msa news

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Marking the MSA Trust's 25th Anniversary

WORKING AGE BENEFITS - PAGE 12

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Welcome to Issue 64

A very warm welcome to your Summer edition of MSA News.

There's a real variety of subjects for you to enjoy in this issue. Our symptom management article, written by one of our MSA Nurse Specialists, is focused on swallowing and MSA. We know that this can be both worrying and troublesome for members so we hope the information included on page 6 will be helpful.

We recommend that everyone living with MSA should see their Specialist at least every six months along with a session with a Specialist Nurse between these six months. Our article on pages 4-5 aims to ensure you get the most out of these appointments.

Looking forwards we want to build upon our 2019 MSA Needs Survey, which was the largest ever for people affected by MSA. We're asking again for you to share your views this year. You can read about what we did as a result of the last survey, and how to take part this time, on page 9.

Finally, this year is a special year for the Trust as we mark our 25th anniversary. We are holding a Summer Social in Sarah's Wood and would love you to join us to celebrate. Find out more information on page 15.

Enjoy reading and please do get in touch if you have any questions or feedback.

Emma and Andy. msa *news*

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NEWS ROUNDUP

New Colleagues

There have been a number of changes with Trust staffing over the last few weeks. In our Fundraising team we are very pleased to welcome back Tanya Mitra from her maternity leave. In addition, the Fundraising team has also been bolstered by the appointments of Donna Quinlan, Eleanor Jarvis and Kathryn Young, so a warm welcome to them.

Our MSA Health Care Specialist Team have been joined by Demelza Stuart who will be covering Ireland and Northern Ireland. Do look out for a forthcoming additional MSA Nurse Specialist appointment in July as we continue to develop our support for you. msa *news*

MSA Study Day – November 2022

We are excited to announce that our next MSA Study Day for Health and Care Professionals will be in Cardiff on Thursday 17th November. With a broad variety of topics covered this is a great chance for professionals to further develop their knowledge of MSA and network with colleagues. We are pleased to say the cost for the day will remain at £25 to enable as many people as possible to take part. For further information and to buy your tickets visit **www.msatrust.org.uk/event/2022-msa-study-day**. msa *news*

MSA Trust Privacy Policy

We wanted to notify our members about a change to our Privacy Policy. Information you give to us will be used to provide and improve our services to you. The revised Privacy Policy states that the MSA Trust will only pass on your information (e.g. an email address) to external agencies that hold a contract with the MSA Trust and are working with us to provide support or services. These agencies hold specific data contracts with us, are also bound by data protection legislation and will destroy all information held on completion.

We **never** pass on your information to external sources for fundraising purposes (unless required to by law e.g. for Gift Aid purposes). If you have any questions, please email **support@msatrust.org.uk** or call 0333 323 4591. msa *news*

Utility Suppliers

With energy prices at an all-time high, please speak to your energy provider as soon as possible if you're having difficulty paying your bill. Under Ofgem rules, your energy provider must support you to agree a payment plan you can afford. Many energy providers are also offering grants and financial support. People living with MSA can join the Priority Services Register (PSR), a free support service to help people in vulnerable situations, such as priority reconnection in the event of a power cut. It's a good idea to join the PSR if you rely on your energy supply for medical reasons. You can apply for the PSR by contacting your energy provider. There are similar schemes for water and telecoms suppliers. Following the recent government announcement of a cost of living support package for all households, you can find further information on the payments, including how and when they will be paid by visiting **www.turn2us.org.uk/About-Us/News/New-Government-Cost-of-Living-support**. msa *news*

Your MSA clinic appointments

You may have mixed feelings about attending your clinic appointments. People may sometimes feel anxious, yet are pleased to be re-assessed. For many just the sheer effort getting to the appointment may be challenging. Our MSA Nurse Specialist, Katie Rigg, looks at how you can get the most out of your clinic appointments with your specialist and health care team…

Whatever your feelings towards clinic appointments you need to make them a positive opportunity to have your concerns and questions answered, and to come away feeling something has been achieved for you. The best way to make this happen is to be prepared.

A few days before the appointment gather together the following things:

1. A list of the health and care professionals that support you

We have a ‘Going into Hospital’ folder which contains a form where all your professional’s contacts can be listed. Checking the list is up to date and annotating it with dates when you last saw each professional can be helpful. This information ensures your consultant clinic letter goes out to all the relevant people to keep them up to date. It will also identify if it would be helpful for re-engagement of a particular professional if there have been changes since you last saw them.

2. Current medication list

This can be your latest repeat prescription list. Also check if there are any medications you take that are not on that list as they have been recently started or are occasionally taken. When you are in an appointment, with the pressure of time, it can be difficult to accurately recall all the medication you are taking.

3. Take any communication aid you use

Most communication aids are small enough to be portable and may enable you to be more fully involved in your consultation.

4. Take the walking aid you usually use

It may not be possible to do this if you are needing to use a wheelchair to access the clinic, but if it is a fold up rollator or stick it can be helpful to have it with you to assist assessment in the clinic.

5. A list of new symptoms or concerns since your last appointment

Keep a note of any new symptoms so you don’t forget to ask about them and can learn what might alleviate these.

What to expect at the appointment

After booking in at reception the clinic nurse may weigh you and take both a sitting and standing blood pressure reading (if these are possible to do) before you see the Doctor.

