa news](#)





# Temperature Control *in MSA*

**It is common for people with MSA to have problems with temperature regulation. Our MSA Nurse Specialist, Jill Lyons, shares some thoughts on what may help...**

The effect of poor temperature regulation can be either excessive sweating or a lack of sweating. Excessive sweating can require a complete change of clothing or bedding. This symptom may occur for a while and then stop. If you are experiencing excessive sweating here are a few ideas that might help.

- **Wear loose fitting clothing that is made of natural - not synthetic fibres**
- **Use bedding and nightwear that is made of natural fibres**
- **Cool cotton pillowcases in the freezer before going to bed**
- **Use a fan or air conditioning to keep the room cool**
- **Stay in the shade/wear a large, brimmed sunhat**
- **Make sure you have cooling drinks available and keep hydrated**
- **Identify and avoid foods that may trigger sweating (e.g. alcohol or spices)**
- **Putting cool gel pads under sheets in bed can help for night sweats.**

Sometimes sweating may be due to an infection, such as a urine infection or a chest infection. Keep a look out for other symptoms or a sudden general deterioration in MSA symptoms and seek medical advice promptly. People living with MSA do not always show a raised temperature when they have an infection, so an infection should not be ruled out if the thermometer is not showing a raised temperature. A study suggests that people with MSA have a lower baseline temperature so it may be useful to know for reference what your usual temperature is when you do not have an infection.

However, an infection may not be present, and sweating may be a part of the autonomic changes that MSA can bring.

If you are menopausal the night sweats might be part of the menopausal change and menopause treatment may be needed, do discuss with your GP.

People with MSA may also experience feeling really cold when others in the room are not, again this is due to the changes in their temperature regulation. People with MSA may experience change in the colour of their fingers and toes they can appear purplish colour and cold to touch.

Ways to manage feeling cold include.

- **Layering clothing**
- **Fingerless gloves and other winter clothing worn indoors**
- **Keep house temperature warm, stay in one warm room if necessary**
- **Make sure you are layered up before going out in cold weather (it is often difficult to get warm once you are cold). You may need more clothing than other family members**
- **Exercise as you are able, seated exercises can be useful**
- **Avoid sudden changes in temperature**
- **Use heated blankets and hand warmers**
- **Aromatherapy massage to hands and feet may be helpful and can sometimes be accessed via your local hospice.**

Do contact your MSA Health Care Specialists for further discussion on this if you would like more information. [msa news](#)





# Team MSAT

## at the London Marathon 2024



A huge thank you to our ten incredible runners who represented Team MSAT at the 2024 London Marathon. Your hard work in both fundraising and training paid off, helping us raise **£21,824.77**! The Marathon day was unforgettable, with each step bringing us closer to our fundraising goal. Special thanks to Bethany, Matthew, Sarah, Stuart, John, Andrew, Oliver, Neil, Jack, and Simon for choosing to support us. Your efforts have made a real difference in the fight against Multiple System Atrophy.



*"It was honestly the most spectacular day, thank you all so much for letting me be a part of such a wonderful team. Hopefully the money raised can make a small difference."*  
Bethany Oxley



*"I wanted to raise awareness of MSA, a condition that my mum (Ruth) suffered from before passing away. 2024 marks 20 years since she passed and will run in her honour, raising vital funds for further research and supporting families that are affected by MSA."* Simon Jenkins



*"I ran in memory of my mum, Janet, who was diagnosed with MSA in 2019 and passed away in November 2022. I want to raise awareness of the condition, and support research into MSA so that other people don't have to go through what she did."*  
Sarah Blainey

## Evie and Dave make waves for MSA Trust

Evie, aged 7, and her grandad Dave recently completed a 2,000m Swimathon in April in support of the MSA Trust. The Trust has been a lifeline for their family during a challenging time, offering invaluable support to Evie's Nanny, Susan Bendon.

