msa *news*

MSA Trust Members Magazine | issue 52 | June 2018

GLOBAL RESEARCH CONGRESS
New York

Getting away from it all
Top tips for travel

Looking after *yourself*

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Welcome to issue 52

A very warm welcome to issue 52 of MSA News. As well as some of our regular updates, in this edition we also look at how you might want to think about taking some time for yourself, be that as somebody with MSA or as a carer. We have an article on travelling with MSA including some great examples of how people have visited near and far and how they managed their trips. We also have information on how to access respite care and its benefits, as well as some suggestions on how to broach the often neglected area of emotional wellbeing.

Just recently you may have noticed your bank or other agencies getting in touch to check that you are happy for them to carry on contacting you. This is all part of the General Data Protection Regulation changes (GDPR) which came into force in May. We have changed our processes in accordance with this and continue to maintain our high standard of data protection. If we do contact you from now on we will always give you the option to ask for no further contact, although of course we hope that will not be the case.

Enjoy your magazine and please continue to let us know if you would like any specific issues addressed in future editions.

Emma and Andy – Editors of MSA News. msa *news*

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NEWS ROUNDUP

NHS Information Standard – why we have it

We are accredited by NHS England's Information Standard. This is a certification that proves that our information materials meet a high standard of writing and have gone through a rigorous process to ensure they are accurate, up to date and relevant to our members. You can find out more about the Information Standard here - www.england.nhs.uk/tis. Our User Information Panel reviews all of the new and existing factsheets we provide so if you would like to volunteer on this please do get in touch with us.

Neurological Alliance patient survey

We are members of the Neurological Alliance in England and continue to participate in much of the work they do around promoting support for people with neurological conditions. Every two years the Alliance develops a survey to assess how well people are managing with their condition. The Trust uses this (anonymised information) to compare and contrast the circumstances and experiences of people with MSA with other neurological conditions and also over time periods to see if things are getting better or worse. The next survey is due to be launched later in the year so please look for its announcement on our website and social media channels as we would really like as many people to help out with this as possible. Please call the office if you would like further information.

MSA Candlelight

MSA Candlelight, formerly Service of Light, was held in Leeds last month. This year's memorial event saw poem readings by members, music from a local choir and an update on MSA research by our Trustee, Professor Clare Fowler. Candles were lit for those lost to MSA and their names were included in our Book of Remembrance. Candles were also lit on behalf of those who couldn't attend and who wanted their loved ones to be remembered. More than £4,000 was raised in memory of loved ones, and this money will go towards funding research into MSA.

Sir Roger Bannister and Elizabeth Brackenbury

We are sad to announce the deaths of two of our loyal and much loved supporters. Elizabeth Brackenbury, our founder Sarah's sister, was one of the Trust's initial Board members and started our very first Support Group, which is still running today. Roger Bannister, whilst not only being well-known for his athletic achievements, was a renowned neurologist who had an interest in MSA. He was our patron for many years and worked hard to raise awareness of the Trusts work. Both will be sadly missed and we send our heartfelt condolences to their families and friends.

Trust Partnership with DWP Home Visiting Service

We know how confusing the benefits system can be and how difficult some of the forms are to fill out. However, claiming the right benefits can make a big difference in managing financially and given these are entitlements, it is important to claim what's yours.

The Trust has recently strengthened our benefits expertise and also signed a partnership agreement with the DWP Home Visiting Service. This means that if you need help completing forms we can arrange for a visiting officer to come to your house to run through entitlements and complete the forms on your behalf.

If you need this service please contact the office and we'll discuss this with you. msa *news*

6th MSA International Research Symposium, New York

In February, over 300 delegates gathered in New York to discuss the latest updates and findings regarding MSA research around the globe. The conference covered a wide spectrum of research and we were delighted to see so many researchers and advocacy groups in attendance. Reporting on the event are Professor Clare Fowler (Chair of the Trust Board) and Professor Niall Quinn (a global expert on MSA and another of our Board members). Both attended the conference under their own steam, and we are grateful to have their joint report:

“The first day included an entire session focused on potential treatments. This was probably the first time it had been possible to include so many treatment trials which is a hopeful indication that research into MSA is becoming more prominent.

Particular attention has been directed at trying to “neutralise”, by active or passive immunisation with antibodies, the abnormal misfolded alpha-synuclein protein in the brain in MSA. This would be by preventing its accumulation and spread or by degrading it. However, very little antibody gets into the brain, so it is uncertain whether, or to what extent, this approach will work. Another current approach is to screen hundreds of small molecules in order to find one or more that will counter the toxic alpha-synuclein. The results of a trial of stem cells introduced into the cerebrospinal fluid by lumbar puncture were introduced.
In an open-label trial (where both researchers and participants know which treatment is being administered) in 24 MSA patients at

the Mayo Clinic in Rochester, USA. The treated patients' disability scores worsened at a slower rate than seen in another MSA trial several years ago testing the antibiotic, Rifampicin. Encouraging, but inconclusive. The real test will be whether a planned double-blind randomised trial will be able to confirm these preliminary results.

Since MSA is commonly diagnosed sometime after symptons arise, much attention is currently being directed at reaching an earlier diagnosis. A proportion of patients presenting with pure autonomic failure (PAF) with postural hypotension or bladder symptoms, or with rapid eye movement sleep behavioural disorder (RBD), will turn out to have MSA. Prospective follow-up studies are aimed at differentiating between Lewy body alpha-synucleinopathies (Parkinson's disease (PD), dementia with Lewy bodies (DLB)) and MSA at the very earliest stages.

A number of biomarkers are being investigated for their potential role in early diagnosis of MSA. Apart from that, the existing clinical diagnostic criteria for MSA, (which Professor Quinn played a leading role in establishing), has been identified as needing revision and work on that has started.