Any Doctor should introduce themselves. Early on do let the Doctor know if you have questions and concerns you want to discuss in the appointment. This alerts them to allow time for this. They may still want to do a recap and examine you as this will help them answer your questions more effectively.

They will often do a physical examination including for example, feeling the movement of your limbs especially if there are new symptoms or changes to your mobility. This physical examination can also be helpful to assess if any medications you are taking to improve movement, such as the Parkinson’s medications, need adjusting or are still being as effective.

Other physical tests may be done to check eye movements, head and neck flexibility, tremor and co-ordination.

Much can be learnt from just seeing you, even such things as how you enter the room, unfasten your coat, along with assessing your posture and speech throughout your consultation. You are likely to be asked direct questions about your experience of symptoms.

Sometimes it can feel as though you cover the same things every clinic and you may question if this is worthwhile. However, consistent assessment can identify subtle changes that may be responsive to other treatment or alert the doctor to the need to involve other professionals or expertise.

If you have any queries that have not been addressed in the appointment then do ask these before you leave the consultation. Check when you are likely to be seen again and ask that you are copied into the letter from the appointment. This is helpful to remind you what was discussed and so you can check in with your GP if there were actions for them.

Virtual Appointments

An impact of Covid-19 has been the wider use of virtual appointments. If your condition has stayed much the same since last being seen, then it may be reasonable to consider asking for a virtual appointment if you have the technology for this. Virtual appointments can also be useful if you are particularly unwell at the time of the appointment and getting to clinic would be difficult. At such times it is good to have that consultation rather than totally miss the appointment, as the doctor can still ensure you are accessing the treatment most likely to help at this time. msa *news*

If you would like to discuss any aspect of your clinic appointments, please do contact our MSA Health Care Specialist Team via our office on 0333 323 4591 or email **support@msatrust.org.uk**.

Swallowing in MSA

MSA can often cause problems with swallowing, which over time can need careful management. Here, our MSA Nurse Specialist Samantha Pavey, looks at the mechanism of swallowing, what problems can arise and how to manage these.

Eating, swallowing and breathing are tightly coordinated. Breathing ceases briefly during swallowing, due to mechanical closure of the airway and by the brain suppressing breathing momentarily.
'Normal swallow' is usually divided into four stages:

01

The 'pre-oral' phase begins as we anticipate eating. Saliva is triggered by the sight and smell of food, as well as feeling hungry.

02

The 'oral' phase occurs when food enters the mouth. The muscles of the tongue and mouth and the teeth masticate (chew) the food and form a "bolus" (a ball-like pellet of food). The brainstem suppresses breathing momentarily to prevent inhalation of food into the pharynx (passageway leading to oral and nasal cavities and oesophagus). The salivary glands secrete saliva to moisten the bolus.

03

The 'oro-pharyngeal' phase allows the epiglottis (a flap of cartilage located behind the tongue at the top of the larynx) to close over the pharynx, ensuring the food goes into the stomach, not the lungs. The larynx (voice box) and nasopharynx (upper part of throat behind the nose) is protected. The tongue propels the bolus into the oesophagus that leads to the stomach.

04

The 'oesophageal' phase allows the oesophagus (a muscular tube that conveys food from the mouth to the stomach) to contract, the sphincter relaxes and the food reaches the stomach.

Abnormal swallowing or dysphagia can be caused by a number of things, including neurological disease. The muscles become weaker and the signals from the brain may be delayed, leading to a slowness of the normal function. The epiglottis is slower to close off the airway to make it safe, meaning food, fluid or saliva can travel into the lungs before the airway is closed off. Dysphagia may lead to serious complications including dehydration, malnutrition, pneumonia or airway obstruction.

Difficulty with swallowing may not always be obvious - the person with MSA may not cough or choke. Aspiration (where food, fluid or saliva enters the lungs) can happen silently, which is why it is important to see a Speech and Language Therapist (SLT) who can assess the person with MSA's swallowing. Added to this, due to the autonomic failure seen in MSA, someone may not show the normal signs of infection, so a chest infection caused by swallowing issues may be missed. This can be serious and can lead to pneumonia if not treated in a timely manner.

Things to look out for include:

- **Coughing more readily, on fluids in particular**
- **Eating more slowly (to avoid coughing or choking)**
- **Decreased enjoyment of food or drinks**
- **Fatigue when eating**
- **A sensation that food is "sticking" in the throat**
- **Coughing or repeated throat clearing during eating**
- **Difficulty in swallowing medication**
- **Weight loss (may be intentionally eating less)**
- **A change in dietary habits - avoiding certain foods that are more difficult to eat**
- **Diagnosis of a chest infection or pneumonia**

Someone with MSA should be referred to a SLT on diagnosis (by their GP or Neurologist) who will continue to follow up if things change. The SLT will assess someone eating different consistencies of food and fluids and may initially advise on things to avoid, for example foods that crumble, such as biscuits. If they are worried that there is a problem, they may order an x-ray called a Videofluoroscopy. This is where a radiopaque substance is swallowed to show where what is being swallowed is going and whether this is going completely into the stomach or if some trickles over into the lungs.

