

MSA SMarT News

The newsletter of the Sarah Matheson Trust

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The Sarah Matheson Trust provides a support and information service to people with Multiple System Atrophy (MSA) and other autonomic disorders, their families and carers, health care professionals and social care teams. We also sponsor and support research into MSA

From the Nurses

We are pleased to enclose our new folder to all our members with MSA. We are delighted in the folder's stylish presentation but remain certain that its contents are of greater importance. It is designed to hold all the information from the SMT with plenty of space to customise it with your individual information from therapists, pharmacists and social workers. We hope that having all this information in one place will make life easier. The folder complements our current leaflets and the bold design means that you should be able to find it easily at home. It is sturdy enough to take to clinic appointments or hospital admissions where we hope staff will begin to recognise the logo and associate it with MSA and the Trust. We are grateful for the generous support of Mr Brian Newman which enabled the production of the folder.



Around 100 people attended the event at the Architectural Association on the 23rd February. The relaxed atmosphere enabled members, researchers, doctors and Trustees to meet and talk to each other. Sir Roger Bannister's presentation was very well received (especially his emphasis on the important role of patient groups) and gave an insight into the history and workings of MSA.

Between the views of French countryside and beautiful architecture Peter Murray's video and commentary managed to leave the audience in awe of his fundraising cycling achievements at the height of the French summer.

Allan Bailey and his band provided wonderful musical entertainment that set the welcoming tone for the evening. Over a delicious supper friendships and alliances were formed that we hope will enable the SMT services to develop. Our grateful thanks go also to the staff of the Architectural Association who supported the event and gave generously of their time and facilities.

Finally, the *Ask the Experts* feature in this edition has only been possible because of the questions provided by you the members and the willing support of the experts who gave their time and thought to their replies. We thought the responses were so good that we have included them all, hence this bumper edition of SMarT News. Thanks to everyone involved. We hope that you learn as much as we did from the feature.

Catherine & Alison

Ask the experts

Answering questions is an integral part of both our daily work. The questions arise from the unusual nature of autonomic disorders and the wide variety of symptoms or how to manage life with a neurological condition. After working with these issues for some time many of the questions we can give a straight forward answer to. However, some questions really make us think. We may need to look for the answer in books or articles or to get the opinions of experts in a variety of areas. We have been fortunate that so many experts over the years have shared their knowledge and experience with us and are happy that we share this knowledge with you.

All of the views and comments from the experts are general and while we know they will be useful it is always advisable to seek further advice from the team involved directly in your care before trying any new intervention.

We are very grateful to all our contributors who have gladly given their views; it is really encouraging that so many professionals are so interested in improving the lives of people with MSA.

Catherine & Alison

Q As a neurologist what is the biggest challenge in MSA?

■ Starting with the easy question! This has got to be finding the underlying cause. We are lagging behind other conditions like Parkinson's disease and Progressive Supranuclear Palsy in finding out clues as to why people might develop MSA. There does not appear to be a straightforward genetic component (although this by no means excludes a genetic predisposition) and because the condition is relatively uncommon, studies of potential environmental risk factors in MSA are extremely difficult to carry out. If we knew more about the cause, it would be easier to devise more effective treatments. *Dr D Burn*

■ The biggest challenge is to provide optimal management of patients which sometimes involves drugs, but more importantly multidisciplinary intervention, in particular support from physio, occupational and speech therapists and from the palliative care movement. *Prof N Quinn*

■ There are a number of challenges in MSA both in diagnosis and management. Making a definitive diagnosis in the early stages can be difficult since there is no one simple test for the disorder. It is important that people have ready access to specialists in order that an accurate diagnosis can be made as soon as possible, recognising that a number of visits may be necessary before the diagnosis can be confirmed. This is crucial in ensuring management is sign-posted and co-ordinated involving members of the multi-disciplinary team from an early stage.

With respect to management one of the biggest challenges is to develop more effective symptomatic therapies for the stiffness and slowness in MSA and for the blood pressure and bladder problems that can occur. Finally, there is an urgent need for an effective treatment that would slow or ideally reverse the progressive damage to the nervous system. *Dr G Macphee*

■ The biggest challenge in MSA is two fold. One is to find the cause of

this degenerative illness which affects the extra-pyramidal, pyramidal and cerebellar systems and the other is trying to find ways we can refine and improve the quality of lives of people with MSA and their caregivers. *Dr R Chaudhuri*

Q As a neurologist what interests you about the disease?

