msa news

MSA Trust Members Magazine | issue 49

MSA-P or C, *what's the difference?*

Thoughts on dealing with MSA

The Trust's 20th ANNIVERSARY

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KAREN WALKER

Welcome to issue 49

Welcome to our 49th edition of MSA News. I hope you like the new look.

We are now well into our 20th anniversary year and it is great to see so much interest in MSA being generated nationwide. We have had some great coverage through print and TV and radio thanks to our dedicated supporters who keep talking to local journalists, making them aware of MSA and the devastating effect it can have. Do check out our website for more information on how you too can become involved.

We are recruiting for our 4th MSA Nurse Specialist and we can't wait to have the first article from our new MSA Research Fellow in a future edition of MSA News. An update on this appointment is given later.

I am also pleased to tell you about our Trustee recruitment, which has been going very well, and our first recruit is introduced in this edition with more to follow next time.

Finally, Andy and Emma would welcome any feedback from our readers on the redesign of MSA News , including what you like, don't like and how we might improve even more. msa *news*

NEWS ROUNDUP

Neurological Alliance Survey

The results are back from this survey which many of you completed earlier this year. Unsurprisingly, people living with MSA were users of many different services, such as speech and language therapy and physiotherapy. More of a surprise is that only around half of respondents with MSA seemed to be claiming the benefits which they would have been entitled to. We have a new leaflet about basic benefits to encourage people to take up their entitlements. Go to our website or call the office to get this.

We will be analysing the results in more detail so that we can ensure we focus on the areas which are most important to you.

Join our growing community

We have recently launched a new online community to help provide support and information to people affected by MSA. This is in addition to our existing forum on our website.

Our new community is part of the HealthUnlocked network which aims to provide a safe place for people affected by MSA to share experiences, stories and helpful information. Anyone can join for free and it's easy to sign up, access help and information and ask questions to other people experiencing similar issues.

The more people that use the website, the better and more tailored information it provides. Initial feedback on the community has been very positive, with people telling us that speaking to others who understand what they are going through is making a big difference.

Why not take a look now and join our online community - www.healthunlocked.com/msa-trust.

Sarah's Wood

Next week we will see the inauguration of Sarah's Wood. Sarah Matheson (pictured) founded the MSA Trust to bring hope and support to people with MSA and their families. In June 2017, 20 years on, we will launch Sarah's Wood in the heart of Sherwood Forest. It will be a lasting symbol of strength and solidarity for all our MSA community.

The event will take place at Thoresby Estate in Nottinghamshire on the afternoon of Tuesday 13th June 2017. If you and others would like to attend please complete the form on our website, www.msatrust.org.uk or contact support@msatrust.org.uk for further information. Places are limited so get your names down quickly!

MSA Trust in the news

We've had some fantastic coverage on TV and in newspapers recently. Will Norman made a beautiful film documenting his dad's life with MSA and was interviewed live on ITV London news.

Our Leicestershire Support Group held a tea party to mark the Trust's 20th anniversary and the group was featured on BBC East Midlands Today. Special thanks to Support Group Leader Alison Parish (pictured) for organising the party and speaking on camera.

Kate MacGregor was named Scotland's GP of the Year for her dedication to a person with MSA. The story was picked up across a number of Scottish newspapers including The Scotsman and Daily Record. msa *news*

ARTICLE BY MSA TRUST MEMBER, JOHN DUNNE

Heads Together? *Living with MSA*

John Dunne, one of our members and a psychologist himself, gives MSA News his view of how to cope with life with MSA.

JOHN DUNNE WITH HIS NIECE

I was diagnosed with MSA in September 2015 and, like all of us, I have had to try to come to terms with all its implications. Although we all have MSA in common, each one of us is also unique, with our own history and "back story". Before retirement I was an NHS Consultant Clinical Psychologist, with much of my clinical working life, perhaps ironically, spent trying to help people come to terms with major life threatening or life limiting conditions. This was also a focus of much of my University teaching.

And so it was that in the midst of my emotional reactions to my own diagnosis I also tried to think of what had helped other people. Reflecting on my own case, a number of themes emerged. MSA seemed to represent a profound if gradual but irreversible change at so many different levels. It was all about loss and loss of control. There is a subtle change in our sense of identity. We gradually begin to identify ourselves as being among the sick rather than the healthy, the disabled rather than the able bodied.

ARTICLE BY MSA TRUST MEMBER, JOHN DUNNE

And among the roles we occupy in life, one new and primary role becomes that of the patient, even as we try to negotiate the other roles we may still continue to occupy in other areas of our lives.

And so it is primarily as a patient, as a fellow person living with MSA, but one with a particular background, that I offer these thoughts on how we all might try to cope, at least to some extent for some of the time.

When faced with loss, whether through bereavement or relationship breakup, or indeed the losses we face at so many levels with MSA – independence, mobility, perhaps speech, loss of continence or sexual function – it has been traditional to describe that grieving process in terms of several stages or phases. These include, shock, numbness and denial, through anxiety, anger and depression to acceptance. Although it has some merit, the trouble with this approach is that it can see the process in very passive terms, something we just have to undergo, in the face of which we are simply victims. A more contemporary approach, however, is to see our dealing with loss, our grieving, in much more active terms, not as a series of stages we undergo, but as a set of psychological tasks we have to accomplish, a set of challenges we have to face.