As MSA progresses, swallowing may become more problematic, and some people may be advised to adopt a soft diet and then later a pureed diet. As things progress, they may be advised to have a feeding tube (Percutaneous Endoscopic Gastrostomy, known as a PEG) if they are unable to take enough fluids or calories by mouth and to help prevent repeated chest infections.

Some people choose to have most of their calories this way, including medication, and may still be able to have some food by mouth for pleasure. A PEG can make it much easier to get more fluids in, which can be helpful if postural hypotension is a problem.

Often people feel better after a PEG has been fitted as they then have a good level of nutrition and fluid intake and are not losing weight. We have a factsheet on PEG feeding we can send to you or you can download a copy from our website - **www.msatrust.org.uk/support-for-you/factsheets**. msa *news*

Please contact the MSA Health Care Specialist Team at the MSA Trust if you have any questions about swallowing difficulties or would like to know more about PEG feeding.

In Memory

Brian Richardson
Bill Webster
Amanda Marshall
Ian Jackson
Sidnei Gerhardt
Denise Budd
Violet Doughty
Sarah Collings
Howard Jones
Diana Whittaker
Douglas Hamilton
Susan Cosnett
Vincent Humphries
Celia Bignell
Stephen Milner
Charles Duggan
John Ground
Christine Burrows
David Perkins
Janet Alsop
David Giles
Jo Innoles
Greta Tidy
Peter Bury
Margaret Rimmer
Jenny Selwyn-Smith
Marlene Rees
Richard Farrell
Bruce Burnett
Karen Adair
Kenneth Mann
Anthony Bowles
Martyn Ellison
Christopher Ruberry
Joseph Williams
Pamela Stead
Gwynneth Emmens
Erica Hinks
Ronald Lingwood
Barrie Williamson
Geoff Wheildon
Aidan Lyons
Neil Anderton
Alan Skinner
Patricia Haigh
Robert Murdoch
Jennifer Page
Susan Potter

HONOURING YOUR LOVED ONES

After losing a loved one many families find solace in gestures or activities that not only honour them, but also can ensure any funds raised are used to support other people still living with MSA.

Summertime can provide opportunities for these. For example, you may want to plan a sponsored family walk retracing your loved one's favourite route. Other activities may require a bit more planning but can prove to be a meaningful way to remember a loved one. Ideas may include fundraisers based on their hobbies such as pub quizzes, football matches or having an open garden in aid of the Trust.

Popular memorial gestures can involve organising wildflower seeds to be scattered or floating candles lit and released at their favourite lake or river (several biodegradable options are available so do make sure to use ones that are kind to our environment). Family and friends can come to share the gesture and make a donation to the Trust.

Our Fundraising Team can provide collection tins, publicity materials, Trust branded clothing and lots of sound advice on how to make the most of your memorial activity. Please contact them at **fundraising@msatrust.org.uk** or call the office on 0333 323 4591 for support. msa *news*

MSA NEEDS SURVEY 2022

Some of you may remember that in 2019 we launched our first ever MSA Needs Survey. Our aim was to find out the needs of people living with, and affected by, MSA in order to best shape our services and campaign on your behalf. Now we're asking for your help again, as we look to launch our new 2022 MSA Needs Survey...

We received responses from 655 people in 2019 making it the largest survey of people affected by MSA ever completed. You can find an article about the results in issue 57 of MSA News or read the full result reports on our website – **www.msatrust.org.uk/2019-needs-survey-results**.

From the 2019 Needs Survey we created our Information and Services Strategy to help guide the support we offer. As a direct response to the findings, we developed the following initiatives:

- Created a new Emotional Impact resource to support people with their mental wellbeing, which is available for free in a printed booklet and on our website
- Increased our welfare grants budget to enable us to support those facing hardship
- Employed an additional Health Care Professional to expand our team and offer more support to people living with MSA (with another on the way this Summer)
- Launched an Introduction to MSA webinar, the first in our series, to explain MSA in an accessible format and started Q&A sessions for new members
- Sent MSA information to every Specialist in the UK and Ireland who had recently diagnosed someone with MSA. To enable accurate information to be given at diagnosis
- Created a Planning for the Future section on our website to support people in making decisions and plans for their future care and needs
- Produced a Web Hub for young people aged 11-17 (to accompany our Activity Book for children) so they have their own area on the website to explore about MSA and their own feelings
- Increased our Social Welfare Specialist support so every member can access a welfare benefits check
- Launched Digital Support Groups, enabling more people than ever to connect with others experiencing similar issues
- Created 10 new information resources including topics such as Breathing and MSA, a Care Workers Guide and an Easy-Read leaflet on blood pressure.

These are just some of the new support initiatives we have developed, all of which came about following analysis of the 2019 Needs Survey. Therefore, in order to ensure we can truly reflect your needs in the same way, we are asking for your help by completing our next MSA Needs Survey which will be launched later in 2022.

There will be three questionnaires – one for people living with MSA, a survey for current carers and another for people that have previously cared for a loved one. You will be sent the survey by email or post (depending on your preferences) from our partners Iqvia, who are again running the survey on our behalf. All responses will be confidential and there will be an opportunity for you to provide further information should you wish.

