msa news

MSA Trust Members Magazine | Issue 58 | June 2020

When life throws thorns, *hunt for roses*

Kindness and self-care in this time of lockdown

CONTENTS

GETTING A GOOD NIGHTS SLEEP - PAGE 8

Research Fellow Update 03

Covid-19 - Update and Information 04

Mental Wellbeing 06

Virtual Fundraising 07

Sleep and MSA 08

In Memory 10

Useful Tips from Past MSA News 11

Research Studies 12

Fundraising Roundup 14

Supporting and Helping Each Other 16

Support Groups in your Living Room 17

Applying for Benefits 18

Giving Regularly 20

CHIEF EXECUTIVE OFFICER:
Karen Walker

MSA NEWS EDITORS:
Andy Barrick
Emma Rushton

ALL ENQUIRIES TO OUR ADDRESS:
Multiple System Atrophy Trust
51 St Olav's Court
City Business Centre, Lower Road
London SE16 2XB
Tel: 0333 323 4591
www.msatrust.org.uk

Welcome to Issue 58

Welcome to your summer edition of MSA News.

But what kind of summer can we expect? Definitely some form of continued shielding for those with MSA and continued distance controls for the public. It's not easy but I hope you have found ways of enjoying this changed life and remain positive.

When in March it became clear that public transport was to be avoided and normal office practices had to be replaced, the team set up remote working. Since then the office has continued to function well, as will be evident from this edition of MSA News. Supporting people with MSA continues at full strength through our Helpline and our new initiative of Virtual Support Groups. We are determined to keep our help to you going, come what may.

As with all charities we have been hit by the cancellation of events and important fundraising initiatives. But, thanks to prudent financial stewardship, we have some funds in reserve and are determined to make the most of other ways to raise income. I am confident we will weather this storm together and even learn better ways of doing things. I hope this magazine will give you plenty to read and think about during this challenging time.

Keep positive, keep safe.

***Professor Clare Fowler CBE** - Chair of Trustees.* msa news

Registered Charity Number 1137652. Scottish Charity Number SC044635. Company Number 7302036

Designed by Base Media www.base-media.co.uk. Printed by INQ Design 020 7737 5775.

Research in the time of a *Pandemic*

VIORICA CHELBAN

Below we hear from our Association of British Neurologists MSA Research Fellow, Viorica Chelban. Life under lockdown can be challenging, however our research must go on…

During these unprecedented times, with no direct contact with patients and no access to labs, we have had to find new approaches to doing research. Myself and my academic doctor colleagues had a challenge: how to adjust to new ways of working, doing high quality research, and in some cases, taking on new responsibilities whilst all the while continuing to provide much needed care and support for our patients and the wider NHS.

> **I am hugely proud of the way our research team mobilised around the national effort against coronavirus, drawing on our collective strengths in interdisciplinary collaboration as well as continuing to work on MSA research.**

At the UCL Institute of Neurology in Queen Square, London, the labs closed in mid-March and the only research allowed to take place was that designated as being in the immediate national interest, essentially only work on coronavirus. Like the rest of the research community, we had to adapt our thinking to this new situation.

Our longitudinal PROSPECT-M study maintained data collection activities by keeping in touch with local sites and participants. Telephone consultations and updates proved very beneficial for keeping the study milestones up-to-date, as well as giving us an opportunity to stay in touch with people with MSA and their families. This frequently led to identifying clinical and other social needs beyond the scope of research questions. Personally, this did not feel to be a closure period for research, but rather a period of remote working necessitated by unprecedented circumstances.

I was fortunate in having a trove of experimental data already acquired by the time the lab closed. As part of the MSA biomarkers study, I am investigating which molecules derived from blood and/or cerebrospinal fluid can be best used to track disease progression. These markers will be used to measure the response to future MSA treatments and trials. I learned that working remotely was possible by having the right access to research data, a secure online research environment and keeping in touch with the rest of the team.

I miss the energy, the buzz and emotions that a successful or indeed failed lab experiment provides and I am looking forward to the day when we can return to work. In the meantime, the absence of noisy and busy labs has provided a much-needed space for thinking and data processing.

For anyone interested in contributing to our research, please do so. With the support of the MSA Trust we continue to recruit patients remotely for both the PROSPECT-M study and the biomarkers study and have plans in place for arranging sample collections when it is safe to do so.

I want to thank everyone for continuing to engage with MSA research. I am drawing inspiration from the enormous effort and dedication of patients and carers during this crisis, supporting our commitment to advance the understanding of the condition and improve care for people with MSA.

For more information about PROSPECT-M see here - **www.msatrust.org.uk/current-research/prospect-m**.

msa *news*

Living life during Lockdown

Given the continuing Coronavirus pandemic, many of us are coping with lots of new information every day. This is our attempt to summarise the topics we have found helpful to everyone affected by MSA.

Government Advice and Shielding

Whilst you may hear slightly different advice about Covid-19 and changes to lockdown across the four UK nations and the Republic of Ireland, the message for those who are shielding and vulnerable thankfully remains fairly consistent.

At the time of writing people who are shielding (or cocooning in Ireland) should continue to take extra precautions. The latest advice is available from **www.gov.uk/coronavirus** or if you live in Ireland information can be found here - **www.gov.ie/en/campaigns/c36c85-covid-19-coronavirus**.

Family members living with people who are shielding do not need to shield themselves, but are advised to strictly observe guidance on social distancing and should support those who are shielding to adhere to shielding advice.

Clinically vulnerable people are advised to stay at home as much as possible and if you do go out, take particular care to minimise contact with people outside your household, while observing social distancing measures at all times.

You should not leave home if you or anyone in your household has symptoms of Covid-19. The most important symptoms to be alert for are a new continuous cough, a high temperature or a loss of, or change in, your normal sense of taste and smell. If a person starts showing symptoms, they should self-isolate for seven days from the onset of those symptoms. Others in the household should self-isolate for 14 days from when the first person became ill. If another person in the household starts to show symptoms during this 14-day period, they should self-isolate for seven days from onset of their symptoms (which may reduce or increase the 14-day period). People can stop isolating after seven days if they no longer have a temperature. The latest advice can be found on the NHS website **www.nhs.uk/conditions/coronavirus-covid-19** or by calling NHS direct on 111.

Exercise

It is worth repeating that keeping moving is really beneficial and helps our mood too. So, think back to exercises you might have been given by your Physiotherapist or have a look at some suggestions from Fiona Lindop in issue 56 of MSA News.

Just doing 15 minutes, four times a day can make a difference. Even doing seated exercises helps – don't overtire yourself but try to make it fun. If the weather is nice get outdoors and exercise sitting in the garden - that way you can top up your vitamin D which helps strengthen your bones and muscles too.