Evie and Dave dove headfirst into their fundraising efforts and together they raised an incredible £2,055. A huge thank you to everyone who supported this fundraiser and made it such a success. [msa news](#)







# Community Support for the Trust

**Several organisations have kindly supported the Trust in the last year, not only raising essential funds for our support services, but also raising much needed awareness of MSA.**

Employees of Fishers Solicitors in Ashby-de-la-Zouch kindly nominated the Trust as the law firm's Charity of the Year. A group of 13 staff members took on a walking challenge covering 1,260 miles which is equivalent to the distance between London and Rome! They completed the challenge within 14 days and this fundraiser, along with others, raised £4,015 for the Trust. Well done Team Fishers!



TEAM FISHERS

Fulwood Hall Hospital fundraised for the Trust after a much-loved member of staff sadly passed away from MSA. They raised funds year-round through monthly and special occasion draws as well as the Hospital's Christmas fair. Hospital Director, Fiona Thornhill, said:

*"I would just like to add what a pleasure it has been to have the MSA Trust as the nominated charity at Fulwood Hall, especially as it's very close to the hearts of staff involved in the fundraising."*

We are ever so grateful to all staff involved, thank you so much for honouring your colleague this way. *msa news*



FULWOOD HALL HOSPITAL



## Summer of FUNdraising

From the 1st June why not embark on a summer adventure that suits your style? Whether you're diving into the pool to swim a mile every day throughout the summer, cycling through the picturesque countryside, or exploring the great outdoors by wild swimming in as many lakes and rivers as possible, there's a challenge for every adventurer. Gather your friends and family or go solo - the choice is yours!

Create your Enthuse page here - [www.bit.ly/44T5qmp](http://www.bit.ly/44T5qmp).

You can also connect your Strava account and set your challenge duration, whether it's a week or a summer-long activity. Get involved, get active and let's make a splash this summer. *msa news*



# Catheters *and* MSA

**This article, written by our MSA Nurse Specialist, Katie Rigg, explains the use of urinary catheters to manage bladder problems commonly experienced by people with MSA.**

**T**hinking about having a catheter can be daunting but many people say that once they have got used to it their quality of life is improved.

For men there is a non-invasive option as the device is attached externally rather than being passed into the bladder. This can be a good option if the bladder can empty properly but getting to the bathroom is difficult or there is persistent leakage. A thin rubberised sheath called a uridom or conveyer is fitted over the penis and any urine passed drains along attached tubing into a bag.

However, often in MSA for both sexes an indwelling catheter is needed because the bladder is unable to completely empty when the person tries to pass urine. Poor nerve messaging and loss of co-ordination of the bladder muscles causes urgency, frequency and difficulty initiating and maintaining urinary flow.

An ultrasound scan of the bladder before and after trying to empty the bladder identifies if more than 100ml of urine is remaining in the bladder. Retaining urine damages the bladder and increases risk of urine infections. If urine is being left in the bladder, or there is an inability to pass urine at all, then catheter insertion is necessary to release pressure in the bladder and protect the bladder lining.

## **What are catheters made of?**

Urinary catheters are made of plastic pvc material, latex or silicone. Silicone catheters are slightly less flexible but have thinner walls that allow a larger lumen (internal hole) within a slim catheter.

Sediment can accumulate due to a reaction from the catheter material being in constant contact with urine; and may result in a catheter change being needed.

Syringing fluid through the catheter to 'flush out' the sediment may help, as may using a catheter impregnated with silver compounds; a larger lumen or trying an open-ended catheter (this has a drainage opening at the tip as well as along the side of the catheter).

## **Type of catheterisation**

The type of catheterisation will depend on each person's circumstances and will be based largely on what is most acceptable and manageable for them.

## **Intermittent self-catheterisation (ISC):**

ISC is often a first option for those who can manage to do this. ISC can be done at intervals





through the day to completely empty the bladder. A small thin lubricated catheter is passed into the bladder through the urethra to drain urine directly into either the toilet, a receptacle or a bag that is an integral part of the catheter. Once the urine ceases to flow then the catheter is removed.