We really hope you will take this opportunity to share your thoughts and experiences with us when the surveys launch. If you have any questions please do get in touch at **support@msatrust.org.uk** or call our office on 0333 323 4591. Thank you in advance for your support, it will make a real difference. msa *news*

Research Roundup

Theravance Biopharma

Theravance Biopharma have announced that their trial of Ampreloxetine for postural hypotension has shown a potential benefit for people with MSA. Initial analysis showed that there was no significant benefit of the drug overall, which was tested on people with MSA, Parkinson's Disease and Pure Autonomic Failure. However, analysis of the MSA participants showed a significant benefit for this sub-group. The company are now considering next steps. We will update you as soon as we know anything more.

Alterity Therapeutics

Alterity Therapeutics have been granted approval by the UK regulator to proceed with a phase 2 trial of ATH434 in MSA. ATH434 is being tested to see if it reduces aggregation of alpha-synuclein in the brains of people with MSA. The trial will give people with early-stage MSA either ATH434 or a placebo and measure its safety and effect over a year. We do not yet know which sites in the UK will be involved with this trial and we will update our members when we know more. If successful, the phase 2 trial will hopefully inform the design of a larger trial in the future.

Tracer shows MSA in PET scans

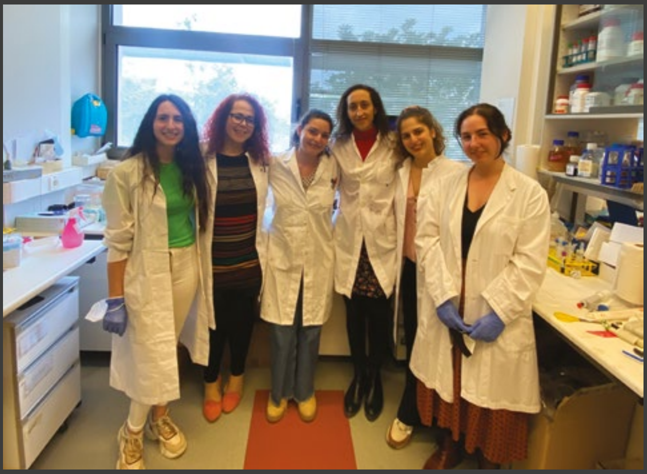
A positron emission tomography (PET) scan is a type of scan that is used in some clinical and research settings. A company called AC immune have announced results of a tracer that can potentially distinguish MSA from other conditions such as Parkinson's disease in a PET scan. This needs to be further researched but if positive, could be an effective biomarker that can be used in future clinical trials in MSA.

MSA Trust Research Funding Programme

On the 10th May our Scientific Advisory Panel (SAP) met to consider applications for our Research Grant Programme. This year more applications were received than ever before, which is encouraging for MSA research. For the first time there was a 'themed call', to encourage studies of 'clinical care and management of people with MSA'. Research funding awards will be announced in the summer, with projects expected to commence in the autumn. We will include more information about the awards in your October edition of MSA News.

Research study spotlight

Professor Maria Xilouri was awarded funding in a previous round of the MSA Trust Research Grant Programme. Here she provides an update on her research study 'Autophagy in the spotlight as a potential therapeutic approach in MSA':



LEFT TO RIGHT:

MARIA VETSI, MARIA XILOURI, FEDRA ARVANITAKI, PANAGIOTA MAVROEIDI, DIMITRIA DIONYSOPOULOU, VANA NALBANDI

A system within the body called the 'autophagy-lysomal pathway'(ALP) is thought to be responsible for the removal of mis-folded proteins and damaged cells within the body. The thinking is that if this process is compromised in some way, the 'cleaning up' doesn't happen properly and mis-folded protein can accumulate in the brain and cause conditions such as MSA. Maintaining proper function of autophagy may provide neuro-protection and so the study of autophagy has been undertaken in many neurodegenerative conditions. Research is also being undertaken to find potential autophagy-associated therapies that may offer protection against such conditions; this is called 'autophagy modulation'.

Previous work done by Professor Xilouri's research team showed that the protein alpha-synuclein and another protein called TPPP/p25α cooperate to form the aggregation of alpha-synuclein 'protein blocks' seen in MSA. Building on the previous research, this study predicted that these 'protein blocks' may be formed because of a failure of the autophagy-lysosomal pathway (ALP) and this research study was therefore designed to test this theory.

Professor Xilouri and her team undertook an extensive study into the role autophagy plays in the accumulation of alpha-synuclein and p25α proteins in oligodendrocytes. Oligodendrocytes are the cells in which protein build-up is seen in the brains of people with MSA. They also looked at whether autophagy modulation may demonstrate any potential future therapy benefit.

Professor Xiliouri explains "we are investigating the possible involvement of autophagy in the accumulation of alpha-synuclein and p25α proteins in oligodendrocytes, as well as the potential therapeutic utility of autophagy modulation in MSA-like models. To do this, we are utilising pathological fibrillar forms of alpha-synuclein produced in bacteria and applying them to oligodendrocytes isolated from a model of MSA that over-expresses human alpha-synuclein selectively in oligodendrocytes. This will be compared to others that express the protein normally in neurons.

We are assessing how the alpha-synuclein acts under these conditions and examining whether this changes when various factors are introduced or changed.

Our data so far reveals that oligodendroglial alpha-synuclein and p25, the two main components involved in the development of MSA, are degraded via the autophagy lysosome pathway. Also, the presence of pathological alpha-synuclein can impair the activity of the lysosome, reducing the efficiency of the 'clean-up' process that removes damaged proteins.