> ***Although we all have MSA in common, each one of us is also unique, with our own history and "back story".***

> *And so it was that in the midst of my emotional reactions to my own diagnosis I also tried to think of what had helped other people. Reflecting on my own case, a number of themes emerged.*

The tasks are described as fourfold:

- ***to accept the reality of the loss,***
- ***to work through the pain of grief,***
- ***to adjust to a new psychological "environment",***
- ***and to emotionally "relocate" our loss by withdrawing emotional energy from the past and investing in the present and the future.***

Accepting the reality of the loss means that we gradually learn neither to deny the fact of the loss, nor its meaning, nor, failing medical advances, its permanence and irreversibility. However, one crucially important thing to recognise here is that all of us will at times engage in partial and intermittent denial, which is not necessarily a bad thing, and may even be healthy and functional. Complete and total denial however is another matter.

Working through to experiencing the pain of our loss(es) is a very necessary and healthy way of coping (often referred to as emotion-focused coping as opposed to problem-focused coping.) Both are equally important. Allowing ourselves to fully experience and share all our emotional reactions is vitally important especially at the beginning, but also at various "new" stages of our illness. It only becomes a problem if it is unremitting and long term without any resolution. Problem-focused coping (exploring practical ways of adjusting) is therefore equally fundamental to our progress. But if it is engaged in too quickly before we have processed our emotional reactions, it can be premature and perhaps not really thought through.

Adjusting to a "new normal" is difficult as we come to terms with so many changes in our functioning previously simply taken for granted. But we gradually learn to adjust if we can maximise what we can still do, minimise the impact of what we cannot, and avail ourselves of as much information, practical help and social support as we can.

Although it is inevitable that we are conscious of so much we have lost, perhaps we can gradually let go of the past and try to accept the present. The practice of mindfulness - where we stay only in the present moment and try to develop a new relationship with all our thoughts and feelings, not identifying with them but accepting them, letting them be without judgement, and then letting them go - can, if practised daily, be a very potent source of greater peace of mind.

Throughout our illness we are hopefully surrounded by compassionate care. At the same time we must also try to maintain a compassionate attitude towards ourselves. This can become an inner resource for us, helping us to deal with the discouragement and the trials, encouraging us forward from day to day and moment to moment. msa *news*

ARTICLE BY EMMA RUSHTON

Volunteering Matters

Emma Rushton outlines some changes to volunteering within the Trust...

The Trust has a staff team of just ten, covering the length and breadth of the UK and Ireland. We therefore have a tremendous reliance on the valuable time given by volunteers who support our work. Previously we had several volunteer roles including awareness raising and managing volunteers, but we have taken the decision to streamline these. Feedback suggested that people felt these roles were quite overwhelming and this stopped people from coming forwards. So we have decided to put more of a focus on our 'Helping Hands' volunteers, offering more flexibility for you and us. We want you to have the ability to use your current skills and knowledge – whatever those attributes might be - to support us. For instance, you may be a great photographer and be able to take pictures for us at events, have a spare few hours to help at a local Support Group meeting, or perhaps you would prefer to volunteer from home and complete some project work for us. We are also keen to support volunteers in gaining new experiences whilst working with us such as IT skills, administration work, event planning and much more.

We welcome applications from all including people with MSA, family members and friends, former carers and people living abroad.

If you are undecided, just hear from one of our wonderful volunteers, Isobel about why she volunteers with us:

"I volunteer for the MSA Trust as the Support Group Leader in South Wales. My involvement with the Trust began in 2008 after my husband Bill was diagnosed with probable MSA.

> *It quickly became apparent that there was a great ignorance of the condition and the only point of contact for us was the Trust.*

This lack of awareness, knowledge and understanding of MSA by medical professionals was scary. We travelled 250 miles to Newcastle to see a movement disorder specialist and get a diagnosis. Our mood on the journey home by train was certainly lightened by the red wine we consumed! We felt isolated and uncertain about what was in front of us as Bill's condition progressed. In 2009 we took the brave decision to relocate from Scotland to South Wales, nearer to our daughter and her family, and closer to our son. Bill sadly passed away in August 2012.


ISOBEL CHERRINGTON

In 2016 I attended the first MSA Support Group in Cardiff and although facing MSA directly again was a difficult experience, I felt the time was right for me to become involved in supporting others with this complex condition. I recognise the Trust provides excellent advice and support - particularly in relation to health needs and I believe that in my volunteering role I can offer additional emotional support to carers and families, with a listening ear.

I have walked in the shoes of those going through this journey, and with my children and grandchildren we will continue to do all in our power to raise awareness of MSA and find a cure."

msa *news*

ARTICLE BY MSA TRUST CEO, KAREN WALKER

Research Fellow

VIORICA

Karen Walker introduces you to our new Association of British Neurologists MSA Research Fellow Viorica Chelban…

Our congratulations go to Viorica who was successful in becoming our first MSA Research Fellow. Viorica is already known to us through her work with Professor Henry Houlden on the MSA 'PROSPECT' Network project, collecting and collating samples from people with MSA. Eager to start work on her research project, 'Defining Clinical and Genetic Biomarkers in MSA, she explains what her project will cover - direct from her application:

'During this Fellowship I plan to study what genes lead to the accumulation of abnormal proteins and therefore the target-pathways that can be used to find treatment. I will initially measure the abundance or the lack of genes from different brain parts from patients that died because of MSA and compare them with the same regions from healthy controls. I will perform similar experiments using cerebrospinal fluid and blood. Identifying genetic markers in brain tissue and validating in blood samples will potentially reveal important clues on the cause of MSA and in combination with clinical and imaging analysis can improve our ability to diagnose the disease early, monitor progression and response to treatment. This approach could be used in the future to study similar neurological diseases.'