This process may be done from once to 5 or 6 times in 24 hours.

### **Indwelling urinary catheterisation:**

This is a catheter that is passed through the urethra and left in the bladder. A small balloon near the internal tip of the catheter is filled with water to hold the catheter in place within the bladder.

There are different lengths, shorter ones are for women as anatomically the urethra is much shorter. The lumen of the catheter varies too and should be the smallest size that is comfortable and does not allow leakage.

The Community Nurses will insert these catheters and usually change it every 12 weeks, though if the catheter becomes blocked or urine leaks round it (bypassing) then they will change it earlier.

Once the catheter is in place the bladder will be constantly draining if the catheter is attached to a urine collection bag. During the day a small bag is used and secured on the leg under clothing. The day bag needs regular emptying so as not to overfill and cause back pressure in the drainage tube and bladder. Overnight a larger bag can be attached.

Alternatively, a flip-flow valve can be attached to the external end of the catheter. This seals off the catheter and be tucked in under clothing. Then, similar to ISC, the valve can be released to drain the bladder over the toilet or into a receptacle every few hours. This can retain bladder tone allowing it to fill over several hours and then be emptied as we would if going to the toilet as normal. The catheter can drain freely overnight into a bag or continue with the flip-flow intermittent release if preferred.

### **Supra pubic catheter:**

This catheter is less commonly used initially. It may be suggested if passing the urethral indwelling catheter has been particularly difficult or uncomfortable due to strictures in the urethra, an enlarged prostate, or rectal or vaginal prolapse. Recurrent urine infections and catheter blockages are the most common reasons for supra pubic catheters to be inserted.

The supra pubic catheter is inserted with local anaesthetic in hospital. The catheter is positioned through a small opening made in the lower abdominal wall just above the pubic bone. The catheter has a small balloon that is inflated with water once in the bladder. The options for attaching drainage bags or flip-flow valve are the same as for other indwelling catheters. This catheter is usually changed by the urology team at the hospital the first time but then can be changed by the Community Nursing service.

For more information and support with bladder management contact your MSA Health Care Specialist [www.msatrust.org.uk/support-for-you/hcps](http://www.msatrust.org.uk/support-for-you/hcps).

*msa news*



# Supporting and Helping Each Other

***Our fantastic members continue to share their tips and tricks on living with MSA in both our in-person and virtual Support Groups. We want to thank you for coming to the meetings, they really don't work without your participation and we so look forward to seeing you at them.***

***Here, Nicole Adam, Senior Services and Volunteering Officer, rounds up some of the tips from the last few months....***

**W**e know that speech difficulties can make all forms of communication challenging. Friends and family can find it awkward if they are not getting the same kind of responses they are used to and may visit less often, which can be very isolating to people affected by MSA. In addition to using the Trust's voice banking support, one wonderful suggestion given at our Carers group was reading aloud. It is more interactive than watching television together and can be a wonderful way to spend time with someone. If you pick a good book, it can be a way to start conversations or provoke some strong opinions. Depending on your preferences you could have a separate book on the go for everyone that might stop by, or if that is a bit much, people visiting can take it in turns to read from the same one. Don't feel it has to be something serious to make it worthwhile. Some suggestions included celebrity or sports star biographies, murder mysteries or light-hearted holiday reads. One thing that is particularly nice about this is it can be done across a variety of ages. Even younger children who are learning to read can be encouraged to practice with someone living with MSA.