It is heartening to hear this summary of the conference from Clare and Niall who write - "This latest Congress was remarkable for a new sense of optimism that we are beginning to make real inroads into the molecular pathogenesis of MSA, and in developing promising treatments for the disease.

msa *news*

For further information about the conference please follow this link to an article written by the Chair of the 6th International Congress highlighting key points from the event - **ow.ly/tNzV30jT5r2**

Research Focus

Last year the Trust opened another round of applications for funding for research projects that would further our understanding of MSA. Following an independent review of each application, our Scientific Advisory Panel, led by the expert guidance of its Chair, Professor David Burn, recommended the following studies for funding over the next three years. In total we will award £375,000 to these projects and updates on their progress will be included in future MSA News editions.

PROJECT 1

Understanding selective brain regional vulnerability in MSA

***Project lead – Janice Holton**, Professor in Neuropathology, UCL Institute of Neurology.*

This research will use brain tissue donated by MSA patients after death, and state of the art technologies to investigate whether alterations of the DNA found in all cell nuclei contribute to the susceptibility of nerve cells in different brain areas. DNA provides the code for cells to make individual proteins and it is known that changes to the DNA influences the activity of genes leading to changes in the amount of protein produced from the DNA code.

Work has already been carried out to identify the differences in the brain DNA of MSA brains compared to controls. The next part of the work is to analyse this information and to identify genes which are altered in different brain regions in MSA.

It is hoped this project will help researchers understand what goes wrong in brain cells in MSA. The scientific panel were impressed by this very innovative research.

PROJECT 2

Identification of Longitudinal Biomarkers in MSA

***Project Lead – Henry Houlden**, Professor of Neurology and Neurogenetics, The National Hospital for Neurology, Queen Square, London.*

The mechanism that causes the death of brain cells in MSA is not known, but we know that the accumulation of an abnormal protein called alpha-synuclein in one type of brain cell is the hallmark of MSA. In this project the researchers plan to study different molecules that are part of the processes involved in causing MSA. The identification of accumulation or lack of such molecules can be used to find more reliable and earlier diagnosis or to assess response to treatment.

Initially the researchers will measure the abundance or the lack of these molecules from the fluid that surrounds the brain in MSA patients and compare them with healthy controls and other neurodegenerative diseases.

Identifying markers in easily accessible fluids and validating in blood samples will potentially reveal important clues on the cause of MSA and in combination with clinical and imaging analysis improve our ability to diagnose MSA early, monitor progression and response to treatment trials. This approach is complementary with the research of our MSA Research Fellow and will be important for MSA patients and those with other degenerative conditions in the future.

PROJECT 3

A multimodal imaging study to improve initial diagnostic accuracy for MSA

***Project Lead – Nicola Pavese**, Professor of Clinical Neuroscience, Newcastle Magnetic Resonance Centre & Positron Emission Tomography Centre, Newcastle University.*

A quicker diagnosis of MSA would help patients through earlier, more focused and disease-specific management and better the co-ordination of the multidisciplinary approach required.

Unfortunately, the initial symptoms of MSA are often difficult to distinguish from the initial symptoms of Parkinson's disease and this can cause delay in the diagnosis of the disease.

This project will aim to use a variety of brain scans, including a recently developed MRI method, to study the earliest brain abnormalities that occur in patients with MSA. This knowledge could potentially allow us to diagnose MSA earlier. It could also help identify areas in the brain which could be targets for future drug research in MSA. msa *news*

Heads Together

Recent research by Rare Disease UK indicates that rare disease patients and carers report a huge emotional impact through being affected by the condition. In addition, if it is progressive then this may also impact upon their mental health.

To read the research in full follow this link: www.raredisease.org.uk/our-work/living-with-a-rare-condition-the-effect-on-mental-health.

This research also points to the lack of recognition by many Health and Care professionals of the emotional aspects of managing rare and complex conditions. This is reflected in the fact that many people affected by conditions such as MSA, including carers, are never asked about their mental health during interactions or consultations.

There may be many reasons for this but there is evidence to suggest that where discussion about emotional wellbeing does take place, and is handled sensitively with genuine concern, then this can be of significant benefit.

You should not, however, feel reluctant to raise this issue with health professionals you come into contact with.

The mental health charity MIND has launched an initiative which they are calling 'Find the Words'. This aims to encourage people to talk about how they are feeling with their GP so that the appropriate help can be provided before things become overwhelming.

They give some very helpful suggestions on how to go about having the conversation, including perhaps asking for a longer appointment. Some key things they advise are:

- ***Be honest and open***
- ***Focus on how you feel, not on whether or not you meet a diagnosis***
- ***Try to explain how you've been feeling over the past few months or weeks, and anything that has changed***
- ***Use words that feel natural to you – you don't have to say specific things to get help***
- ***Try not to worry that your problem is too small or unimportant – everyone deserves help and your GP or practice nurse is there to support you.***

Depending on your circumstances your GP may be able to:

- ***make a diagnosis***
- ***offer you support and treatments (such as talking therapies and medication)***
- ***refer you to a mental health specialist***
- ***recommend local support options.***

The Trust also has details of how to find a local counselling service on our website at this link **www.msatrust.org.uk/support-for-you/key-contacts**.

And remember that a lot of what you do to look after yourself will be during your day to day life – not just healthcare appointments – so it's always worth thinking about what helps you feel better in general. This might be getting out and about with family and friends. The website **www.disabledgo.com** has a wealth of information about accessible locations, such as restaurants, shops, hotels or museums and theatres, and includes the ability to search within a particular postcode or region.