Therefore, our data suggests that augmenting autophagic pathways may potentially prevent the accumulation/aggregation of alpha-synuclein and/or p25 in oligodendrocytes that is seen in MSA."

Next steps:

Professor Xilouri concludes that **"continued research in pre-clinical models may pave the way for the use of autophagy modulators as therapy that may slow or stop disease progression in MSA in the future"**. msa *news*

Working Age *Benefits*

Following her article on benefits for people over retirement age in our last MSA News, Sam Fitzgerald our Social Welfare Specialist, highlights some of the benefits you may be entitled to if you're currently aged between 16-66 years.

Personal Independence Payment (PIP)

PIP is a benefit for those who need help or have difficulty with daily living tasks and/or mobility. Daily living tasks include preparing food, washing and bathing, dressing and undressing, toilet needs, communication and managing medication or therapy. PIP is not means-tested or taxable. There are two components to PIP (daily living and mobility) and each can be paid at a standard rate or an enhanced rate. PIP is usually paid every four weeks and is worth up to £156.90 per week, as of 2022.

Receiving PIP may 'top up' certain other benefits and may entitle any unpaid carer you have to Carers Allowance (restrictions apply, please see www.gov.uk/carers-allowance).

A claim for PIP must be made **before** you reach state retirement age, currently 66 years. Provided you're receiving PIP when you reach state retirement age, you will remain on this benefit. If you're approaching state retirement age and are already receiving PIP, it's important to ensure that you're on the correct rate of the mobility component. Once you reach state retirement age, your PIP mobility component cannot be increased.

If you receive the mobility component, you may automatically qualify for a Blue Badge for parking concessions (this depends on the number of points awarded). You will also be eligible for a discount on your car tax - if you get the standard rate of mobility, you're entitled to a 50% discount and if you're receiving the enhanced rate of mobility, you'll get free car tax.

If you receive the enhanced rate mobility component, you can use this to lease a vehicle, mobility scooter or powered wheelchair through the Motability Scheme. For more information visit www.motability.co.uk.

For further details about PIP visit www.gov.uk/pip. You can apply for PIP by calling the PIP New Claims Helpline on 0800 917 2222 (ensure you have your national insurance number, bank account details, and GP details available as you'll be asked for these).

New Style Employment & Support Allowance (New Style ESA)

If you have limited capability to work or have stopped working because of your MSA, you may be entitled to new style ESA. New style ESA is not means-tested so savings and most income (such as a partner's wage) is disregarded. Eligibility is based on whether you have paid enough National Insurance contributions in the past 2-3 years. You can check your National Insurance record by visiting www.gov.uk/check-national-insurance-record or call HMRC on 0300 200 3500.

New style ESA is usually paid every two weeks and is worth up to £117.60 per week. Please note, a private or occupational pension of over £85 a week will affect the amount of ESA payable.

For more information or to begin your claim visit www.gov.uk/guidance/new-style-employment-and-support-allowance. If you cannot claim online, you can call the Universal Credit helpline on 0800 328 5644 (choose option 3).

Universal Credit

Universal Credit is a means-tested benefit for people on a low income, who may be in or out of work. Universal Credit replaces several working age means-tested benefits and tax credits – please seek independent advice before choosing to switch from your current benefits to Universal Credit. Even an unsuccessful application for Universal Credit will result in the immediate loss of the benefits it replaces, and it will not be possible to reclaim those lost benefits.

You cannot claim Universal Credit if you have savings above £16,000. If you are a couple, you must make a joint claim and you cannot have more than £16,000 between you.

Universal Credit is paid monthly. The amount you'll receive depends on your circumstances and can include help with housing costs and an additional monthly payment if you're unable to work because of your MSA.

For more information visit www.gov.uk/universal-credit.

Council Tax Reductions and Support

You may be entitled to help with your council tax. Contact your local council or see their website for more information. Council tax reductions and support may be means-tested or you may be eligible on a range of other grounds. You may be able to claim a reduction if your home has been adapted for a disabled person or if someone has a severe mental impairment.

General information

Remember that it's important to tell the benefits agencies about any changes which may affect your entitlements, for example, if you start receiving an additional benefit or move house. These changes may affect your entitlements in a positive or negative way.

There are small differences across each of the countries of the UK. In Scotland, PIP is being replaced by Adult Disability Payment, which is very similar to PIP. Please note, the system in the Republic of Ireland is completely different and is not covered here. Advice on entitlements for those in the Republic of Ireland can be obtained from Citizens Information www.citizensinformation.ie/en.

msa *news*

If you need more information or support with benefit related issues, please get in touch with us. Our Social Welfare Specialist will be happy to help.

Young People's Fabulous Fundraising

*Courageous **Elena Mischler** did a charity haircut in memory of her Granny, Lindsay Jones. It was her first ever haircut and she was committed to her challenge, raising £290 for the MSA Trust. Thank you so much Elena and your new look is very lovely!*

__Scott Cullen__ set up a stand in his neighbourhood serving delicious hot chocolate to his local community. He managed to raise an incredible £120 in memory of his Grandad Christopher 'Kit' Byrne. A brilliant achievement, well done Scott!