Appointments

Many appointments are now by telephone and they may not be as long as when you see health care professionals face to face. Try to prioritise your questions:

- Have a list of current medications, doses and times you take them
- Note any improvements or changes since last reviewed
- Prioritise symptoms that you need advice on
- Have your partner with you so they can help prompt you if needed, add things you may have forgotten and make notes of what has been said
- Be honest about how you are feeling and coping, if you don't highlight a particular issue it may not be addressed
- Remember that your specialist is there to help you and to support you through these difficult times.

Shopping

Online shopping for groceries has been recommended for anyone who is shielding. The procedure for registering as an extremely vulnerable person varies depending on what part of the UK you are in – full information can be found here: www.gov.uk/coronavirus-extremely-vulnerable.

If you are shielding, your Local Authority can help with delivering essentials and arranging support if needed, perhaps using the volunteer service set up by the NHS. If you are having any problems accessing supplies, please call us at the MSA Trust Office and we will look at what services are available for you.

Try to eat healthy, well-balanced meals, drink enough fluids and try to get some fresh air or sunlight each day, if possible. Taking 10 microgrammes of Vitamin D supplement daily can help support healthy bones and muscles.

Benefits and Entitlements

Most Local Authority duties under the 2014 Care Act towards people requiring care support, and carers, remain unchanged although they may be carried out in a different manner.

You should apply for Attendance Allowance (if you are over state pension age) and Personal Independence Payment (if you are under state pension age) but no face to face assessments are currently taking place. If additional information is required, you or your health professionals may be contacted by telephone. See page 18 for more information.

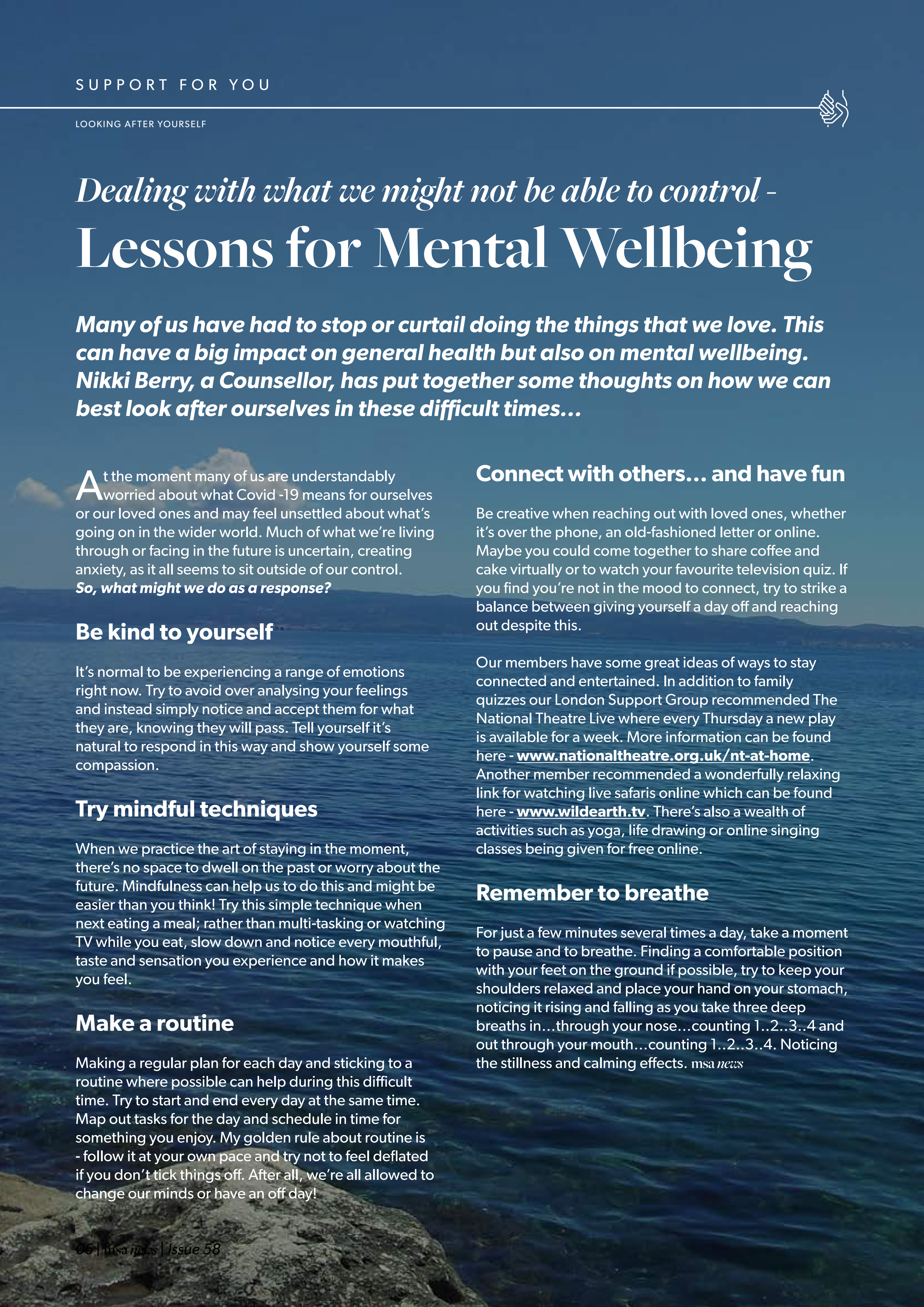
Whilst NHS Continuing Healthcare (CHC) assessments are generally not being carried out, local Clinical Commissioning Groups (CCG's) should be keeping a record of people who will require assessment when the restrictions are lifted. CCG's should be in regular contact with people who already have CHC funding and who hold individual Personal Health Budgets.

It is important to have plans in place should your usual carers be unable to carry on. We have advice on this on our website but things to consider include keeping detailed written care plans and important documents in an accessible place, alerting family to care needs and liaising with your health and social care providers (care agency, social services, GP etc).

Keeping in touch

It really helps to remain connected to family, friends and those in our community - even if this is happening remotely. There is a wide range of virtual ways you can keep in touch. You could try 'meeting' over Zoom, Skype, Microsoft Teams or Houseparty. All of these applications allow small or large groups of people to come together and some have the functionality to play remote games. See over the page for more ways of connecting with others at this time. The MSA Trust is also running virtual Support Groups to help people keep in contact - find more information about these on page 17.

If you have further specific questions do get in touch with our MSA Nurse Specialists or Social Welfare Specialist on 0333 323 4591 or email **support@msatrust.org.uk**. msa *news*



Dealing with what we might not be able to control -

Lessons for Mental Wellbeing

Many of us have had to stop or curtail doing the things that we love. This can have a big impact on general health but also on mental wellbeing. Nikki Berry, a Counsellor, has put together some thoughts on how we can best look after ourselves in these difficult times...