Finally, the Trust has a leaflet on complementary therapies which many people find very beneficial and relaxing. Visit our website or call us at the office on **0333 323 4591** and we'll get a copy sent out to you. msa *news*

TRAVELLING AND MSA - ARTICLE BY MSA NURSE SPECIALIST, KATIE RIGG

Anchors away

We are approaching the time of year when the weather allows us to make the most of being outdoors and maybe travelling both near and far. Holidays are invaluable to all of us, they provide a change of scene, refresh us, provide an opportunity to have a break from usual routines, meet people and try new experiences. The whole point is to relax and enjoy a holiday so it is important not to arrive at your destination so exhausted and stressed it takes you the whole holiday to recover and then you repeat the process to get home!

Deciding where to go on holiday can be a tricky decision for everyone in the family to agree on. Planning is always necessary to get the most out of any break. If you have MSA then that planning is crucial.

Wherever you are thinking of going, it can be helpful to make a list of all the pieces of equipment and aids you use to make daily life manageable. When you start to explore location options do ask which, if any, of the aids are available for your use during your stay. If there are things you need that are not provided ask if they are able to access these and have them available for you – there may be a cost involved, but better that than not being able to manage comfortably. If the venue can't access what you need is it possible to take your own with you? It could also be possible to hire from the Red Cross or a local supplier in the area you are visiting.

Make sure you check with the venue that your room is on the ground floor with level access or easy ramp access out and about where possible.

Ian and Jackie Pickford have continued to enjoy many holidays following Jackie's diagnosis of MSA. Read some of their helpful tips... ⇢

It is necessary to check that your room has an en-suite with an appropriately accessible bathroom for you. Also, ensure there are accessible facilities to places such as the bar area, toilets, dining areas etc.

If you plan positively and request and accept all assistance that is available you will very likely manage well and arrive at your destination without being too tired to enjoy your holiday. Don't be reluctant to make full use of all the assistance available. Whether travelling by train, boat or airplane there are designated staff to assist people but this needs to be booked in advance of your travel. Equally, if you use a wheelchair but are not taking your own, it is wise to book a wheelchair with the travel provider or hire one to take with you.

Many people with MSA are tempted to persevere and try to manage without using their walking aid. The problem with this is that the distances and surfaces to be covered are not predictable. Also, if you turn up at security not having requested assistance it is assumed you can manage to remove shoes, belts, and unpack hand luggage unaided. You may also be expected to stand still with your arms above your head unsupported for some time in the security x-ray machine. The staff in these areas are under enormous pressure and do not have the capacity to assist people appropriately. If you have booked assistance you will have a designated person to take you through security and get you up on to the plane.

Whatever the type of holiday you are considering you need to include

TRAVEL TIPS

BE POSITIVE

Travel with a positive outlook, accepting that things won't always go to plan. Being stuck in a mini-lift with a lift engineer in the middle of Serbia, carried up a long spiral staircase by four waiters in St Petersburg or being lifted Sedan Chair style up a flight of steps by four burly sailors on the edge of the Danube was much more fun than everything running to our previous perceptions of 'ideal'.

PREPARATION

We have sent bulky items in advance on recent trips such as a large bag with a Rollator and folded perching stool. We used 'theBaggageMan' company who collect the items about a week before we go and when we arrive the bags are waiting in the room for us. This helps reduce what you may need to carry through the airport, train or ferry terminals. We always check in through special assistance at airports when available. Often they will help us jump the queue for security or passport control and are essential to board or unload from the aircraft. Don't forget to insist that the chair must be at the aircraft door on arrival – we always say that we will not be able to get off the plane without it!

PACKING

We all know the frustration of packing for two. We've carefully gone down the packing list making sure everything's in and here we are in the hotel with shirts, pants, trousers, blouses and pills all over the place – there has to be an easier way! One thing we do is pack groups of items separately in zip bags. Plastic bags would work but we tend to have a load of 'packing cubes' available. These are lightweight zipped net bags – Blue for Jackie, black for Ian, green has all the medical stuff and red for chargers, iPads etc.

PERCHING/SHOWERING STOOLS

These seem to be the bane of our lives when travelling – so simple to provide and yet all too often, not! With a bit of badgering (and that all important smile) hotel management will find something suitable. If not, early in our stay we go to the local market and buy a cheap plastic stool. At the end of the holiday, we leave it for the hotel – our gift to them!

RISK ASSESSMENT

We always have a laugh when we arrive somewhere new – even in the UK – as Ian goes in and does what he calls a 'risk assessment'. What's the easiest way in? Do we need to get a ramp put out? Is there an accessible loo? Ian will quite happily open double doors, rearrange the furniture, put a chair out ready for Jackie to transfer into, put a portable ramp in place etc. Of course for the lone traveller this may be more difficult but then resort to the internationally accepted currency, a big wide smile to get the help you need!

BE CONTENT

Finally, we always travel with an attitude of 'we will do what we can'. People around us sometimes fuss – will you be able to get over the cobbles? How will you cope with that steep path? Will the wheelchair be able to get into the museum? We tend to ignore all this and just 'do what we can'. Half an hour having a coffee on our own whilst the group go around the museum without us is far better than half a day of worrying with special arrangements being made etc. We enjoy every moment travelling, every day together and with a bit of preparation we hope others can too.

in your hand luggage a letter from your Consultant – the last clinic letter may be enough; emergency contact numbers of family, GP, MSA Nurse Specialist; your current prescription list and enough medications for a week. If you use catheters or other continence products for bladder management then keep a spare supply of these to hand too. Often airlines will allow people to take an extra hand luggage bag to be used for medication or equipment so contact your airline provider about this option.

Trying to second guess how you may feel and whether you will be infection free by the time you reach the planned date is never possible. However, if you are prone to urinary tract infections discuss this with your GP before you go away. They may be able to give you a supply of antibiotics, just in case you start to experience symptoms.