Sisters on the Camino Trail

*Amazing sister duo **Stacy and Ceri Westhead** decided to walk the 100km Camino Trail after their mum Patsy, was diagnosed with MSA in 2019. Completed over 4 and a half days in sunny Spain, they set out to raise awareness and vital funds for the Trust- setting themselves a lofty fundraising target of £3,300 - £1 for every person in the UK and Ireland currently living with MSA.*

"We ended up raising £3,980, with friends and family (as well as strangers who had been affected by MSA) exceeding our expectations and overwhelming us with messages of support. We felt so proud when we got to the finish in Santiago wearing our fluorescent MSA Trust shirts!"

A dedicated team effort, thank you Stacy and Ceri!

Supreme Dalek

*Doctor Who enthusiasts **Tracy and Ian McTeague** have been honouring their dear friend, whose husband is currently living with MSA, through a creative fundraising idea. The pair have been travelling and visiting numerous Comic Conventions around the UK, offering the public the opportunity to take a photo with their incredible Supreme Dalek. This fun idea has allowed them to raise funds and help promote awareness of MSA.*

"We have a lot of fun making fans and the public happy, but also feel a massive sense of achievement in being able to raise funds for carers, people living with MSA and supporting research into this condition."

Thank you for your creativity and for representing the Trust across the UK.

A birthday celebration at Sarah's Wood

Saturday 16th July

We are excited to welcome everyone back to our favourite place in the heart of Sherwood Forest in Nottinghamshire, Sarah's Wood. Our summer social will this year celebrate the Trust's 25th birthday. For 25 years we have worked to fulfil our founder Sarah Matheson's wish that people with MSA and their families would have somewhere to turn to find information and support.

We hope you can join us for a lovely day at Sarah's Wood to see the latest bricks on our Path to a Cure, enjoy a walk in the grounds (with an adventure trail for the children) and have afternoon tea in the Walled Garden of Thoresby Hall. Let's hope the weather is kind to us and we can enjoy some garden games along with tea and cake.

When: **Saturday 16th July, 2 - 5pm**

Where: **Thoresby Park, Nr. Ollerton, Newark, Nottinghamshire, NG22 9EP (main car park). Parking is £3, payable at the car park.**

Entry donation: To cover the costs of the event, we kindly ask for a minimum donation of £15 per adult. Children under the age of 12 go free!

Book your place by **Monday 11th July** on our website - **www.msatrust.org.uk/event/summer-social-at-sarahs-wood**. Alternatively, call our office on 0333 323 4591 to pay by card or raise a cheque payable to MSA Trust and send to our office. msa *news*

Upcoming Half and Full Marathons in 2022

Below is a selection of some best known running challenges, all with exciting routes, that are being organised later this year. If you are interested in participating in one of these, or any other active event, please contact our fundraising team at **fundraising@msatrust.org.uk**. msa *news*

FULL MARATHONS

OCTOBER 2

Loch Ness Marathon

Chester Marathon

OCTOBER 16

Yorkshire Marathon

Amsterdam Marathon

HALF MARATHONS

OCTOBER 2

Cardiff Half Marathon

OCTOBER 9

Royal Parks Half Marathon

Manchester Half Marathon

OCTOBER 16

Oxford Half Marathon

An interview with a Bladder and Bowel Specialist

SARAH GREEN

Sarah Green is a Bladder and Bowel Specialist working for Northern Devon Health Trust. Here she speaks to Jill Lyons, MSA Nurse Specialist, about her role and how she and her team can support people living with MSA…

What training do Bladder and Bowel Specialists undertake?

Although traditionally given the title Continence Advisors, we are now commonly referred to as Bladder and Bowel Specialists. This reflects the breadth of the role, which has expanded year on year, and also aims to highlight the work we do in helping patients manage problematic bladder and bowel symptoms. A large proportion of our referrals are for patients who are not incontinent, and we aim to keep them that way!

My own training was a traditional nurse training course, I then went on to do a community health care BSc (HONS). I gained valuable experience working in community and out of hours nursing and, in that role, took a further module in the management of continence and prevention of incontinence. Not all of us are from a nursing background, there are also specialist women's health Physiotherapists in the team.

I am lucky to work for a team that places a high value on continuing professional development, and we are able to attend specialised training courses and conferences each year. Many of the team have gone on to take their non-medical prescribing qualification which is at Master's level.

Where do Bladder and Bowel Specialists work?

Predominantly we work in out-patient settings, in Devon that is in community hospitals, community health hubs and some GP surgeries.

Patients who are house bound are assessed by the community nursing service, but we do work very closely with them in a training and advisory capacity. We have assistant practitioners who are not qualified nurses but have gained a higher-level specialised qualification, they may occasionally visit patients at home and work closely with Nursing and Residential homes.

Where do you work?

I work in Exeter and East Devon. Some clinics are general clinics, some are telephone review and triage clinics. Some weeks I work in a different setting each day. I hold an Erectile Dysfunction clinic once a month and a diagnostic Urinary Flow clinic once a week in Tiverton. This clinic is predominantly aimed at diagnosing bladder outlet obstruction caused by prostate enlargement/disease.

How can a Bladder and Bowel Specialist help?

We will get a comprehensive history and symptom profile from the patient, or carers and family members if appropriate, to give us a working diagnosis of the problem. We perform a number of diagnostic tests such as bladder scans and physical examinations. We aim to always treat symptoms to resolve or minimise the impact they have on the patient. We recommend conservative approaches at first and then may go on to recommend medications and more advanced treatment with referrals to urology, colorectal or gynaecology.