At the moment many of us are understandably worried about what Covid -19 means for ourselves or our loved ones and may feel unsettled about what's going on in the wider world. Much of what we're living through or facing in the future is uncertain, creating anxiety, as it all seems to sit outside of our control. ***So, what might we do as a response?***

Be kind to yourself

It's normal to be experiencing a range of emotions right now. Try to avoid over analysing your feelings and instead simply notice and accept them for what they are, knowing they will pass. Tell yourself it's natural to respond in this way and show yourself some compassion.

Try mindful techniques

When we practice the art of staying in the moment, there's no space to dwell on the past or worry about the future. Mindfulness can help us to do this and might be easier than you think! Try this simple technique when next eating a meal; rather than multi-tasking or watching TV while you eat, slow down and notice every mouthful, taste and sensation you experience and how it makes you feel.

Make a routine

Making a regular plan for each day and sticking to a routine where possible can help during this difficult time. Try to start and end every day at the same time. Map out tasks for the day and schedule in time for something you enjoy. My golden rule about routine is - follow it at your own pace and try not to feel deflated if you don't tick things off. After all, we're all allowed to change our minds or have an off day!

Connect with others... and have fun

Be creative when reaching out with loved ones, whether it's over the phone, an old-fashioned letter or online. Maybe you could come together to share coffee and cake virtually or to watch your favourite television quiz. If you find you're not in the mood to connect, try to strike a balance between giving yourself a day off and reaching out despite this.

Our members have some great ideas of ways to stay connected and entertained. In addition to family quizzes our London Support Group recommended The National Theatre Live where every Thursday a new play is available for a week. More information can be found here - **www.nationaltheatre.org.uk/nt-at-home**. Another member recommended a wonderfully relaxing link for watching live safaris online which can be found here - **www.wildearth.tv**. There's also a wealth of activities such as yoga, life drawing or online singing classes being given for free online.

Remember to breathe

For just a few minutes several times a day, take a moment to pause and to breathe. Finding a comfortable position with your feet on the ground if possible, try to keep your shoulders relaxed and place your hand on your stomach, noticing it rising and falling as you take three deep breaths in...through your nose...counting 1..2..3..4 and out through your mouth...counting 1..2..3..4. Noticing the stillness and calming effects. msa *news*

The New World of *Virtual Fundraising*

With organised mass participation events and community activities postponed or cancelled, virtual events present a new avenue through which you can continue raising vital funds for our MSA community. A virtual event means there is no need for a specific location as the event can be 'hosted' online or completed locally and shared online. Unlike its physical counterparts it gives the freedom to fundraise wherever, and whenever, you can.

We are grateful to supporters who have embraced this new initiative and have continued fundraising in the face of adversity. Some runners completed their mass participation runs locally. Our Brighton 10K runner Emma Rose Barber did a local 10K in support of her brother who has MSA, while Robyn Smith completed her 'Sidcup' Southampton Marathon in her back garden!

Miles for MSAT is our new initiative where you can challenge yourself to cover a certain distance within a chosen time while walking, running or cycling. You can even connect your fitness tracker to a fundraising page so that others can 'see' your effort and sponsor it. How about taking the stairs whenever you can and eventually completing a climb equivalent to Mount Everest (8,848m) or take on the Big Charity Run completing 30, 60, 90 or 120 miles in one month.

While our runners were doing their bit, our family supporters (and Trust staff) 'came together' on 26th April for the 2.6 virtual challenge. This was the date for the now postponed 2020 London Marathon and we were set to lose out on vital income. Instead, our supporters rallied round doing various activities around the numbers 2.6 or 26 in their homes or localities. Families did everything from a virtual 26 minute sing-a-thon, covering 26 miles of a marathon and cooking 26 different recipes. One of our London Marathon runners, Carla Cumberland took part with her family. Over £5,000 was raised by these home-based heroes!


CARLA AND FAMILY


ROBYN


EMMA ROSE

2.6 challenges showed us that not all virtual events need to be physically demanding. This can be an opportunity to bring people 'closer' during a difficult time and one in which social distancing is encouraged. For example, you can ask family and friends to participate in a virtual quiz, talent show or open mic night in return for a donation to the Trust.

To get started on any of these virtual fundraising ideas, visit **www.msatrust.org.uk/get-involved/events/virtual-events** or email **fundraising@msatrust.org.uk**.

No matter how you support us, please know that your efforts are much appreciated and come at a time when your fundraising is needed the most. msa *news*

Getting a Good Sleep – these tips could lead to better kips...

Whilst we know for certain that sleep is vital to our mental and physical wellbeing, sometimes it is hard to manage when living with MSA.

Experts tell us that we should be getting between six and nine hours of sleep every night. Normal sleep goes through different cycles, known as circadian rhythms, but people with MSA may not enter the deep sleep part of this cycle. During light sleep they may kick out or throw their arms around, waking their partner and may wake not feeling refreshed.

Sleep hygiene can help towards getting a good night's sleep. This includes trying to do the following things:

- Have a regular night time routine - try to get up and go to bed at the same time each day/night
- Avoid having lie-ins as this can disrupt your sleep pattern
- Prepare for bedtime - wind down an hour before you go to bed
- Have a routine that prepares your mind for relaxation such as a warm bath or shower, do some yoga or stretches, if you are able to

- Listen to some soothing music, read or listen to an audio book, a podcast or a relaxation CD. There are several sleep apps detailed at the end of this article that you may find helpful
- Make a list of things that are worrying you or things you need to do tomorrow; this will help you to switch off
- You could try a few drops of essential oil such as lavender on your pillow or light an aromatherapy candle - lavender and chamomile are good for aiding sleep (avoid citrus oils as these are uplifting)
- Your bedroom should be at a temperature between 18-24 degrees centigrade, dark, quiet and tidy
- You might wish to buy some ear plugs or a sleep mask if noise or light are disturbing you
- Using a laptop, mobile phone or other electronic device with a screen in the bedroom can disrupt your sleep pattern. Try not to use these an hour before bedtime. Try not to have a TV in your bedroom - ideally the bedroom should be for sleep and sex only.

Sleep diary

If you are having difficulties with sleep and see your GP or a sleep expert, they may ask you to keep a sleep diary to help them diagnose your sleep problems. If you wake in the morning regularly with a headache, this could be an indication of low oxygen levels in the bloodstream - talk to your Neurologist as you may need to have an overnight sleep assessment. Heavy snoring shouldn't be ignored, it may be stridor which can indicate problems with the vocal cords, which needs addressing by your specialist.

Addressing pain and anxiety

If you are experiencing pain at night, discuss this with your Neurologist, Parkinson's Nurse Specialist or MSA Nurse Specialist. Different types of pain can be managed with medication depending on the cause. Anxiety and depression are common symptoms in MSA and there are medications that can be helpful in treating these – discuss this with your specialist or GP. Counselling can be helpful if you are able to access it via your GP or local hospice. Aromatherapy, acupuncture and reflexology can also help with sleep, pain and anxiety - download the factsheet on Complementary Therapies from our website.