Lastly, always ensure your travel insurance is up to date. There is a list of insurers other people with MSA have used in the 'Travelling and MSA' factsheet available from the Trust.

Here is wishing you all a happy summer however, and wherever, you choose to spend it! Do send us pictures we can use to inspire others and show not only that it can be done but that you can have a great time. msa *news*

IAN & JACKIE ENJOYING A RECENT TRIP

Research Update

The latest from Viorica Chelban, ABN MSA Research Fellow

Our MSA Research Fellow, Viorica Chelban, has been busy over the past few months. Here we give a brief summary of what she has been up to:

VIORICA CHELBAN

- Viorica presented a teaching course on MSA at Addenbrookes hospital in Cambridge for all the neurologist specialist trainees from the East of England region. Approximately 30 neurologists-in-training attended the event. Hopefully this will raise awareness amongst young specialists and improve the quality of care that people with MSA receive in hospitals.
- Viorica's study into wet biomarkers is going well. The study has completed 29 Magnetic Resonance Imaging (MRI) scans so far and will soon start an analysis of some of the imaging data. Hopefully there will be results to share at the end of the year. Viorica thanked the Trust for extending the funding on the imaging, as this will allow for the follow up of patients for at least two more years.
- Recruitment continues for the Prospect-M study and this means numbers are reaching a very good level. The Trust will continue to reach out to people with MSA through the website and on social media to add to those numbers for as long as possible. If people want to join please call Viorica on 07825 076394.
- Viorica also supports Professor Henry Houlden, her study supervisor, in his MSA research and was pleased to report that Professor Holden has been successful in getting MSA included in the 100,000 Genomes England (GEL) project for whole genome sequencing. This will be a great resource for genetic studies in the future and gives MSA a similar research significance profile as diseases such as Alzheimers, other types of dementia and Parkinson's Disease. Viorica has met with the GEL team and provided them with all the information they need in order to start recruiting people with MSA through their established protocols. msa *news*

In Memory

Halina Wojtowicz
Unruen Burns
John Dunne
Eleanor Quinn
Denise Alcock
Michael Collins
Phyllis Golding
Melville Dunnett
Jean Twiddy
Brenda Ridley
Caroline Parker
Christopher Byrne
Stacey Bareham
Roger Fudge
Peter Aitchison
Bryan Fisher
Michael Fenwick
Robert Gamewell
Linda Chilvers
Dave West
John Hindmarsh
Jacqueline Doyle
Gill Eastburn
Brian Chalcraft
John Clark
Reg Walters
Joyce Drummond
Diana Street
Kevin Donal
Bernard Browning
Kevin Bowles
Wellesley McCullough
Christopher Taylor
David Brookman
Denis Corton
Margaret Clark
Malcolm Cooper
Dennis Hall
Paul Campion
David Abel
Jonathan Rogers
Chris Blake
Graham Dennis
Kenneth Ott
Roy Wood
Anthony Cooke
Michael Taylor
Margaret Byfield
David Rose
John Liddicot
Bruce Blair
Jean Spence
Stefania Husak
David Edmonds
Maureen Lloyd

Ensuring the memory of Eric Armitage lives on

Angela Armitage and her late husband Eric started fundraising for us after his diagnosis in 2007. In February this year, we announced that Angela's fundraising had reached a staggering £50,000. Obviously, this took great determination so how did she reach such an astounding amount?

Angela told us that they seized every opportunity to contribute to the total such as asking for donations at wedding anniversaries and birthdays, selling handmade jewellery and Angela giving Reiki sessions in return for a donation. They organised popular fundraising days, like the Mandarin Masquerade Charity Ball and a Summer Fair in a local park in Oldham, which the Mayor of Oldham, Olwen Chadderton attended. One interesting fundraising idea was to ask the Mayor if she could include the MSA Trust in their vision statement and the Oldham Mayor Charity Appeal. The Mayor kindly donated £500 from her appeal fund and a further £1,500 was donated by Lord Mayor of Manchester, Elaine Boyes. Angela felt this was an easy way to support the Trust and you can perhaps do the same - just call or write to your local Mayor and ask them to support us. Every year the mayor changes so there are numerous opportunities. It is also great for raising awareness of MSA within the local community.

Eric sadly passed away in 2015 but Angela has continued his legacy of fundraising for the Trust. She continues to organise volunteer fundraising collections in local shops such as ASDA, Morrison's and Sainsbury's, whose many branches run a scheme letting them have a collection for the Trust. Angela would like to share her knowledge and experience from these events so if you are thinking of doing one yourself, email **fundraising@msatrust.org.uk** and we will put you in touch with her. Whilst we value all contributions to our work, no matter how small, we would like to take this opportunity to thank Angela, and her family and friends, for such a phenomenal effort. The funds raised will go a long way in helping reach our vision of a world free of MSA. msa *news*

AN ARTICLE BY MSA NURSE SPECIALIST, EMMA SAUNDERS

The Power of Hugs, Cuddles *and* Love

Our newest member of the MSA Nurse Specialist team, Emma Saunders, explores a sensitive but important topic for people affected by MSA.

A diagnosis of MSA may affect your relationship with your partner if you have one. It can take time for both of you to come to terms with the changes that MSA can bring and how the future you may have planned together has taken a different direction. Sex is an important part of life for many people, and sexual problems can be a concern. However, sexual problems can be overcome or other forms of intimacy and togetherness can be found.

Anxiety, fear, tiredness and depression can all affect how you are feeling generally, and other conditions and medications can also affect sexual function. Fatigue can also have a significant impact on sexual desire and you might feel you simply do not have the energy. This can sometimes be misinterpreted by a partner who may come to think that you are no longer interested in sex or intimacy. It is important to discuss these feelings. If tiredness is an issue try being intimate at a different time of the day, when you are more alert.