If mobility is an issue an unusual entertainment suggestion came up at one of our online meetings. Scent based games are sensory based board games where the main activity is focused on your sense of smell. There are a variety of styles available, including ones you can make at home using what is in your cupboard, but there are also board game versions that can be found online. 'Wow Wee What's That Smell' is a game for all ages asking them to identify a variety of pungent smells. Not for the faint of nose, this game is designed to make the whole family laugh. It can be found on Amazon or other games websites. A similar and possibly a less pungent version is 'Follow Your Nose' which can also be found online. It features a variety of scents found in nature and challenges you to identify them. [msanews](#)

Have you found one of the tips from our Supporting and Helping page helpful? Please let us know at [support@msatrust.org.uk](mailto:support@msatrust.org.uk).





# Connecting with the MSA Community

As our members will know, MSA is such a rare condition which means it can be nearly impossible to meet others affected by it by chance. Our Support Groups are therefore one of the main ways we try and connect the MSA community with each other. Our in-person Support Groups are a wonderful chance to meet face to face in an informal setting with one of our MSA Trust Health Care Specialists present.

We know our in-person groups will not be close enough for everyone to attend and, for some, our online Zoom groups are easier to pop in and out of. However, if you have been wondering about attending an in-person meeting and have any questions or concerns we hope you will consider it. One of our members says:

*"We love the in-person support group meetings. The digital support groups are great, but it is so much nicer to meet up in person, physically meet and get to know the other people in your area going through a similar journey, and just have a good chat, a cuppa and a slice of cake. And of course, the valuable one to one access to the MSA*



*Trust Nurse Specialist or other Trust Professional to ask the things which you may not want to do in the open forum of the zoom."*  
Gill and Paul

If you are interested in Support Groups and are a registered member you should receive invitations to our in-person and digital groups by your chosen contact method. You can also check when your local group is

next scheduled to meet by visiting the Support Group Calendar on our website - [www.msatrust.org.uk/support-for-you/local-support/map](http://www.msatrust.org.uk/support-for-you/local-support/map).

If you are planning on attending, it is important you let us know by RSVPing. If circumstances result in a meeting cancellation, we will make sure every person down to attend is personally contacted so they do not travel unnecessarily. We do know that MSA can be unpredictable, and plans might change at the last minute which we will always understand. [msa news](#)

## Regional Volunteering

Our Support Groups run best with the help of our wonderful volunteers. Our volunteers assist our MSA Health Care Specialists in hosting the meetings and helping to organise the day. Several of our groups are currently looking for volunteers, so if you are interested please visit our website [www.msatrust.org.uk/get-involved/volunteering](http://www.msatrust.org.uk/get-involved/volunteering) to see the areas currently in need and for details of how to get in touch. Or just call our office on 0333 323 4591.



# THE IMPACT OF YOUR DONATION

**£14**

pays for a crucial half hour introductory call with one of our MSA Health Care Specialist Team for people newly diagnosed. We answer initial questions and reassure people they are not alone on their MSA journey.

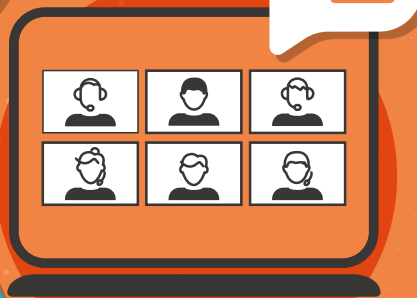


**£20**

helps us keep in touch with people affected by MSA throughout the year, through MSA News, our information materials and invites to our Support Groups.

**£28**

contributes towards a Digital Support Group session with one of our specialist team, where people affected by MSA address common concerns in a supportive environment.



**£35**

covers an hours MSA Healthcare Specialist attendance at NHS clinics, as these are funded entirely by donations.



**£100**

can help us provide Voice Banking to aid communication for people with MSA when they are no longer able to use their own voice.

**£250**

can contribute to our hardship fund for families who are facing extreme challenges living with MSA.



Your donation, no matter how big or small, will always make a difference to the MSA community and will be used where it is needed most. You can donate via our website - [www.msatrust.org.uk/donate](http://www.msatrust.org.uk/donate) or make a payment over the phone by calling our office at 0333 323 4591.