If any incontinence symptoms remain significant and untreatable, we are able to support patients with management options such as incontinence pads, urinary sheaths and anal irrigation, to name a few.

Where do referrals come from?

Mainly our referrals come from GPs, hospital consultants, nurses and other health care practitioners. We don't take self-referrals.

Is the role different from a Urology Nurse Specialist?

It is, Urology Nurses work in the acute setting and see patients with acute urological symptoms such as bladder or prostate cancer.

What do you like most about your job?

I enjoy the autonomy of the role; often I can see, diagnose, treat and discharge a patient without involving any other service.

The most enjoyable and rewarding aspect for me is the very real difference I can make to a person's quality of life and that of their relatives and carers. Issues with incontinence can often be the 'final straw' for some people. They can cope with and manage other disabilities caused by their condition or illnesses, but incontinence can feel like the final insult. It can sometimes be the major factor in deciding whether a person can remain in their own homes with carer support and if I can help facilitate that in some small way it is great. msa *news*

The MSA Health Care Specialist for your area can support you with bladder and bowel issues you may be experiencing and help with a referral to a Bladder and Bowel Specialist as needed. To find the MSA Health Care Specialist for your area visit our website, email **support@msatrust.org.uk** or call 033 323 4591. We also have Bowel and Continence Management factsheets available to download for free here - **www.msatrust.org.uk/support-for-you/factsheets**.

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

Supporting & Helping Each Other

As we always say in our Digital Support Groups, we are so grateful to members who share their experiences and advice with each other. Here, Nicole Adam, Services and Volunteering Officer, rounds up some of the tips from the last few months...

We know that staying in touch when you don't live locally to your family can be a difficult thing to manage. A variety of new 'smart' technologies can offer some innovative ways to address this. One such system is **www.howz.com** which uses a variety of smart monitors to build up a pattern of behaviour in your home. For example, it will recognise if the kettle is normally turned on in the morning, if this does not happen it can alert designated loved ones so they can check in. We do not know of any members who have trialled this system yet and would welcome any feedback on it. In general, the MSA Trust does not endorse any one system but would encourage you to look for what works best for you. Independent Living has produced a helpful article on assistive technology and Disabled Facilities Grants which can be found here - **www.independentliving.co.uk/bettercarefund/dfg-and-assistive-technology**.

Eating and drinking has come up at a few different meetings recently. Eating can cause anxiety if you are worried about controlling the food on your plate. There are several aids that can be helpful for this depending on your needs. Easier to grip and angled cutlery can be purchased from speciality shops like **www.completecareshop.co.uk** or even from sites such as **www.amazon.co.uk**. One member has found angled bowls to be particularly good at stopping food from slipping around. While high sided bowls can be found on the speciality website they can also be found at many high streets shops where crockery is normally sold. If you look for asymmetric or high sided bowls there are a variety of options. After finding a style that worked one member has bought them for the whole family so everyone can have the same.

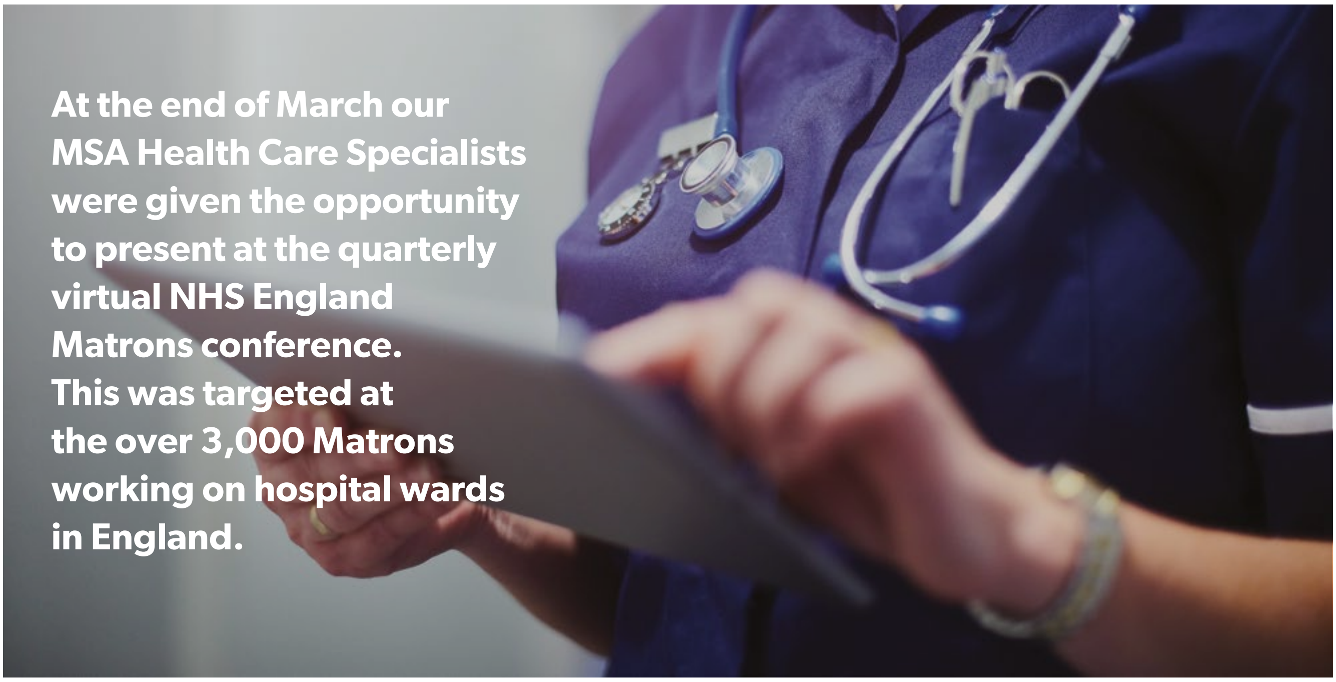
As some of you will be familiar with, drink thickeners may be prescribed if you have difficulties swallowing. Thickeners can be used to reduce the risk of choking. There are different companies selling thickener and it can be worth comparing them to see which works best for you. Slodrink came to our attention as they have a variety of drink specific solutions and they even have special thickeners for liquids such as tea, beer and wine. They can be purchased online here **www.slodrinks.com**. One member had a helpful suggestion if you struggle with mixing your thickener. They use a little whisk, the kind often sold to whisk milk for cappuccinos at home, and found this helped create a much smoother consistency. These can be bought at many supermarkets, Argos or Curry's.