> *Viorica has already met some of our members at the Surrey Support Group and I know she is keen to meet lots of you to develop her understanding of the condition and to support the research she is undertaking.*

The Trustees are delighted to have her researching MSA as this helps us realise our ambition to have more clinical movement disorder specialists in MSA. We are looking forward to regular updates from Viorica as her research develops. msa *news*

Health & Care Professional's Study Day

We will be holding our very first study day for Health and Care Professionals in Southampton on 13th October 2017. We know how important our members feel raising awareness of MSA is, especially amongst those who work to support them. This day will provide an overview of MSA, an explanation of the main needs of those affected and practical information and examples of how Health and Care professionals can best support people with MSA. The programme will feature an excellent panel of presenters with opportunities for plenty of discussion and networking with others engaged in helping people with MSA. The venue will be the Doubletree Hilton, Chilworth, Southampton SO16 3NG and the cost is £20.00. If you're a Health or Care professional please contact the office on *support@msatrust.org.uk* or to register visit *www.eventbrite.com/e/multiple-system-atrophy-health-and-care-professionals-study-day-tickets-33304955017?aff=es2*.

Places are limited on what promises to be a great learning experience. We look forward to seeing you on 13th October! msa *news*

ARTICLE BY MSA NURSE SPECIALIST, SAMANTHA PAVEY

Restless Legs Syndrome

Many people with MSA report difficulty in getting a good night's sleep. A previous edition of MSA News (issue 43) gave some suggestions as to how to deal with problems sleeping. Our Nurse Specialist Samantha Pavey considers a particular issue that frequently crops up in enquiries - that of Restless legs syndrome.

What is Restless legs syndrome?

Restless legs syndrome (RLS) is a neurological disorder characterised by throbbing, pulling, creeping or other unpleasant sensations in the legs accompanied by an uncontrollable, and sometimes overwhelming, urge to move them. Symptoms occur primarily at night when a person is relaxing or resting and can increase in severity during the night. Moving the legs relieves the discomfort. The sensations range in severity from uncomfortable to irritating to painful.

This syndrome is not to be confused with Rapid Eye Movement (REM) sleep behaviour disorder, where people may kick or punch out in their sleep.

RLS occurs in both men and women, although the incidence is about twice as high in women. It may begin at any age. Many people who are severely affected are middle-aged or older and the symptoms typically become more frequent and last longer with age.

Up to 1 in 10 people in the UK experience RLS at some stage in their life and it is not necessarily related to any other condition. RLS can also run in families. This means there may be over 5 million people with RLS in the UK alone.

> *In people with Parkinson's, RLS is thought to be more common and may occur in up to 20% of people affected. Exact figures aren't known in people with MSA but one study gave an estimate of prevalence as between 10-28%.*

What causes RLS?

Although doctors still don't know the exact cause of RLS, a chemical in the brain responsible for movement called dopamine is suspected to be

involved.

Where there is no obvious cause, RLS is called idiopathic or primary restless legs syndrome.

Restless legs syndrome may also be triggered by pregnancy, iron deficiency anaemia and kidney failure. This is known as secondary RLS.

Certain medications can cause RLS so it's always advisable to take medications and herbal remedies only as directed by your doctor.

What are the symptoms?

Many people who have RLS experience varying degrees of pain. The condition can cause considerable discomfort during waking hours, particularly when in a relaxed state. However, RLS is usually most acutely experienced in the evening or at night when people are trying to sleep.

In many cases the symptoms begin when a person goes to bed. Just as they are beginning to relax the symptoms appear and the person has no choice but to get out of bed to stretch - this can happen many times in one night. RLS can lead to long, sleepless nights and daytime fatigue and invariably impacts on quality of life.

The sensations associated with RLS are most often compared to an itching or tickling in the muscles like "an itch you can't scratch" or an unpleasant "tickle that won't stop." It has also been described as a 'creepy-crawly' feeling or like there's fizzy water inside the legs.

What can you do?

A number of lifestyle changes may be enough to ease the symptoms RLS. These include:

- ***avoiding stimulants in the evening*** *– such as caffeine, tobacco and alcohol*
- ***not smoking***
- ***taking regular daily exercise*** *– but avoid exercising near bedtime*
- ***practicing good sleep habits*** *– for example, going to bed and getting up at the same time every day, not napping during the day, taking time to relax before going to bed, and avoiding caffeine close to bedtime*
- ***avoiding medicines that trigger the symptoms or make them worse*** *– if you think medication is causing your symptoms, continue to take it and make an appointment to see your GP.*

During episodes of restless legs syndrome, the following measures may help relieve your symptoms:

- *massaging your legs*
- *taking a hot bath in the evening*
- *applying a hot or cold compress to your leg muscles*
- *doing activities that distract your mind such as reading or watching television*
- *relaxation exercises such as yoga or tai chi*
- *light movement and stretching*

Treatment

> *Some people find magnesium helps to relieve their symptoms. This can be in the form of supplements or sprays, which can be used directly on the legs, all available from health food stores or online.*

Dietary sources of magnesium include legumes, whole grains, vegetables (especially broccoli, squash and green leafy vegetables), seeds and nuts (especially almonds). Other sources include dairy products, chocolate, and coffee (during the day!). Water with a high mineral content, or "hard" water, is also a source of magnesium.