Equipment

It's difficult to get restful sleep on a bed that isn't comfortable. You may find it difficult to turn over in bed or get into a comfortable position due to upper body rigidity. Talk to your Occupational Therapist (OT) about a slide sheet or similar that may help with this. You may find that satin pyjamas or satin sheets enable you to turn more easily - but don't use both together or you may slide out onto the floor! An OT can provide a wedge-shaped cushion if you have postural hypotension and need to sleep more upright. Depending on the type of bed, they can also help raise the head for you (ideally 30 degree head up). They can advise on the best type of mattress, especially if you are unable to move at night - you may require a special mattress and a hospital type bed to prevent pressure ulcers (sores).

Other tips

Cut down on caffeine in tea, coffee, energy drinks or soft drinks, especially in the evening. Instead, have a warm, milky drink or herbal tea. Alcohol may make you feel sleepy initially but is actually a stimulant and will disturb sleep later. Smoking will also disturb your sleep pattern.

If you are able to do some form of exercise each day this will aid sleep but avoid doing this in the evening. Walking and swimming are particularly good at relieving muscle tension as is hydrotherapy if you are able to access this locally. If you are a carer sleeping in another room, you might want to use a two-way monitor. If your pet sleeps in the room with you but wakes you often, you should consider moving their bed to another room.

Identifying you need help

You should contact your GP if your lack of sleep is affecting your daily life and lasts for more than four weeks (this applies not just to people with MSA but carers too). The GP will either suggest medication or equipment or may refer you through to specialist sleep support. Our MSA Nurse Specialists can also give information, advice and help support you.

Further information

There are various apps that can help you with sleep such as Pzizz, Sleepstation and Sleepio. More information about the importance of sleep can be found at the links here:

www.sleepfoundation.org/sleep-topics/sleep-related-breathing-disorders

www.nhs.uk/live-well/sleep-and-tiredness/10-tips-to-beat-insomnia

Please speak to your MSA Nurse Specialist if you have further questions about sleep and MSA.
msa *new*

In Memory

Rosemary Holland
TJ (Thomas) Waters
Paul Basson
Ken Forster
Roger Harris
Carol Bateman
William Clarke
Deborah Logan
Michael Culhane
Richard Thompson
John Brain
Kenneth Bailey
Mark Rose
Christine Banks
Janis Bradburn
Margaret Price
Gillian Rowlands
Teresa Brown
Neville Clifford-Jones
John Baker
Brian Musgrave
Graham Chesher
David Farleigh
Ron Lygo
Alan Stocker
Breda Doyle
George Oliver
Barbara Case
Lawrence Green
James Brown
Susan Forbes
Lynda Hornyak
David Ward
John Howbrook
Christopher O'Leary
Suzanne Gibbs
Michael Southgate
John Longcake
Verjinder Panesar
Maureen Chalmers
James Goddard
Robert Simmons
Anthony Meredith
Irene McNally
Ann Summerfield
Joseph Wylie
John Rothwell
Linda Hewitt
Pat Corbett
Anthony Robinson
Maureen Cox

MSA CANDLELIGHT - POSTPONED

Every other year we bring our community together for our memorial event - MSA Candlelight, held to remember lives lost to multiple system atrophy.

This year we had planned for MSA Candlelight to take place in MSA Awareness Week in March. Sadly, as with other social events, we had to postpone.

We are currently assessing the possibility of holding the event later in the year (at the same venue, just outside Bristol) but cannot yet confirm a date as it is difficult to predict when public gatherings will be allowed.

Please keep checking our website at **www.msatrust.org.uk/msacandlelight**, call or email the Office for updates on this. If you had previously confirmed your attendance, you will be sent another invitation.

We do still hope to have an afternoon of music, poems and discussions on MSA research that will end with lighting candles, but we will follow the relevant Government advice at the time.

We are very grateful to the families who donated to enter their loved one's name into the Book of Remembrance. A copy of the book will be presented to those who can attend the postponed event or posted to those who cannot. We still have time to accept further dedications, up to Friday 14th August. You can do this with a minimum donation of £12. This will be used to cover expenses and fund MSA research.

To donate visit **www.msatrust.org.uk/product/msacandlelight**, call 0333 323 4591 to pay over the phone or send a cheque payable to 'MSA Trust'.

Roundup of Useful Articles

Our MSA News magazine has been going for 21 years (with a few name changes along the way!) and so far we have released 58 editions.

The majority of magazines (from 2002 onwards) are available to download and read on our website – **www.msatrust.org.uk**. Inside these magazines there is a wealth of information available to members. Some topics covered are not currently in our factsheets but people still find them helpful.

Over the next year we will be outlining previous articles covering three topics – Symptoms and Management of MSA, Living with MSA and Caring. In Issue 57 we focused on Symptoms and Management so in this issue we move on to 'Living with MSA':

Subject Matter	Issue	Page	Article Title	Factsheet Available
Respiratory issues in MSA and ways to help treat these	57	10	**Breathe in… and Breathe Out**	
Support available through the third sector (not-for-profit organisations)	“	12	**Making the Most of the Wide Net of Support**	Basic Benefits and Entitlements
How to help someone if they have a mild or severe choking episode	“	18	**How to Deal with Choking Episodes**	
The support you can expect from a Physiotherapist and exercises to try at home	56	6	**Physiotherapy, Exercise and MSA**	Equipment – Posture and Mobility
Wheelchair Accessible Vehicles and how to purchase one	“	10	**Wheelchair Accessible Vehicles**	Equipment – Posture and Mobility
How to access GP support and what you are entitled to	“	12	**Making the most of your General Practitioner (GP)**	
A review of NHS Continuing Healthcare	55	10	**When Needs Become Complex**	Continuing Healthcare
How to make adaptations to your home safely	54	10	**Home Sweet Accessible Home**	Equipment – Posture and Mobility
The emotional and mental health impact of living with a rare disease such as MSA	52	7	**Heads Together**	
Tips for holidays and travel	“	8	**Anchors Away**	Travelling and MSA
The affect of MSA on sex and relationships	“	12	**The Power of Hugs, Cuddles and Love**	Relationships, Sex and MSA
Minimising the impact of the cold and winter on your health	50	8	**Winter Health**	
A member's experience of coping with a diagnosis of MSA	49	4	**Heads Together? Living with MSA**	
How music therapy might help you	48	10	**The Power of Music Therapy**	Complementary Therapies
What help a dietician can give people with MSA	47	6	**The Role of the Dietician**	
Examining some possible benefits of CoQ10	“	17	**Coenzyme Q10 (CoQ10)**	
How a Community Matron, or similar role, can help coordinate your care	46	12	**The Role of a Community Matron**	
The Importance of hospices in maximising overall quality of life	“	10	**How Hospice Care Can Help You**	Understanding Palliative Care
Things to consider when choosing a wheelchair	44	6	**Going Mobile**	Equipment – Posture and Mobility
Benefits of the flu vaccination for people with MSA and carers	41	17	**Keeping well - Seasonal Flu Vaccination**	
Role of an Occupational Therapist and how they can help you	40	19	**Meet Your Care Team (OT)**	

MSA Trust Funding

Our Scientific Advisory Panel (SAP) met in February 2020 to review applications and award funding for innovative research projects into MSA. We received a record number of applications, which were peer-reviewed and rated by MSA researchers and clinicians prior to the discussions.