■ It is complex and challenging. As indicated in the M for multiple in the name, it affects several systems within the brain and spinal cord leading to a wide range of symptoms. *Prof N Quinn*

■ The fact that the condition may be indistinguishable from Parkinson's disease in its early stages particularly the MSA-P form and may respond equally well to levodopa and dopamine agonists. It is also interesting to note that while MSA can be of two types, there can be so many clinical differences between the two variants and I am interested to find out how we can robustly differentiate between early PD and early MSA. *Dr R Chaudhuri*

■ Its selectivity, both in terms of who it affects and how it affects – there seems to be no rhythm or reason to this, as far as I can see. *Dr D Burn*

Q Why does it take so long to get a diagnosis?

■ It is only possible to diagnose MSA when sufficient features are present. Most cases start with parkinsonism (slowness, stiffness and often tremor), often with some faintness or urinary symptoms, all of which can be seen in Parkinson's disease which is much commoner than MSA. Often the only way to make the diagnosis is to wait for additional features to appear which takes time. *Prof N Quinn*

Q I've heard that Parkinson's medication doesn't help in MSA: Is this true?

■ No. "Doesn't help" is too strong; although it is fair to say that the

invariably beneficial and prolonged response to drugs like levodopa used to treat people with Parkinson's disease (PD) is not commonly enjoyed by a person with MSA. Up to 25% of MSA sufferers may experience a very good response to this drug in the initial stages of the condition, however, and a further 50% or more can show some improvement. Unfortunately, the good early response tends not to be maintained, although even then the drugs appear to have some benefits, as attempts to withdraw them can lead to worsening of the motor symptoms. I tend to avoid other antiparkinsonian drugs such as the dopamine agonists in MSA, since these drugs can cause unacceptable worsening of blood pressure control when standing. *Dr D Burn*

■ Parkinson's medications can help MSA particularly in the early stages when the response to such drugs may be as good as in people with Parkinson's. This is why MSA-P may be so hard to distinguish from PD in the early stages. However, typically with MSA, the response to drug therapy gradually wears off although even in late stages drugs such as amantadine may have a role. *Dr R Chaudhuri*

■ The medication used in controlling Parkinson's disease may be less effective when used in MSA. However, some people get a very good response particularly at the beginning of the illness. Unfortunately, as time goes by, it may be noticeable that the medication is having less effect. However, most people do continue to derive benefit particularly in terms of helping to reduce stiffness. It is not advisable to withdraw your medication without discussion with your specialist. *Dr G Macphee*

Q Why does my condition fluctuate from day to day?

■ If only I had a pound for every time had been asked this by both MSA and PD sufferers! I honestly don't know the answer, although variability in how the

What is the most likely cause of MSA?

The exact cause of MSA is not known at present. We do however, have some clues. MSA patients have a particular pattern of nerve cell involvement. This is strikingly seen in the case of the glial cell inclusion bodies. Glial cells normally make up the scaffolding which supports our brain cells (neurones). This support includes provision of nutrients to the neurones, and so damage to the glial cells can clearly have an impact on the neurones themselves. It is likely that the inclusion bodies are associated with damage to the neurones. For example, we know that some of the compounds, like ubiquitin, that make up an inclusion body are those you would expect to find associated with damaged protein. It may be, however, that we are unfairly blaming the inclusion bodies when in fact they are just "bags of rubbish" in the cell which have been produced by whatever process underlies MSA. Whether cause or effect these inclusion bodies certainly seem to be important in understanding the damage that occurs in MSA. One of the interesting recent findings in research is that an important component of these inclusion bodies is alpha synuclein. This is a protein which is thought to be important in allowing nerve cells to talk to each other. Alpha synuclein has also been implicated in other degenerative conditions of the nervous system such as Parkinson's disease.