Medication for RLS

There are several types of treatment with medication:

Dopamine agonists (a Parkinson's medication) may be recommended if you're experiencing frequent symptoms of restless legs syndrome. They work by increasing dopamine levels which are often low. These are prescription drugs only so discuss with your Neurologist, Parkinson's Nurse Specialist or GP. Usually a night time dose is all that is required. These include Pramipexole or Ropinerole tablets and Rotigotine patches

Anti-epileptic medication such as Gabapentin or Pregabalin (also used for neuropathic pain)

Muscle relaxants such as Clonazepam

Analgesia such as codeine or oxycodone or Tramadol, which are opiods, may be beneficial (but may cause constipation)

Drugs for sleep such as Zoplicone or Zolpidem may also be used to treat RLS. msa *news*

Your MSA Nurse Specialist will be happy to discuss any issues you are having with RLS or other sleep problems so please contact them at ***support@msatrust.org.uk*** and they'll do their best to help.

In Memory

John Watling
Tehtman Framroze
Anthony Smith
Sam Stirling
Thomas Smith
David Hawkes
Pamela Swain
Terence Barrett-Gray
Susan Howard
David Murfin
John Grice
Esme Matthews
Philip Peart
Michael Stone
John Evans
Susan Yates
Celia Smith
Philip Webb
George Gostelow
Yvonne Regan
June Doggett
Janet Fordham
Josephine Holman
John Douglas Lloyd
Duncan Harper
Patrick Sheridan
Rodney Edmonds
Margaret Buick
Robert Freeman
Garrett Nelson
Peter Benson
Marie Carne
Peter Walker
Bernard Lakeland
Janet Roach
David Hargrave
Michael Ginns
Angelo Ettorre
Chris Worbey
Madeleine Bone
Andrew Bell
Nicholas Booth
Dave Couldwell
Glenn Forbes
Gloria Anne Franklin
Terence O'Shea
Jane Martin
John Blower

SHARON CANNON CHARITY BALL

In November 2016 Joe Cannon held a charity ball in loving memory of his mother, Sharon Cannon, who was diagnosed with MSA and sadly passed away in 2013. He was inspired to fundraise for us in the hope that one day there will be a cure for MSA.

The ball was held at Formby Hall near Liverpool and was a glamorous affair with guests enjoying a three course black tie dinner and lots of exciting entertainment. They raised a staggering ***£32,000*** though ticket sales, donations and a charity auction.

We're very grateful to Joe and all those who helped to organise and attend. We are also excited to hear that Joe is holding another MSA Ball in November!

This year Joe is teaming up with fellow fundraiser Rachel Bache whose mum, Elaine Bache, also sadly passed away in 2013 after being diagnosed with MSA. The Ball will be in memory of both Sharon Cannon and Elaine Bache. It will be held at the Shankly Hotel in Liverpool on the 25th November 2017.

Tickets are now on sale for the 2017 MSA Charity Ball and if you are interested in attending you can find more information and buy tickets on their website www.msacharityball.co.uk. msa *news*

ARTICLE BY MSA TRUST MEMBER, GEORGE MOYES

Member Stories

George Moyes - committed cyclist

Cycling gave me the first clue that all was not well - I kept falling off my bike!

When MSA was finally diagnosed, I knew that I'd not get better, so riding my beloved bike again would not be an option.

I was determined to be as active as possible, for as long as possible. I also still wanted to enjoy cycling days and weekends with my friends and family.

> *I was always a keen cyclist, in fact we enjoyed many family cycling days with our children and every year I had at least one weekend away with friends cycling. In 2008 I cycled from Land's End to John O'Groats with my fifteen-year-old son, Richard.*

> *After a lot of research, I decided to bite the bullet and buy an Ice trike - £1800, second hand. I took to it straight away and I revelled in my new-found three-wheeled freedom.*

Despite regular banter from local teenagers I continued to cycle on a regular basis. The only risk was falling asleep at traffic lights!

I also bought a Radar key. This not only lets me access disabled toilets nationwide but it also allows me to open the padlock on a large gate through to my favourite ride, the Middlewood Way. This is a disused railway line between Marple and Macclesfield which is fairly flat and traffic free.

Although the Ice trike is quite long, it can fold down and fit easily into the boot of a car, so I could still go on cycling days and weekends with family and friends.

Nowadays, I do not go out on my own but I still use my bike to get out into the countryside with my friends and family walking beside me.

My legs are definitely less purple and swollen after a cycle ride so I know it's doing me good. I also have static pedals at home so I can continue with my cycling when it's too wet or cold to do the real thing.

As you can see from the photograph my bike is very versatile and it can be used on and off road. Unfortunately, my condition has worsened and I find hills and even slight gradients difficult to manoeuvre but friends and family can easily push the bike, and me, and because my average speed is walking pace, this works well. I've met a couple of other Ice trike cyclists on my travels - able bodied or with a disability - but no one else with MSA, so if you're inspired by this article, buy a bike and get cycling!

I look forward to meeting many of you, in the very near future, cycling your own bikes or trikes. msa *news*

ARTICLE BY MSA NURSE SPECIALIST, KATIE RIGG

MSA-P or MSA-C

What is the difference & does it matter?

If you are reading this article then you will already be only too well aware of what a complex condition MSA can be. Our MSA Nurse Specialist, Katie Rigg writes about the different types of MSA diagnosis and what they might mean to you…

Before you knew about MSA you may have heard that you had a condition that is 'Parkinsonian'; 'atypical Parkinson's' or a 'Parkinsonism'. What does all of that mean?! Well, simply put (if that is possible with MSA) it means you have a condition that initially looked similar to Parkinson's Disease (PD) but which your Doctor suspected was not actually PD.