1

Investigation of somatic DNA copy number gains of SNCA (alpha-synuclein) in different brain regions in MSA subtypes. ***Lead Researcher: Dr. Christos Proukakis, Institute of Neurology, University College London***

The protein alpha-synuclein aggregates in clumps in parts of the brain in MSA. Given MSA does not appear to run in families the researchers propose that mutations may occur to the gene in someone's lifetime. Such mutations are called 'somatic' mutations. Certain cells with somatic mutations are more likely to have protein clumps, suggesting that these mutations may directly contribute to cell damage in MSA. So far, the group have studied two regions of the brain. This new research will focus on further study of four regions of the brain affected in MSA, and compare the regions affected in both types of MSA (MSA-P and MSA-C). The aim of the project is to see if somatic mutations are more common in the regions of the brain affected by MSA, if the level of somatic cells corresponds to the extent of tissue damage and if they frequently occur in the same cells as protein clumps.

Dr Proukakis says:

> ***"The generous support of the MSA Trust will allow us to work out whether certain changes we acquire in our brain DNA influence the risk of getting MSA, and the exact features that come with it."***

2

Dissecting the role of the Autophagy-lysosome pathway (ALP) in multiple system atrophy pathogenesis. ***Lead Researcher: Dr. Maria Xilouri, BRFAA, Athens, Greece***

ALP is an automatic process responsible for the removal of misfolded proteins and protein aggregates in the brain. MSA is thought to be caused by the aggregation of mis-folded alpha-synuclein protein in oligodendrocyte cells in the brain, but the cause is not yet known. This study aims to explore the possible involvement of autophagy failure in the accumulation of alpha-synuclein in MSA.

This project will explore if manipulation of autophagy will reduce levels of alpha-synuclein and restore myelination (insulation) to protect neurons from degeneration. This will be done by using cells obtained from a mouse model of MSA. They also will examine post-mortem brains of people with MSA and controls to analyse components of the autophagy pathway.

The researchers hope to identify mechanisms that can clear abnormal forms of alpha-synuclein, which might have potential benefit to develop treatments for MSA.

Dr Xilouri comments:

> ***"We hope that this line of research will lead to a better understanding of the mechanisms that mediate the death of nerve cells in MSA. Funding of this project by the MSA Trust provides a great opportunity for us to pursue our ideas and test our scientific hypothesis."***

for Research 2020

Four projects met our criteria and will be eligible for our funding. While there will be a delay in starting these projects due to the COVID-19 pandemic, we are confident that all will most likely be underway by January 2021. We will be bringing you updates on the projects as they progress.

3

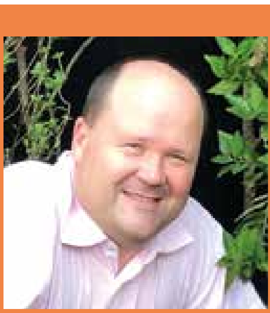
Unravelling the molecular pathology of multiple system atrophy through an integrative approach to alterations in DNA methylation, transcripts and proteins. ***Lead Researcher: Dr. Conceiao Bettencourt, Queen's Square Brain Bank, University College London***

DNA provides a code that is the same for all cells in our body. Different cells require instructions telling them how to behave e.g. a blood cell or a nerve cell. These instructions are given by chemical modifications to the DNA and include a change called DNA methylation. It works like a dimmer switch to vary the amount of proteins produced by each cell. Research has shown that DNA methylation plays a role in neurodegenerative disorders like MSA. This study aims to better understand the molecular changes that are unique to MSA by studying DNA methylation changes in brain tissue. If MSA can be distinguished molecularly from other conditions, this could improve diagnosis and provide a biomarker to measure the effect of any potential new treatment. If changes in DNA methylation and other molecules are potentially reversible, understanding where the molecular damage occurs may be important in the development of future treatments.

Dr. Bettencourt says:

"This MSA Trust award will enable us to build on our previous findings. We hope to improve diagnosis and aid development of biomarkers to monitor the disease."

4



The Identification of Longitudinal Biomarkers of MSA. ***Lead Researchers: Prof. Henry Houlden (pictured) and Dr. Viorica Chelban, Institute of Neurology, UCL***

This project will extend and develop the work currently being undertaken by the team at the institute of Neurology, University College London. An update of this work is given on page three. We are delighted to report that this project will be jointly funded by The Manx MSA Trust, set up in 2016 by Chris Blake, who had MSA.

His wife, Nicola Blake, who is director of The Manx MSA Trust said:

"We are delighted to have been invited to partner with the MSA Trust, in co-funding this three year project, led by Prof. Holden. It is vital we continue to push the boundaries in MSA research, which we feel this study achieves on a number of levels. We have worked with Karen Walker and her fantastic team over the past four years, so to embark on this project together, is really exciting and one we hope will bring the Isle of Man and UK closer to one day finding a cure."

IN THE COMMUNITY

The Wellingborough Bowling Club*'s President, Peter Byworth nominated the Trust as their 2019 Charity of the Year in memory of his wife, Jeanette. A great year of fundraising resulted in £1,000 raised for the Trust.*

The League of Gentlemen Golf Society *in Nazeing has been going for the last twenty years with the group playing two or three times a week. Each year the Society nominates a charity and donates £1 every time a member's golf ball goes into a bunker on any of the par three holes. This has raised £600 in memory of Joan, wife of member, John Brown.*

Robyn Smith *was hoping to complete several challenges as part of her 2020 events in memory of her cousin, Joey Quinn. She managed to complete the Victoria Park Half Marathon just before the pandemic restrictions were applied, finishing her Herne Bay 10km and Southampton Marathon 'virtually', running in her local streets and back garden. Robyn has already raised more than £1,500 and is now looking forward to her postponed Manchester Marathon later this year and her Isle of Wight 100km trekking challenge in 2021. All the best Robyn!*

THE SUN WILL RISE AGAIN...