In medicine, once we identify a protein that may be faulty in a disease it is often useful to see if the gene that codes for that protein is at fault. In the case of synuclein we find that there are some families in whom a mutation in the gene for synuclein is inherited, as is a young onset form of Parkinson's. However, this cannot be the whole answer as only a minority of Parkinson's cases have these mutations, and (as yet) no known cases of MSA.

Another obvious problem with a genetic explanation for MSA is that the disease does not seem to run in families; indeed, using current guidelines, a disease which runs in families cannot be diagnosed clinically as MSA.

So is that the genetic story over with? - Not at all. Genetic influences are often far more subtle than a family where every generation has a disease. Most conditions have multiple genetic factors and very important environmental factor. For example, we know that there seems to be a weak link between previous pesticide use and MSA. If we imagine that someone with MSA has inherited a genetic make up which leaves them in some way vulnerable to pesticides, then only those who are exposed to pesticides (and possibly only those exposed at high doses) may develop clinical MSA.

Even when a single genetic defect is involved, the results in terms of who develops the disease within a family are not always obvious. A good example is that of Fragile X associated Tremor and Ataxia Syndrome (FXTAS) which I wrote about in the winter edition of SMART news. This is a condition which has only just been recognised because, not only does it "skip" a generation, but it produces different clinical effects. Thus, typically a man would gradually develop tremor and unsteadiness late on in life, while his grandson may develop fragile X syndrome.

A possible genetic factor in MSA is therefore still very much possible, and possible associations with genes involved in FXTAS and others including genes involved in the regulation of body iron and the development of antibodies in celiac disease (which can also produce MSA-like symptoms) will need further investigation. *Dr T Young*

body handles medication and interaction with food may be factors. Fatigue can be a common symptom in MSA and low blood pressure, which is also very variable, may be an important factor in determining this. *Dr D Burn*

■ Fluctuation can be a feature of MSA itself but often other factors may be involved. Quality of sleep, mood and quality of nutrition may contribute to fluctuation. Sometimes other incidental illnesses like urinary infections of constipation can make symptoms worse. Ensuring adequate amounts of sleep, rest, diet and fluids is important. *Dr G Macphee*

Q What is sleep apnoea?

■ People with MSA may stop breathing at night (sleep apnoea) and this is sometimes associated with snoring. This can also cause fatigue and tiredness during the day. There are often other associated breathing problems with increased sighing and stridor (noisy breathing). The management of these issues may require special sleep tests to be done. If the diagnosis is confirmed then a specialised piece of equipment called "CPAP" may be suggested. This is a machine that gives CONTINUOUS POSITIVE AIRWAY PRESSURE to help breathing when someone is asleep. The equipment is transportable but does require electrical power. *Dr G Macphee*

Q I am very restless when I'm asleep – is this normal in MSA?

■ Sleep patterns and disruption has been exhaustively investigated in MSA. From the question, this may be referring to a feature of the condition call REM Sleep Behaviour Disorder (RBD for short). RBD can also occur in Parkinson's disease. It comprises violent thrashing of the limbs, often accompanied by crying out, as if being chased. This can lead to injury to the bed-partner, or the sufferer themselves, as they may fling themselves out of

Is physiotherapy useful?

Physiotherapy is very useful in the management of MSA in terms of assessment and optimisation of mobility and also in the management of falls. A physiotherapist can advise on appropriate footwear and walking aids and can develop programmes to optimise muscle strength and mobility. An occupational therapist can also provide a useful input in assessing you for aids and adaptation for common activities of daily living such as dressing, eating and cooking and advising if and when a wheelchair may be appropriate. *Dr G Macphee*

bed. RBD may respond quite nicely to a drug called clonazepam. *Dr D Burn*

Q I have to get up to pass water 4 or 5 times a night, I'm exhausted. Is there anything to help me?

■ The bladder is known to be severely affected in multiple system atrophy. It is not clear from your question as to whether you also have problems during the day time and whether those problems are being treated. If not starting an anti-cholinergic such as Detrusitol or Oxybutynin is likely to lessen urgency and frequency and self-catheterisation may be necessary if you are shown to have incomplete bladder emptying. If, however, you are already doing these things and still have excessive night time frequency it is worth adding Desmopressin (Desmospray or Desmotabs) taken at night. This reduces the amount of urine you produce over night which may be abnormally high if you have a degree of postural hypo-tension. There is some evidence that Desmopressin also improves the symptoms due to low blood pressure during the day. *Prof C Fowler*

Q Why do I have difficulties starting to pass water?