For some people, the enormity of their diagnosis can affect their whole emotional life, sex life included, whilst for others the sexual side of their relationship may become less important. Some people find other shared activities and time spent together becomes more

AN ARTICLE BY MSA NURSE SPECIALIST, EMMA SAUNDERS

rewarding.

When your partner is also your main care provider, they may find it difficult to shift between the roles of carer and partner. You might also find it difficult to switch from being 'cared for' to partner. Completely separating caring activities from sexual or romantic activities can help. There may also be some caring tasks that you would perhaps prefer paid carers to carry out. The physical and emotional aspects of being a carer can also affect energy levels and libido. Our Carers Guide contains more information on how carers can look after themselves and the person they are caring for.

Physical intimacy is an important part of many relationships. Some symptoms may make it more difficult to be spontaneous, but touch is an essential part of being human and you can experience this, whatever your physical condition.

The best relationships are built on honest, open communication. Allow time to talk through your worries together, when you are not overtired or likely to be disturbed. Once you have had a discussion about each other's needs, keep this going.

MSA can affect all types of communication – verbal, written, and facial expression, but it's important to keep talking as much as possible so you know what the other person is thinking and you can understand one another.

MSA causes autonomic dysfunction and occurs when the nerves that control involuntary bodily functions are damaged. Sexual dysfunction can be an early symptom due to these changes. For men this can include erectile and ejaculation difficulties, impaired sex drive and reduced libido. In women it can include difficulties with reaching an orgasm, pain during sex, vaginal tightness, loss of lubrication, impaired sex drive and reduced libido.

Medication for problems with erectile functioning are available. These include oral medications, taken as a tablet, and non-oral therapies that include gels and injections. Some men with MSA may find these medications effective. Unfortunately, there is less research into treatments for sexual dysfunction in women, and no medications are licenced. Women may find the use of lubrications, or other factors such as being relaxed and in a comfortable position, helpful.

It is recommended that you see a Specialist for advice before starting on any treatment for sexual dysfunction. They will undertake an individual assessment and consider factors such as other medications, side-effects and most appropriate treatment. Medications can cause blood pressure to drop, so this and other side-effects need to be considered. For this reason, it is not recommended that medications be bought online or over the counter, but used only on the recommendation and advice of an appropriate specialist. Specialists are experienced in working with both individuals and couples, and are sensitive to the needs of people from varying cultures, backgrounds, sexual orientation and genders. Referrals to local services can be made by your GP, or in some cases by the Consultant you see for MSA.

Therapy services can offer an opportunity to talk about sexual issues. Many psychosexual therapists are also relationship therapists and can address both the practical problems you may be experiencing and help with any emotional or relationship difficulties. They can help people who are struggling to adapt or communicate.

Most health care professionals understand sexual issues and will discuss these with you. But they might not wish to be intrusive, so they may expect you to raise your concerns with them, rather than take the lead themselves. Similarly, Neurologists, Urologists and Nurse Specialists will be experienced at discussing sexual issues in an appropriate way and will put you at ease. They can also act as a liaison between other health and social care professionals to make sure your needs are met. msa *news*

Our factsheet on Relationships, Sex and MSA goes into more detail and lists useful contacts and sources of further information. This can be downloaded on our website or is available from the Trust office.

FUNDRAISING STARS

A ROUND UP OF YOUR LATEST FUNDRAISING STORIES

Lace up those trainers

__London Marathon__ was a hot one this year, but that didn't stop __Julian, Tani, Elissa, Andy, Matt, Lisa and Kieran__ from crossing the finish line! Their fundraising reached more than £23,000 this year - well done Team!

__Kirsty Rayner__ wanted to support her Dad, who is living with MSA, by taking on the __Brighton Half Marathon__. Kirsty raised a total of £280.

__Julia, Steve and Claire__ did the 'Run for Mum' in memory of Julia's mother. Julia took on the __Southampton 10k__, whilst Steve and Claire did the __Southampton Half Marathon__. Together, they raised over £2,000.

Our supporters, __Jaclyn, Anita & Alex__ took part in the __Brighton Marathon__ this year and raised close to £4,500. Here is a photo of Jaclyn in action.

__Peter Dunn__ ran the __Greater Manchester Marathon__, in memory of a dear family member. Peter raised close to £600 to support our work.

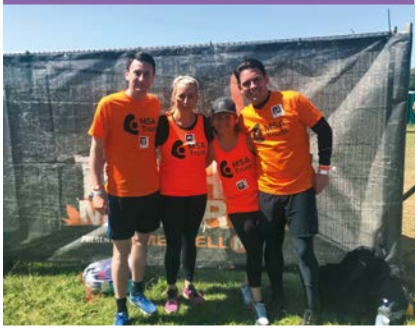
Well done to __Derek Lambert__, who has a diagnosis of MSA, and his daughter, __Kym__, for running in the __Great Midlands Fun Run__.

A big team of Trust supporters will be taking part in the **Great North Run** on **9th September**. If you managed to gain a ballot place, contact us to join the team at **fundraising@msatrust.org.uk**.

Get Active for MSA

Sarah Hayward and her sister organised a fundraising **Zumbathon** session that 65 students attended. They were able to raise more than £450 and the event was so successful, that Sarah is planning an Aqua Zumbathon next!

Candice Derby, her brother and their partners took up the popular **Tough Mudder challenge** in memory of Candice's father. They raised over £600 from this 12-mile Obstacle course – great work!