Earlier this year ***Anna Manley*** *completed the Sahara Desert Trek in memory of her aunt, Eileen Shaw, while also raising £2,521 for the Trust. Unfortunately, Anna had to leave the trek prematurely as she was required to travel back to the UK before COVID-19 restrictions were introduced. However, she did get to complete the main part of the trek - walking up the biggest dune in the Sahara (Erg Chigaga) at dawn to watch the sunrise.*

emf edinburgh marathon festival

MANCHESTER MARATHON 2020

Although many of our running events did not go ahead as planned, they have been postponed to later this year.

Contact ***fundraising@msatrust.org.uk*** *if you, or anyone you know, would like to take part in these events to raise vital funds for the MSA community.*

- ***Edinburgh 10K on 5th September***
- ***Edinburgh Marathon on 6th September***
- ***Bournemouth Half Marathon on 4th October***
- ***Manchester, Royal Parks or Oxford Half Marathons on 11th October***

Cycling Inspiration

Clare Hart has completed a couple of cycling fundraisers for the Trust, the most recent being from Mumbai to Goa. This amazingly raised over £4,000, and here, Clare recalls her experience:

"The year before last I cycled coast to coast across Costa Rica to raise money for the MSA Trust. It was one of the most gruelling challenges of my life and I swore never to be repeated. Like childbirth, it is amazing how one forgets the pain! For this ride I looked at the map and foolishly thought it's all downhill. Turns out India has far too many hills and the ride was equally as challenging. We cycled distances of about 450 km on both challenges over various different terrains and elevations and were met with much local support and hospitality."

Clare's inspiration is her sister Jill who has MSA, and Jill's husband and fulltime carer, Fraser.

"Every day is a struggle for Jill but she gets immense pleasure from her family and doting grandchildren Islay and Sandy. Fraser is truly amazing, every minute of the day making Jill's quality of life as good as it possibly can be. During this pandemic and period of self-isolation Fraser has taken the decision to cancel all external support for Jill and manage entirely himself to reduce infection risk."

"When my muscles cried out on some of our more challenging days, I thought of my big sister Jill and her daily struggle. She approaches every day with good humour, never uttering a word of complaint."

msa *news*

A little reminder makes all the difference!

Our member, Jackie Pickford, who has MSA, was finding it hard to remember to take her medication on time. Her husband Ian then discovered the DrugStars app...

DRUGSTARS®
Giving by taking

"It's surprisingly easy to use. After a little time setting up all the medicines, through taking photos of the packaging, we are reminded every time a pill should be taken. For us, this is four times a day. A simple acknowledgement on the app then earns 'Stars' which can be exchanged for a donation to the MSA Trust.

We're told that the Trust gets 1p for every Star donated, which soon adds up. In just a few months we have almost £40 built up!

We have also found that one gets stars for supplements as well as prescription drugs - so even those vitamin C tablets earn a star every time Jax pops one down!"

You can download the DrugStars app on your Android or Apple phone and can find out more information here - www.drugstars.com. msa *news*

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

Supporting & Helping Each Other

As many of you will know our in-person Support Groups have been suspended but that does not mean we have stopped finding new ways of helping each other. Nicole Adam, reports on some tips shared at our Digital Support Groups...

Lockdown has changed the ways we access many of our basic services. Some members of our Essex Support Group have now arranged to have their prescriptions delivered. This has saved them time at the pharmacy and is a change they intend to make permanent even after lockdown is over. To see if this is possible for you speak to your local pharmacy or GP. Other members have found it helpful to have an NHS volunteer pick up their prescriptions and drop them to their door. If you need a volunteer to help pick up supplies, please contact us at the office and we can see what is available locally to you.

Many health services are now only doing phone or video consultations but there has been a small upside to this. At our Three Counties Group a member reported that their Neurologist had been doing phone consultations for several months before lockdown, this had allowed them to save patients from travelling in and give them a longer slot while also helping to reduce the backlog of appointments. To get the most out of your virtual appointments have a list of questions ready before the call - see page 5.

It was pointed out in our London Support Group that some Speech and Language Therapists and Occupational Therapists can do phone or video assessments without coming to your home. If it has been some time since you have seen these services and you feel there have been changes to your symptoms, do enquire about a new referral.

All our Support Groups discussed the difficulties with staying active during the lockdown. 'Little and often' was emphasised as there are lots of positives from doing regular bits of small exercise. One member suggested setting a timer next to their chair to remind them to stand up and sit down. Some people with access to outdoor spaces had been inspired by Captain Tom and were doing laps outside but taking frequent rests. There are also many videos online for chair exercises, including chair yoga, chair dancing or stretches to suit all activity levels. One member had been doing them every afternoon as a family activity with his household. Many can be found on YouTube or through specific websites, here are a few to get you started - www.nhs.uk/live-well/exercise/sitting-exercises.

Even in these difficult times some members are discovering new equipment. One of our members in Ireland has recommended a toto lateral turning system. This device rocks people in bed from side to side throughout the day or night to keep them moving to reduce pressure ulcers. Contact your local support team to see if this might be an option for you.

Much of this advice has come from our new Digital Support Groups. We know not everyone is very comfortable with technology but, if you have access to the internet it can be a great way of staying in touch and avoiding isolation. AbilityNet provides qualified volunteers who offer support with technology over the phone or online, for more information see www.abilitynet.org.uk/at-home/request-free-it-support-home or call 0800 269 545. msa *news*

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

Virtual Support Groups

We have sadly suspended our in-person Support Groups for the foreseeable future due to Covid-19. The ongoing uncertainty around Coronavirus and the nature of MSA means our Support Groups will not be able to return until the situation stabilises significantly.

To help fill the gap we have started Digital Support Groups. The early feedback has been positive and we appreciate the help of everyone who has taken part with this new service. We know that, even before Covid-19, attending a Support Group was not possible for everyone. A small positive in this situation is that, even after we can resume our in-person Support Groups, our Digital Support Groups will remain part of our service in some capacity. The safety of our members and volunteers will always be our top priority.

How do they work?

Each Digital Support Group is hosted by an MSA Trust office staff member, one of our MSA Nurse Specialists and we have been fortunate to have some of our volunteer Support Group Leaders join us as well. We are currently hosting our Digital Support Groups using Zoom, a digital teleconferencing facility. We are keeping groups to a limited number where necessary to make sure everyone has a chance to share and be heard. You can join the group using a computer, tablet or ipad, smartphone, or you can dial in using a normal landline or mobile phone. Just like our regular Support Groups they are a chance to ask questions and share information with others who have experience of MSA.

Why are they regional?