Support Group Calendar

We are carefully rebuilding our in-person Support Group Network, while maintaining our Digital Groups as well. You should receive information about any groups in your area by post or e-mail. We know plans change but if you are thinking about coming, please do let us know to avoid any disappointment, as we may have to cancel groups if attendance is too low. For more information, please check the Support Group calendar on our website **www.msatrust.org.uk/calendar/category/support-groups**. msa *news*

If you have any questions about anything mentioned on this page, please contact our MSA Health Care Specialists. You can find the person for your area by visiting here - **www.msatrust.org.uk/support-for-you/hcps**.

Raising Awareness with Ward Matrons



At the end of March our MSA Health Care Specialists were given the opportunity to present at the quarterly virtual NHS England Matrons conference. This was targeted at the over 3,000 Matrons working on hospital wards in England.

This opportunity came about because our MSA Health Care Specialist Team were becoming increasingly aware of the difficulties people with MSA were having with the lack of awareness of ward staff to their needs, given its rarity. Our Team are often asked by families of people with MSA to contact hospital wards when people are admitted, in order to explain to them what MSA is and how they can best support people in hospital.

However, we, despite our best efforts, and like everybody else, have limited abilities to get through on phones and there is often no generic email addresses for specific wards.

Whilst we will continue to push for better ward communication, as an interim measure we were offered the chance to speak to Matrons to raise awareness of MSA and to explain what problems people have if their needs aren't met.

The session gave a introduction to MSA and then highlighted the importance of understanding the most effective means of providing care and support.

This included the need to recognise that a sudden, serious (acute) issue causing hospital admission can sometimes overshadow the needs caused by MSA as the chronic condition. Any such acute issue can make the symptoms of MSA worse so it can be difficult for staff to establish a functional baseline. It is therefore vital that staff focus on maintaining function during the hospital stay otherwise this can deteriorate or be lost.

We reminded Matrons that we have a range of factsheets for symptom management, professional guides and are in the process of developing a guide for hospital staff addressing key issues around ward care and support.

For people with MSA we also have a 'Going into Hospital' factsheet and our hospital information folder which can be personalised to include specific information on you as a person with MSA to guide staff on how to meet your needs. Please contact the office for these.

Finally, we are always interested to hear about the quality of services that people with MSA are experiencing, (good or less good) and this equally applies to hospital stays.

Please email us at **support@msatrust.org.uk** if you would like to contact us about your experience. msa *news*

Raise a cup *in our 25th Year!*

With restrictions easing, we once again encourage you to gather family and friends to host one of our **M**ilk, **S**ugar **A**nd **T**ea parties on or around World MSA Day, 3rd October. Small or large, these gatherings raise awareness of a rare condition like MSA and provide a fantastic opportunity to raise funds for our MSA Health Care Specialists. They are often the only source of information and support for families who have received this life-changing diagnosis, and we count on your help to enable us to continue this vital service.

The scale of the fundraising event is entirely up to you, we welcome anything from large garden parties to small family gatherings. You could ask guests to pay a donation to enter a raffle or tea party quiz, or simply have a collection in return for their invitation to tea and scones! This year you can even keep the theme on the number '25' to celebrate 25 years of the Trust supporting people with MSA.

To order your pack, email fundraising@msatrust.org.uk or call us on 0333 323 4591. Alternatively, fill out the slip below and return to our office.

We can send you a do-it-yourself pack with invitations, posters and complimentary tea. For a minimum donation of £10 we will also include one special tea party mug. Additional mugs can be brought from our online shop.

Name:..

Address:..

Telephone:.. Email:..

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

How many people are you expecting? ....

Please tick any additional items you will need:

○ Collection tins ○ MSA handheld flags

Tea party mug (Qty):....................... Total donation enclosed £...

Please let us know how you want us to keep in touch for fundraising news and events:

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

Please make all cheques payable to 'MSA Trust' & return slip to MSA Trust, 51 St. Olav's Court, Lower Road, London SE16 2XB