In the Community

Jodie Owens and family and friends organised a Charity Dinner to support **Keith Spratt**, who has MSA. £1,500 of the proceeds went to the Trust and we are so pleased with the effort they all made.

We started off the year with our very first **Dry January Campaign**, asking supporters to take a whole month off from alcohol. This raised a terrific £1,700 - cheers!

Let's Match It!

If you intend to fundraise for the Trust and work at a company, why not ask them about Matched Giving. This is a fantastic scheme that allows companies to match your fundraising amount and double it! We can help by issuing a letter confirming the fundraising or assist with the application.

Sarah Wood first came across MSA when her housemate's mother sadly passed away from it. To support the Trust, back in December, she got her choir together to do a Christmas choir collection at South Bank. She asked her friend Ellie to nominate the Trust for her employers, Lloyds Bank, to match that. This made the collection total a great £256!

Our dedicated community fundraiser, **Joe Cannon**, hosted the Good Friday Catch this Easter – a great night of music and fundraising. Barclays Bank have kindly matched the money raised so the total comes to more than £2,000! Joe is also bringing back his Charity Ball this year. For tickets visit **www.msacharityevents.co.uk**.

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

Supporting & Helping Each Other

Its summer time and our Support Groups are in full flow – We now have 41 groups that usually meet three to four times a year. As well as making friends, members share lots of useful information and experiences and often one of our MSA Nurse Specialists or another healthcare professional will be there too. To see when your nearest Group will be meeting have a look at page 17 then read on for some tips and hints from our recent Support Groups…

Our MSA Nurse Specialist, Katie Rigg, covers Northern Ireland and the Republic of Ireland and makes a visit three times a year to run Support Groups, attend clinics and provide teaching sessions for healthcare professionals. There is a wealth of information shared at these meetings including at the recent Belfast Support Group where they discussed the use of ICE (In Case of Emergency) cards. The cards have a designated social care telephone number written on them and can be carried around by a carer. This means that if the carer is taken ill, social care can be made aware that the person is a carer and there may be a dependant at home. You can find out more about ICE cards here - **www.icecard.co.uk**. Find out further advice on steps you can take if you're a carer and are taken ill through Carers UK - **www.carersuk.org/help-and-advice/practical-support/planning-for-emergencies**.

In the Republic of Ireland the Cork Support Group reflected on the importance of speaking with loved ones about getting Power of Attorney in place and ensuring a Will has been made. Although this is a sensitive topic, the group acknowledged how important it was that prior wishes were known and that the people who know you best have a legal right to act and speak on your behalf. Both Citizens Advice and Age UK provide good information about Power of Attorney processes and how to set this up.

Members at the South Yorkshire Support Group spoke about having some sliding sheets (or even plastic bags) handy in the car to help with getting in and out of vehicles. A member also suggested a company called Neater Eater which makes products to help people that find eating difficult. You can arrange a free assessment with them and find out more at **www.neater.co.uk**.

Linking in with our travelling and MSA article on page eight, holidays are often a topic brought up at Support Groups. At the first Merseyside Support Group they discussed numerous points about holidays including; checking about the hire of medical equipment through the venue or booking agent beforehand, asking if your airline provides a free extra luggage allowance for people with medical needs and also how helpful a folding walking frame can be to travel with. These can be purchased online from many retailers and at relatively low-cost.

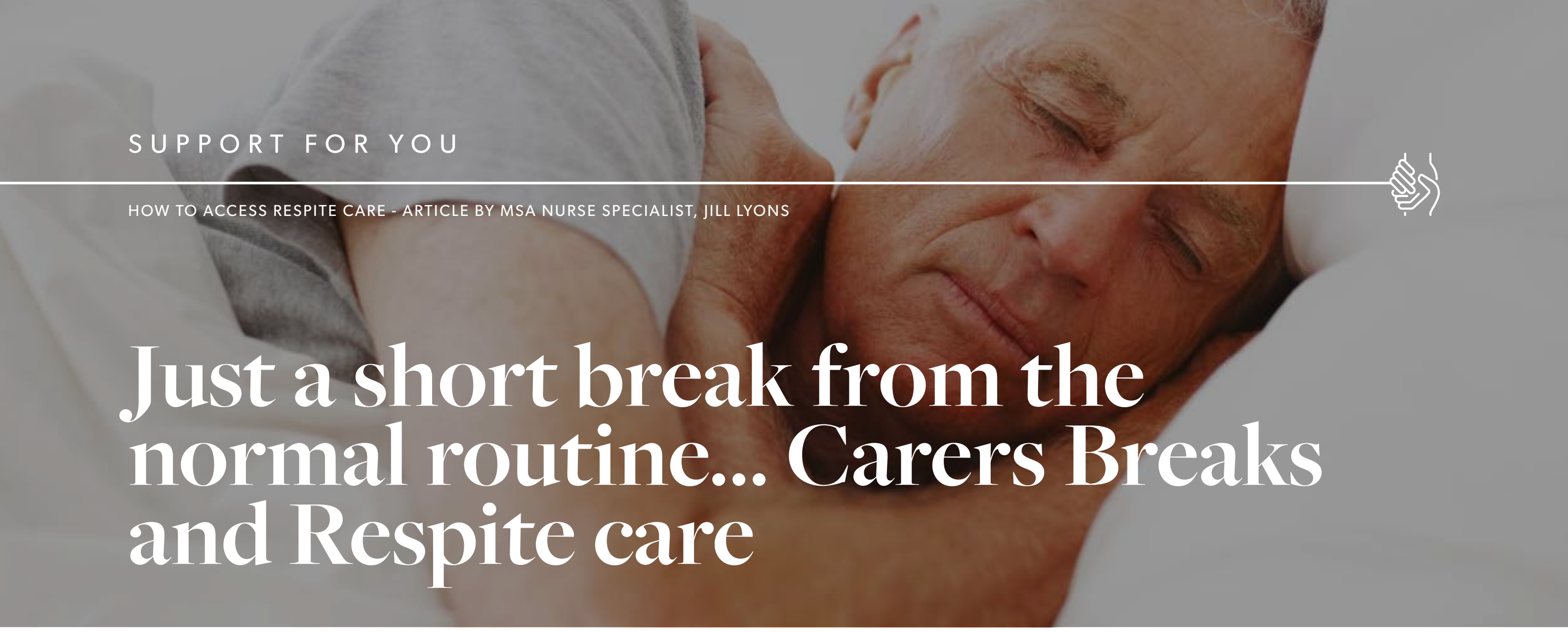
The Norfolk and Suffolk Support Group spoke about Boots pharmacies offering free medicines checks for people that have a long-term condition. They are able to explain exactly what your medicines do, when the best time is to take them and if there are any over-the-counter medicines which you should avoid. Most pharmacies now offer a repeat prescriptions service where they liaise with GP's and let you know when your medication is ready to be collected. msa *news*