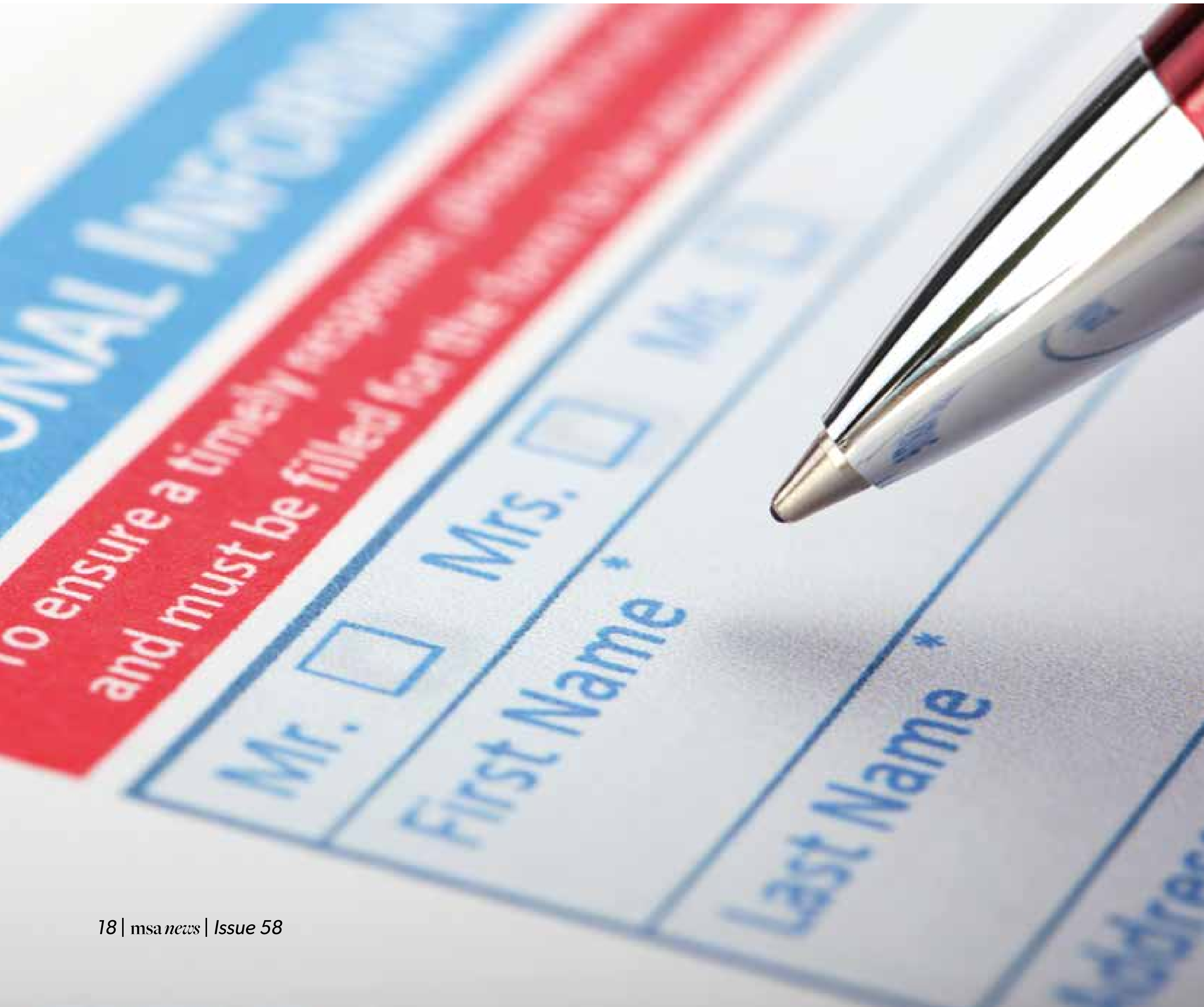
We are roughly grouping our Digital Support Groups into regions, where possible with their own MSA Nurse Specialist. Services can vary greatly depending on location and we find this helps people better exchange information on local services.

You will receive invitations to the Digital Support Groups if you already receive our regular Support Group invitations by e-mail. If you are interested in attending and would like to make sure you are on the list to receive our next set of invitations, please contact us at support@msatrust.org.uk or call 0333 323 4591 to update your contact preferences.

msa *news*

Feel the Benefit(s)

Jane Stein, our Social Welfare Specialist looks at two benefits people with MSA are likely to be entitled to in the UK.



Personal Independence Payment (PIP) and Attendance Allowance (AA) are benefits to consider claiming if you require assistance with personal care or have limited mobility. Neither benefit is taxed or means tested. If you are under state pension age PIP is the relevant benefit, if you are over state pension age (and not already in receipt of PIP) then AA is the relevant benefit. If you are approaching state pension age it is very important to look at applying for PIP before you reach this milestone as AA has no mobility component so you may lose money.

> ***There is no restriction on how you choose to spend either PIP or AA. You do not have to spend the money on care support.***

PIP and AA are not awarded on the basis that you have MSA. You will need to explain how MSA, and any other medical conditions you may have, affect you. The assessment looks at the difficulties you have in managing tasks of daily living, your need for supervision and (in the case of PIP) on your mobility.

To help ensure you are awarded the correct rate of benefit you will need to complete the claim form in a very detailed way. Help with this is available via Citizens Advice, your local Age UK office or from myself, Jane Stein, Social Welfare Specialist. We have factsheets about both benefits at: www.msatrust.org.uk/support-for-you/factsheets.

When completing the form try to paint a picture. For example, when describing how you would prepare a meal talk about the actual tasks involved (the peeling of potatoes, the opening of cans, the lifting of saucepans, the use of a hob and oven, the turning on and off of taps) and detail difficulties with these tasks.

It does not matter whether you actually receive help from anyone else (family members included) - or do not need to do the activity - it is about whether you do, or would, require help with the activity.

When completing a task if you cannot do it safely, to an acceptable standard, repeatedly, without pain and in a reasonable time frame, clearly explain this.

When considering safety think about any dizzy spells you may suffer, how changes in temperature (for example in a hot kitchen or bathroom) may affect you. When looking at eating and drinking detail any swallowing difficulties and any coughing or choking episodes. When looking at tasks involving moving about list any falls or stumbles.

Doing tasks to an acceptable standard means, for example, being able to get dressed in clothes of your choice (rather than clothing with no zips or buttons).

The frequency with which you do tasks will depend upon the task but if you could only complete the task once when others could do so repeatedly then this should be explained on the form. Talk about any exhaustion, discomfort or pain experienced.

If a task takes you more than twice as long as it takes others explain this.

Many people living with MSA will find that their abilities fluctuate. Again, explain this in detail and quantify where possible. For example say ‘On average I am unable to do this task 5 days a week but on the remaining 2 days I may do so with great effort but I am left needing to sit and rest for 30 minutes afterwards’.

It is worthwhile asking someone who knows you well to complete the form with you. Add in their comments.

Anyone who meets the Department of Work and Pensions criteria for a DS1500 form (which is related to prognosis) has automatic entitlement to the enhanced rate of the daily living component of PIP or the higher rate of AA and does not need to complete the entire claim form. Your GP or palliative care team can advise on this.