At some point you will then have been told (hopefully not just read on a letter) that you have 'probable MSA'. Why 'probable'? This is because we do not as yet have any test or investigation that can definitively confirm MSA.

Results from any test alongside your clinical presentation (that is the symptoms and problems the Consultant picks up from talking to you and examining you) will be what leads the Consultant to believe that you have probable MSA.

So you have probable MSA; then you hear, or see, the terms MSA-P or MSA-C.

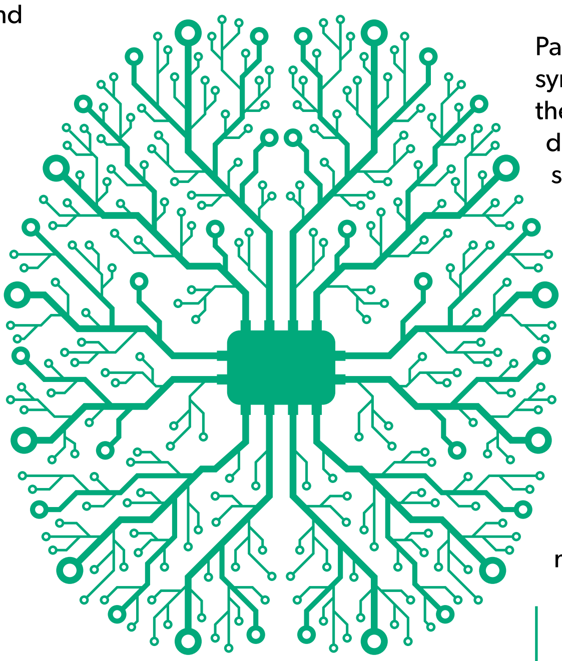
> *Historically MSA-P was known as striatonigral degeneration and MSA-C as olivoponto cerebellar atrophy. The general term Multiple System Atrophy is certainly easier to get the tongue round!*

MSA causes brain cells to die and thus shrinkage occurs in three key areas of the brain, with symptoms reflecting the damage in each area. However, the damage is not uniform and does not occur in the same way, at the same rate and in the same areas in everyone with MSA. The pattern of cell death in each brain area for each person will be individual so there does not appear to be a predictable pattern of how things change across everyone with MSA. This is why we emphasise that everybody's journey with MSA is different.

The initial symptoms in any individual often reflect greater damage from MSA in one of the three brain areas more than the other two. The area of the brain causing the predominant symptoms will determine whether the diagnosis is differentiated as MSA-P or MSA-C.

> *For example, someone with MSA-P will initially look very similar to a person who has PD, and be given this diagnosis. It may be many months, and occasionally years, before damage in the other two key areas of the brain causes demonstrable symptoms that lead to amendment of the diagnosis to MSA.*

Someone who has MSA-P will have similar problems to a person with PD for example, struggling to get moving and be slow and rigid in their movement. However, with dopamine replacement and /or enhancing medication, the person with PD can achieve much improved movement for many years because the damage in PD is primarily limited to the dopamine cells in the brain. In MSA-P the same medications may give only limited and less enduring improvement as the damage is more widespread. When someone looks like they have PD but do not respond well to the medications the Consultant will suspect they have another condition, such as MSA.



Someone who has MSA-C has most of their initial brain cell damage in the cerebellum area of the brain and may be diagnosed as having Cerebellar Ataxia (CA). Once the symptoms from the other two areas of the brain become apparent, the diagnosis is adjusted to MSA-C.

Cerebellar damage causes difficulty with balance, spatial awareness, a tendency to clumsiness and slurred speech so they can be mistaken for being drunk. Co-ordination is poor so picking up small objects and dealing with buttons and zips is difficult. There are changes to eye movements and swallowing. There are no specific medications to treat the cerebellar symptoms.

Virtually everyone who has MSA will present with symptoms of either PD (most commonly) or CA in the first instance; some people will have symptoms of a mix of both and be diagnosed directly as MSA with no added differentiation.

Once someone has some Parkinson's and cerebellar symptoms alongside those of the autonomic system due to cell death in the third area – the brain stem - then a diagnosis of MSA can be made. Our autonomic functions are essential body functions that constantly adapt and tweak our body's responses to changing circumstances. Common autonomic symptoms in MSA may be sexual dysfunction, temperature control problems, respiratory changes, bladder and bowel changes and difficulty maintaining a safe blood pressure.

> *Until research finds a cure for MSA, the focus is on managing symptoms as effectively as possible, so as an individual the differentiation of MSA-P or MSA-C is not so important.*

However, for drug trials it may be important depending on what the drug is hoping to make better. Also, over time projects such as the 'PROSPECT' study may help us understand if ,and how, the MSA journey differs if people start as MSA-P compared to MSA-C. If you want to know more about the PROSPECT study please contact Dr John Woodside on 020 7679 4272. msa *news*

For more information on anything you have read in this article please contact your MSA Nurse Specialist whose details can be found on our website *www.msatrust.org.uk*.

MSA Walk

__Clare Chesterman__ along with family and friends, walked 20km from Leith Hill Tower to Holmwood Common in Surrey in January raising almost £1,500. They wanted to show support for their friend, Georgette McCrystal, who has MSA. Clare said: __"All who walked felt so pleased to be raising money and awareness for MSA. And on a personal note, to show support to our friend Georgette, and her partner Frank."__

MSA WALK IN SURREY

Milk, Sugar And Tea party in memory of husband

__Jennifer Blackaby__ organised a Milk, Sugar And Tea party at the Shrewsbury United Reformed Church, raising funds in memory of her husband Bob, who passed away from MSA. Friends, family and church members came and enjoyed tea and cake and raised close to £700 for the MSA Trust.