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

Support Groups are a great way to meet other people affected by MSA, listen to presentations from healthcare professionals who 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
North London	Southgate Hockey Centre, Snakes Lane, London EN4 0PS	Mon, 18 June – 2pm
South Yorkshire	St Peter and St Paul Church Hall, Todwick, Sheffield S26 1HN	Wed, 20 June – 1.30pm
County Durham	Chester Le Street Hospital, Day Room, Front Street, Chester le Street DH3 3AT	Mon, 25 June – 1.30pm
Dorset	The Grove Hotel, 2 Grove Road, East Cliff, Bournemouth BH1 3AU	Mon, 25 June – 11am
East Yorkshire	Etton Village Hall, 37 Main Street, Beverley HU17 7PG	Wed, 27 June – 1.30pm
Glasgow	Alexandra Court Care Home, 332 Edinburgh Road, Glasgow G33 2PH	Thur, 28 June – 1.30pm
Cornwall	Echo Centre, Barras Place, Liskeard, Cornwall PL14 6AY	Mon, 2 July – 1.00pm
Dublin	St. Francis Hospice Raheny, Station Road, Raheny, Dublin 5	Tue, 3 July – 1.00pm
County Sligo	Therapy Room, St John's Community Hosptial, 8 Ballytivanan Road, Sligo	Wed, 4 July – 1.30pm
South London	St. James Church, Bermondey, Thurland Rd, Bermondsey, London SE16 4AA	Wed, 4 July – 1.30pm
County Limerick	Nurses Residence, Western Regional Hostpital, Limerick	Thur, 5 July – 1.30pm
Scottish Borders	The Old Gala House, 8 Scott Crescent, Galashiels TD1 3JS	Mon, 9 July – 1.30pm
Greater Manchester	Bolton Hospice Day Therapy Unit, Bolton Hospice, Queens Park Street, Off Chorley New Road, Bolton BL1 4QT	Mon, 9th July – 1.30pm
Cumbria	Burton Memorial Hall, Main Street, Burton in Kendal, Carnforth LA6 1NA	Thur, 12 July – 1.30pm
Merseyside	St John the Baptist Church Hall, Forest Road, Meols, Wirral CH47 0AF	Wed, 25 July – 2.00pm
West Yorkshire	Small Hall, Kirkgate Centre, 39a Kirkgate, Shipley BD18 3JH	Fri, 27 July – 1.30pm
Devon	Baptist Church, High Street, Cullompton EX15 1AA	Wed, 1 Aug – 2pm
Lancashire	Tesco Extra branch at Clifton Retail Park, Blackpool FY4 4UJ	Fri, 3 Aug – 1.30pm
Northumberland, Tyne & Wear	St. John's Church Community Hall, West Lane, Killingworth, Newcastle upon Tyne NE12 6BL	Mon, 6 Aug – 11am
North Yorkshire	St Columba's Church, 119 Dean Road, Scarborough YO12 7JH	Thur, 9 Aug – 1.30pm
West Sussex	Worthing Quaker Meeting House, 34 Mill Road, Worthing BN11 5DR	Tue, 14 Aug – 2pm
Lincolnshire	Tesco Superstore, 186 Wragby Road, Lincoln LN2 4QQ	Thur, 16 Aug – 2pm
County Tyrone/ Strabane	Please contact the trust office for details	Mon, 20 Aug – 12pm
Belfast	Marie Curie Hospice, 1A Kensington Road, Belfast BT5 6NF	Tue, 21 Aug – 1.30pm
County Down	Downe Hospital , Primary Care Conference Room 1, 1st floor, 2 Struell Wells Road, Downpatrick BT30 6RL	Wed, 22 Aug – 1.30pm
Cardiff	City Hospice, Whitchurch Hospital Grounds, Whitchurch, Cardiff CF14 7BF	Wed, 5 Sept – 11am
Hertfordshire	Hospice of St Francis, Spring Garden Lane, Off Shootersway, Berkhamsted HP4 3GW	Wed, 5 Sept – 2pm



HOW TO ACCESS RESPITE CARE - ARTICLE BY MSA NURSE SPECIALIST, JILL LYONS

Just a short break from the normal routine... Carers Breaks and Respite care

For many people caring responsibilities can gradually creep up on them without realisation that there is often vital support to give them, and those they love, a real helping hand. This can help both you as a carer and those you care for and we explain here some possible options.