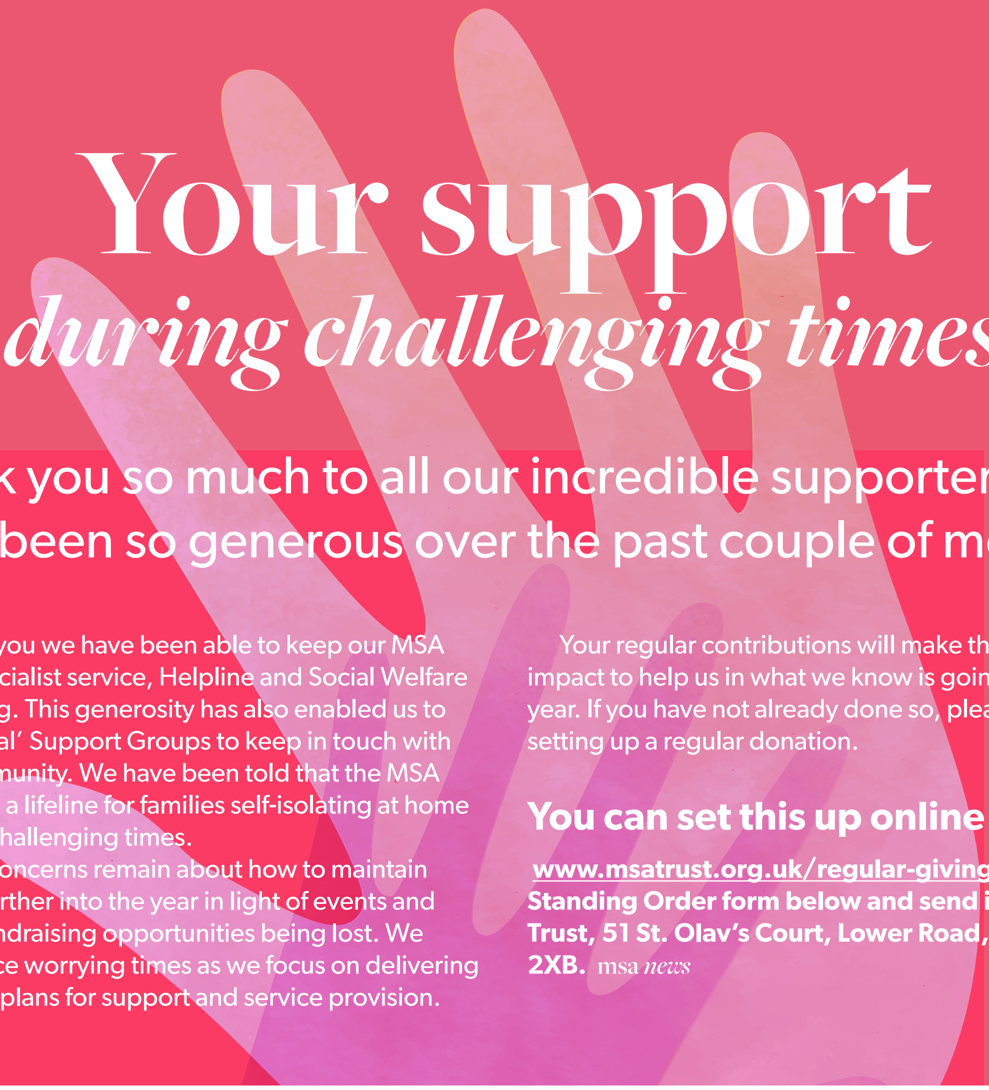
People in receipt of the enhanced rate of the mobility component of PIP usually have an automatic entitlement to a blue badge. Others may be eligible for a blue badge (including people receiving AA) but further assessment may be required. Information about blue badges can be obtained from your local council or see www.gov.uk/apply-blue-badge.

People in receipt of the enhanced rate mobility component of PIP are, in most cases, eligible to use the Motability scheme. This scheme allows you to use the mobility component of PIP to obtain a powered wheelchair, scooter or vehicle. You can read more about this here www.motability.co.uk. Sadly, there is no mobility component to AA so people in receipt of AA are not able to use the Motability scheme.

Those in receipt of the enhanced rate of the mobility component of PIP can obtain an exemption on their vehicle tax, people in receipt of the standard rate of the mobility component can receive a 50% reduction in their vehicle tax. This only applies if the vehicle is used solely for the benefit of the person receiving PIP.

The benefit cap (which limits the amount that can be paid to a household in receipt of means tested benefits) does not apply if someone in the household receives PIP or AA. Being in receipt of the daily living component of PIP, or receiving AA, may entitle a carer (often a family member) to Carers Allowance. Please see www.gov.uk/carers-allowance.

Please note different benefits exist in the Republic of Ireland. Please see www.citizensinformation.ie or contact us for more information. msa *news*



Your support *during challenging times*

Thank you so much to all our incredible supporters who have been so generous over the past couple of months.

Because of you we have been able to keep our MSA Nurse Specialist service, Helpline and Social Welfare service running. This generosity has also enabled us to develop 'virtual' Support Groups to keep in touch with our MSA community. We have been told that the MSA Trust has been a lifeline for families self-isolating at home during these challenging times.

However, concerns remain about how to maintain our services further into the year in light of events and community fundraising opportunities being lost. We continue to face worrying times as we focus on delivering our long-term plans for support and service provision.

Your regular contributions will make the biggest impact to help us in what we know is going to be a tough year. If you have not already done so, please consider setting up a regular donation.

You can set this up online at:

www.msatrust.org.uk/regular-giving or fill out the Standing Order form below and send it back to: MSA Trust, 51 St. Olav's Court, Lower Road, London, SE16 2XB. msa *news*

To The Manager:.. Bank/Building Society:..

Address:..

Your Bank Sort Code:.. Your Account Number:...

Starting on: / / I would like to set up a standing order, to be paid monthly/annually (please delete as appropriate),

of £ ____________ to the account below:

Bank: CAF Bank Charitable Banking **Account Name:** Multiple System Atrophy Trust
Sort Code: 40-52-40 **Account Number:** 00096281
Address: 25 Kings Hill Avenue, Kings Hill, West Mailing, Kent, ME19 4JQ

Please Gift Aid my donation of £ __________ (annually) and any donations I make in the future or have made in the past 4 years to: Multiple System Atrophy Trust. I am a UK taxpayer and understand that if I pay less Income Tax and/or Capital Gains Tax than the amount of Gift Aid claimed on all my donations in that tax year it is my responsibility to pay any difference.

○ I do not qualify for Gift Aid (please tick if applicable)

Title............... Forename................................. Surname..

Address..

Post Code.................................. Telephone...

Email...

Signed... Dated...