JENNIFER BLACKABY TEA PARTY

Quiz Night and Cycle Ride to support best friend's mother

When their best friend's mother was diagnosed with MSA, __Rebecca Corner and Natasha Blanchett__ wanted to support our work. They organised a Fundraising Quiz and a night of music and fun, raising close to £2,000. Special mention to __BMI Sloane physiotherapy team__ who generously supported the cake sale and raffle. Natasha is also cycling Land's End to John O'Groats in June. Good luck Natasha!

REBECCA, NATASHA AND FRIENDS AT THEIR FUNDRAISING NIGHT

Climbing Kilimanjaro for mum

February saw __Sarah Bishop__ climbing Mount Kilimanjaro in memory of her mother. From holding a Race Night to doing a cake sale, she did a lot to reach her fundraising target. Sarah raised close to £3,000 - well done!

A Marathon effort for the MSA Trust!

In April ***Christiana, Paula, Amy and Carla*** *ran in the Brighton Marathon and raised close to £5,000!*

BRIGHTON MARATHON RUNNERS - CARLA & CHRISTIANA

A few Sundays later, 11 of our fantastic runners ran in the epic ***Virgin Money London Marathon****. We are delighted to say that they surpassed their fundraising target and have raised £35,000 (including Gift Aid).*

A BIG thank you to Claire Styles, Oliver Hassall, Hayley Clark, Ellie Hunt, Lisa Wells, Nia Wiiliams, Nic Willison, Barnaby Kean, Michael Stanley, David MacLennan and Elaine Holmes.

LONDON MARATHON RUNNER – HAYLEY CLARK

Special thanks to the ***singers from London City Voices Choir*** *for cheering on our London Marathon runners!*

CHOIR AT WESTMINSTER CHEERING POINT

LOOKING AHEAD

We're a few weeks in to our '20 events in 20 weeks' for the 20th Anniversary but there's still time to get involved! We have launched a campaign page on Just Giving where you can donate or set up a fundraising page: ***www.justgiving.com/campaigns/charity/msatrust/anniversary***

Here are a few ideas of what you could do to be a part of #20in20:

- Ride London 46 mile cycle – 30th July – Contact us by 19th June for a place
- Skydive – any date!
- Tough Mudder – lots of dates to choose from!

Get in touch with the fundraising team for more information: *fundraising@msatrust.org.uk* or call us on 0333 323 4591.

EMMA RUSHTON PRESENTS HER REGULAR ROUNDUP OF YOUR TOP SUPPORT GROUP TIPS

Supporting & Helping each other

Spring & Summer are the seasons when most of our Support Groups are held all around the UK & Ireland. Here, Emma Rushton presents her regular roundup of your top tips so far...


EXCERCISING AT THE HERTFORDSHIRE SUPPORT GROUP

I was lucky enough to attend our North London Support Group earlier this year and met with some our members who had travelled from near and far. There was a lot of lively discussion and information sharing, and one of the key items noted was about fire safety. We were informed that it was a good idea to tell your local fire service that there was someone with a disability living in the house. This was so that should there be an emergency the fire service would be fully informed about the circumstances to which they are attending. You can find your local department easily on this website ***www.fireservice.co.uk/information/ukfrs***, or please do contact us for assistance with this.

Our MSA Nurse Specialist, Katie reminded people at the County Durham meeting that they should make sure any 'odd' symptoms get checked out by their GP. This might be symptoms such as having a ragingly hot head but the rest of your body feeling cold. It's important not to assume that all symptoms are MSA-related so anything unusual should be looked into by your doctor.

One of the members at our West Country-based Devon Support Group shared information on a jacket he was wearing that is adapted to help people that have difficulties with fastening up items or need to take off the jacket when in a wheelchair. The member had found it very useful and it can be purchased here – ***www.disabled-clothing.co.uk/r215-adults-back-fastening-hunter-jackets.html***.

A discussion at the Northumberland Support Group highlighted another useful product that members had recently found - touch sensitive lamps. These can be turned off and on, and the intensity of light can be changed by simply touching the base of the lamp. It was found to be helpful when using a small lamp switch became too fiddly. These can be bought quite cheaply from a number of high street stores such as Argos.

We hold a number of Support Groups across Northern Ireland and Eire and at our Dublin and Sligo Groups they discussed a new product called 'Gloup'. This can be used as a possible solution if swallowing tablets is a problem, if the tablets are not available in liquid form or if you don't like the taste. You simply put the pill on a teaspoon of 'Gloup' and swallow. It can be purchased from a number of online stores. A cheap alternative to help with this could also be to put the tablet on a teaspoon of yogurt to ease swallowing. If you have any further questions about this please contact one of our MSA Nurse Specialists via the office. msa *news*

Support Groups are a great way to meet other people affected by MSA, listen to presentations from healthcare professionals that can support you and meet our MSA Nurse Specialists.

Please contact the Trust's office on 0333 323 4591 or email support@msatrust.org.uk for more details. These groups are subject to change, so please check the Trust's website or ring the office for up-to-date information.