The purpose of carer's breaks are for the carer to look after their own health and wellbeing without compromising the care of those they love. There are different forms of break available. Domiciliary care is where someone comes into your home and takes over the caring role for a few hours a day or perhaps overnight. Sitting services are similar, but do not usually provide personal care (for example, toileting). One example of a sitting service is the Crossroads Care scheme - a network of local, independent charities that support carers and the people they look after, often through the provision of flexible breaks. You can find out more about Crossroads Care and other respite services in your area on the Carers Trust website – www.carers.org. Respite care can also be provided in a residential or nursing home. Respite is really important to help prevent the carer becoming exhausted and unwell themselves and so they can continue to care for longer.

There are a number of reasons why people don't take a break from caring and some of these are considered below.

Some people don't view themselves as a carer and therefore don't feel they need a break.

MSA is a progressive condition and changes generally occur slowly over time, so when does a family member start being a carer? Main carers tend to be family members, perhaps a spouse or partner, a child or a parent. These family relationships are important and people define their relationships in this way and don't want to define themselves as carer and cared for, this is totally right and important. However, at some point the level of care increases. For the purpose of claiming Carers Allowance the amount of time spent caring that defines a "carer" is 35 hours per week (there are 168 hours in any week and some people care a lot more than 35 hours). No nurse or professional carer works 24 hours a day, 7 days a week- they would be too exhausted to care, nor should a family carer.

Some carers feel reluctant to let someone else take over the caring role and some people with MSA don't want anyone else to take over the caring role, as they feel the care wouldn't be as good.

In truth it is likely that no paid carer will be as good or understand the person as well as the family carer particularly if there are difficulties with speech and communication. However, paid carers choose caring as their career because they like working with people, and can bring fresh conversation and interest. When looking for a provider of care ask about keeping the number of carers small so the person with MSA and the family carer can get to know and trust them. The family carer needs to carry on being a good carer and having a break is important, even if it is to sleep.

Can't paying for care be costly?

It is important to talk to your social worker or specialist nurse to find out what carers breaks, respite care and funding are available locally. Local carers groups can advise on this. In the first instance ask for a carer's assessment from your social worker or phone your local authority. Ask them to visit you and the person you care for at home to do the assessment, you can request a needs assessment for the person with MSA at the same time. Alternatively, a carer can have a carers assessment independently without the permission of the person cared for. The following link gives more information about ways of paying for respite care - www.nhs.uk/conditions/social-care-and-support/breaks-for-carers-respite-care.

The Trust has a Carers Guides available for you and our MSA Nurse Specialists are always happy to provide more information. msa *news*

Weddings & an Anniversary!

Following the wedding of Prince Harry and Meghan, weddings have been a hot topic here in the office.

If you have a wedding in the family or are getting married soon, then first and foremost many congratulations! But you may not realise that weddings can provide a great opportunity to support the Trust.

One idea is to accept donations to the Trust in lieu of wedding presents. We can help you create an online page where your guests can donate and leave you personalised messages. We can also send you donation envelopes and tins or buckets to have a collection on the day. If you are thinking of giving wedding favours, we can send you our charity ribbons or you can buy our Wedding Favour Cards. These come in packs of ten and are great for being displayed at place settings or to thank your guests after the wedding. Get the cards online at www.msatrust.org.uk/product/wedding-favour-cards or call us at 0333 323 4591. msa *news*

Sam and Amelia Tant got married in November last year and accepted donations from their guests. Amelia said she felt very blessed to have her father walk her down the aisle just before he passed away earlier this year. They managed to raise more than £3,000 and continue to support us in other ways.

MSA Trust

Thank you for celebrating our special day

or our wedding favours, we've made a donation to a charity hat is close to our hearts **Multiple System Atrophy Trust**

To find out more

www.msatrust.org.uk ☎ 0333 323 4591 support@msatrust.org.uk

20TH ANNIVERSARY

This March marked the end of our 20th Anniversary year. The 20th year was truly a milestone year for us, and with your generous support we have been able to achieve a huge amount, including the recruitment of our fourth MSA Nurse Specialist and the Trusts first ever MSA Research fellow.

From supporters and staff taking part in a Superhero fun run to a sponsored Lindy Hop dance event – the 20th year had it all!

We also asked for your contributions through our 20th Anniversary appeal and are delighted that your one-off and regular donations alone has already raised more than £8,500. Thank you so much - this will enable us to continue the best possible support for people with MSA and fund much needed research into the cause and cure.

If you want to continue to support the work of the Trust, why not sign up for a regular donation? Call us on 0333 323 4591 and we'll guide you through the simple process. msa *news*

Sarah's Wood, Thoresby Park, Newark, Nottinghamshire NG22 9EF.

MSA Trust *fundraising events*

On **Saturday 21st July 2018**, we will be holding a summer event at Sarah's Wood, our symbol of hope and strength for the MSA community.

Join us for:

- ***The unveiling of our brand new 'Sarah's Wood' sign***
- ***An afternoon of tea and cake and good company***
- ***Updates on the future of the Wood and information on our winter tree planting days***

Please let us know by **7th July 2018** if you would like to attend, by emailing us at **fundrasing@msatrust.org.uk** or by giving us a call on 0333 323 4591. msa *news*

You can help us mark World MSA Day – Wednesday 3rd October - by holding your own **M**ilk, **S**ugar **A**nd **T**ea party. As well as raising much needed awareness of MSA they are a friendly and fun way of fundraising to support our invaluable MSA Nurse Specialist services. We will help you with advice and provide your tea party pack, just contact us at **fundraising@msatrust.org.uk** or call 0333 323 4591.

Cycling Jerseys
(introductory offer)
£24.99

Fundraising T-shirt
£10

Running Vest
£8 **£6**

Buy them online at ***www.msatrust.org.uk/shop*** , send a cheque payable to MSA Trust or call 0333 323 4591 to place an order. Please include £3 for P&P. For ROI, please contact us for P&P rates.