GROUP	VENUE	DATE & TIME
Glasgow	Kilbryde Hospice, Therapy Room 5, McGuinness Way, (grounds of Hairmyres Hospital) East Kilbride, Glasgow G75 8GJ	Tues, 6 June - 1.30pm
Aberdeenshire	Community Room, Tesco's Store, Harlew Road, Inverurie AB51 4SR	Wed, 7 June - 1.30pm
Dundee	Day Hospice, Roxburghe House, Jedburgh Road, Dundee DD2 1SP	Thur, 8 June - 3.30pm
Worcestershire	St Richards Hospice, Wildwood Drive, Worcester WR5 2QT	Thur, 8 June - 11.00am
Oxfordshire	The Girl Guide Hall, Southern Road, Thame, Oxfordshire OX9 2EE	Mon, 12 June - 1.00pm
Kent	Room B028, University of Greenwich, Chatham Maritime ME4 4TB	Thur, 15 June - 2.00pm
Bristol	The West of England MS Therapy Centre, Bradbury House clinic, Wheatfield Drive, Bristol BS32 9DB	Thur, 15 June - 1.00pm
Surrey Carers' lunch	Please contact the Trust office for further details	Thur, 15 June - 12.30pm
West Sussex	Worthing Quaker meeting house, 34 Mill Road, Worthing BN11 5DR	Tues, 20 June - 2.00pm
South Yorkshire	St Peter and St Paul Church Hall, Todwick, Sheffield S26 1HN	Wed, 21 June - 1.30pm
Hertfordshire	Hospice of St Francis, Spring Garden Lane, Off Shootersway, Berkhamsted HP4 3GW	Mon, 26 June - 11.00am
Dublin	St Francis Hospice, Station Road, Raheny, Dublin 5	Wed, 28 June - 1.30pm
County Cork	St Joseph's Church (SMA) Parish Centre Wilton Road, Wilton, Cork	Fri, 30 June - 1.30pm
North London	Southgate Hockey Centre, Snakes Lane, London EN4 0PS	Mon, 3 July - 2.00pm
Cardiff	Ty George Thomas Hospice, Whitchurch Hospital Grounds, Whitchurch, Cardiff CF14 7BF	Wed, 5 July - 11.00am
County Sligo	Saint John's Hospital, Ballytivnan Rd, Ballytivnan, Sligo, County Sligo	Thur, 6th July - 1.30pm
Devon	Baptist Church, High Street, Cullompton EX15 1AA	Fri, 7 July - 2.00pm
County Durham	Chester Le Street Hospital, Day Room, Front Street, Chester le Street DH3 3AT	Fri, 14 July - 1.30pm
Dorset	The Grove, 2 Grove Road, East Cliff, Bournemouth BH1 3AU	Mon, 17 July - 11.00am
East Yorkshire	Etton Village Hall, 37 Main Street, Beverley HU17 7PG	Wed, 19 July - 1.30pm
Lincolnshire	Franklin Hall, Halton Road, Spilsby PE23 5LA	Thur, 20 July - 11.00am
Staffordshire	M & S Wolstanton Stoke, Wolstanton Retail Park, Wolstanton ST5 0AP	Thur, 20th July - 12.00pm
Cornwall	Carnons Downs Village Hall, Tregye Rd, Carnon Downs, Truro TR3 6GH	Thur, 20 July - 1.30pm
Northumberland	TORCH Centre, Corbridge Road, Hexham NE46 1QS	Wed, 30 Aug - 11.00am
Hertfordshire	Hospice of St Francis, Spring Garden Lane, Off Shootersway, Berkhamsted HP4 3GW	Mon, 4 Sept - 11.00am
Shropshire	The Lantern, Meadow Farm Drive, Shrewsbury SY1 4NG	Mon, 4 Sept - 1.30pm
Surrey Carers' lunch	Please contact the Trust office for further details	Thur, 7 Sept - 12.30pm
Oxfordshire	The Girl Guide Hall, Southern Road, Thame, Oxfordshire OX9 2EE	Mon, 11 Sept - 1.30pm
Southport	St James Church Hall, Lulworth Road, Birkdale PR8 2BQ	Thurs. 14 Sept - 2.00pm
Lancashire	Grimsargh Village Hall, Preston Road, Grimsargh PR2 5JS	Fri, 15 Sept - 1.30pm
Leicestershire	Village Hall, Main Street, Swannington, Coalville LE67 8QL	Tues, 19 Sept - 11.00am
South Yorkshire	St Peter and St Paul Church Hall, Todwick, Sheffield S26 1HN	Wed, 20 Sept - 1.30pm
Surrey	Shalford Village Hall, Kings Road, Shalford GU4 8JU	Thurs, 21 Sept - 2.00pm
Bristol	The West of England MS Therapy Centre, Bradbury House clinic, Wheatfield Drive, Bristol BS32 9DB	Thur, 28 Sept - 1.00pm

20TH Anniversary Roundup

Multiple System Atrophy Trust
20th ANNIVERSARY

Our 20th anniversary events continue to bring us all together and inspire…

We started our year with a lovely party at the Leicestershire/Midlands Support Group. Alison Parish, our Support Group Leader, informed local journalists and we were filmed on the day by BBC News - Health, for 'East Midlands Today'. Our thanks to all the people with MSA and carers who were so willing to speak and be filmed. Sadly, Alison's Mum had recently passed away from MSA at Christmas, so our heartfelt thanks to her in carrying on with the event and preparing a delicious lunch for everyone who attended. She has also been successful in getting her local open gardens scheme to choose the Trust as its charity of the year for their big event day on 9th July. What a fantastic effort Alison, it is much appreciated.

We also took part in the Superhero Run in May, which took place in London's Regents Park. Participants included 'superheroes' that have been affected by MSA and you may also recognise some faces from our staff team who puffed their way round to raise funds. As already mentioned, Sarah's Wood will launch in June and is dedicated to people with MSA, their carers and families. Pictures and a report will be in your next MSA News.


SUPERHERO RUN

Take a look at the other events available on our '20 events in 20 weeks' section of our website - www.msatrust.org.uk/get-involved/20th-anniversary. We will also be updating our Facebook and Twitter with events. msa *news*

LEGACIES

One of the greatest gifts our supporters can ever give is to remember us in their Will. A legacy ensures we can continue both our work to support all who are living with MSA and our research efforts to find a cure.

The work of the Trust relies entirely on donations. Gifts from Wills form an essential part of our income and we simply couldn't carry on doing all our work without them.

In the last financial year, the Trust received notifications about several legacies. This generosity has enabled us to secure three year funding for our ABN MSA research fellow and begin planning for a further research grant round.

Remembering the Trust in your Will means that in the future we can continue to help more people affected by MSA, and also commit further funding to our key goals of both finding a cause and cure for this devastating condition. Please contact our Fundraising Team at the office via email or telephone to find out more, or request your copy of our legacy pack to help you decide how you might like to leave a gift to MSA Trust. msa *news*

A *warm welcome* to our new Trustee

At our Board meeting in March 2017, we were delighted to welcome Professor Niall Quinn as a new Trustee. Professor Quinn has been a wonderful supporter of the MSA Trust for many years giving his expertise on our research panel and lately our Scientific Advisory Panel. He has recently retired from clinical practice so it is fantastic that we have been able to add another renowned expert on MSA to our Trustee Board.


PROFESSOR NIALL QUINN

A short biography of Professor Quinn is given on our website, but to outline here; Niall has been a specialist in movement disorders for most of his 40-year career with a particular interest in MSA. He has written countless articles and delivered many lectures on MSA to colleagues and students around the world and significantly, helped to devise the first set of diagnostic criteria for MSA in the 1980's.

In the article below, Niall shares with us a short update on a recent meeting in Innsbruck which he attended and where he gave the keynote lecture.

17th Meeting of the European Federation of Autonomic Societies (EFAS), Innsbruck, 16-17 February 2017

Autonomic failure (AF – cardiovascular or urogenital) is a feature of all patients with MSA. Hence the EFAS meeting included a session on AF at this meeting.

Niall Quinn (London) delivered a clinical overview of the many faces of MSA.

Dr Stankovic (Belgrade) presented an overview of results of studies of potential biomarkers from blood or spinal fluid (CSF) that may help differentiate, potentially at a very early stage, between MSA, Parkinson's disease (PD), and other atypical parkinsonian disorders.

Alessandra Fanciulli (Innsbruck) dealt with diagnosis and prognosis of cardiovascular AF, and Horacio Kaufmann (NYU, New York) presented therapeutic advances in cardiovascular AF in MSA, including Atomoxetine, a noradrenaline transport inhibitor, which will be investigated for potential effects on orthostatic hypotension.

Professor Madersbacher (Innsbruck) addressed the other axis of AF, namely bladder dysfunction, in MSA and PD. Among other treatments he talked about Mirabegron, a beta-3 adrenoceptor agonist that increases bladder relaxation and helps detrusor muscle overactivity, and intravesical botulinum toxin injections which can help the overactive bladder.

Nadia Stefanova (Innsbruck) described preclinical models of MSA in transgenic mice in which her group have identified increased alpha-synuclein in substantia nigra and increased microglial (inflammatory) activation in striatum. Possible treatment approaches in this animal model are targeting alpha-synuclein and/or neuroinflammation.

Finally, Florian Krismer (Innsbruck) reviewed the seven completed interventional trials of possible disease-modifying treatments in MSA, all but one of which have had negative results, and examined why they failed. One particular reason was the fact that, for this rare disease, not enough subjects were entered into the trials (4 of the 7 had insufficient participants) in order to definitively conclude whether the intervention was useful or not. This underlines the importance of international collaboration in research on this rare disease. msa *news*

Raise a cup *for MSA*

World MSA Day is the **3rd October 2017** and we're once again asking if you can hold a **M**ilk, **S**ugar **A**nd **T**ea party to mark it.

Whether it's a tea party in the community, a garden party with family and friends or a cake sale at work or school, we'd love it if you could help us raise vital awareness and funds to support the work of our MSA Nurse Specialists. We aim to recruit our 4th Nurse in the Autumn so holding a Tea Party would be a great way to celebrate this achievement!

Or why not raise a cup to mark the 20th Anniversary of the Trust, perhaps with a cake for the occasion? Our Leicestershire Support Group held a party after their meeting in March and our Essex Support Group had a great cake and tea party at their meeting in April.

*So if you'd like to hold a **M**ilk, **S**ugar **A**nd **T**ea party on World MSA Day (or any other date for that matter) then send back the slip below or email **fundraising@msatrust.org.uk** to order your pack today!*

*I would like to hold a **M**ilk, **S**ugar **A**nd **T**ea party and order my pack*

Name:..

Address:..

....

Telephone:..

Email:...

When will you hold your tea party? 3rd October / Other:...

Tell us a little about what you are planning?

*Please return slip to **MSA Trust, 51 St Olav's Court, Lower Road, London SE16 2XB***