■ The neural control of the bladder is a highly complicated process which, when it is working well, people take for granted. When I am teaching medical students or even post graduates and I ask them "how do you pass your urine?" it is clear that many of them

have never thought about this. It is a process that is achieved by a relaxation of the muscle at the outlet of the bladder, the sphincter, which is then followed by a contraction of the bladder muscle itself the detrusor muscle. This message to relax the sphincter passes from a centre in the brain stem down the spinal cord and out through the nerves to the sphincter muscle. It is a long a complex pathway and it is highly likely that some component of it is affected by the disease process of MSA which seems to attack the neural control of the bladder at several different points in the pathway. *Prof C Fowler*

Q Does everyone end up with a catheter?

■ If you have bladder symptoms with multiple system atrophy, and not everyone does, it is likely that you have a combination of an overactive bladder together with one that does not empty. Long term catheters need to be used either if bladder over activity is so troublesome that very frequent visits to the toilet are necessary, which may become very burdensome with reduced mobility, or if incomplete bladder emptying is a major problem of bladder function. The best treatment for incomplete bladder emptying is intermittent catheterisation either done by the patient or by their carer. If that becomes difficult then a long term indwelling urethral catheter is necessary and probably a supra pubic catheter is preferable to a urethral catheter. *Prof C Fowler*

Q What happens to the sexual function of women with MSA?

■ Very little is known about this topic. There is a single study from Germany which reported that women with MSA lost "sexual sensitivity" early on in the course of their illness. They were obviously questioned in their native language and the translation of quite what was asked is not entirely clear. By analogy of the effect of MSA on male sexual function it would be expected that female function is also affected.

I would be interested by any personal observations on this subject from women with MSA and would be pleased if you would e-mail me at clare.fowler@uclh.nhs.uk – and please only on that topic! *Prof C Fowler*

Q Do many people suffer with depression?

■ As with all chronic disabling diseases, a proportion of patients do suffer from depression, but this is perhaps not as common as you might think. More often patients with MSA have an apathetic state with a loss of motivation and interest but lack other features of depression (such as hopelessness, pessimism, early wakening, loss of appetite and preoccupation with negative thoughts), are not present. This apathetic syndrome reflects under activity of the frontal lobes of the brain. *Prof J Hodges*

Q I think my memory is getting worse, is this part of MSA?

■ Memory loss is not a prominent feature of MSA. We have undertaken a number of studies in Cambridge, funded in part by the Sarah Matheson Trust, comparing MSA with other related parkinsonian syndromes such as Progressive Supranuclear Palsy (PSP), as well as Alzheimer's disease. Of these three conditions Alzheimer's disease causes profound memory loss. PSP causes a mild but consistent impairment in memory. MSA causes the least degree of memory loss. When

memory impairment does occur it tends to be related to the retrieval of new information such as names and the details of recent events. *Prof J Hodges*

Q Will a special diet help with MSA?

■ Some of the symptoms of MSA can affect your eating habits i.e. slowness of movement and poor co-ordination making feeding yourself difficult, episodes of dizziness after eating, constipation or swallowing problems.

Dietary changes can not cure MSA but could help you feel better, by helping to control some of the common problems mentioned above. It is important to eat a healthy balanced diet and your dietician can advise you on how best to achieve this.

Managing low blood pressure There is a small amount of research suggesting that the following dietary advice maybe useful.

- Eating small frequent meals. Try eating 6 small meals over the day rather than 3 large meals. Large meals are thought to lower blood pressure more.

- Increasing salt intake. Increasing the salt content of your diet may help to increase blood pressure. Try eating salty foods and adding salt to meals.
- Eating less sugar. It is thought that sugar, sugary foods and drinks can cause blood pressure to fall more than other types of food, so try to eat as little as possible

If you know a certain food causes you problems its best avoided or limit it to times of the day when blood pressure is easier to control, e.g. in the evening. If you are concerned that this may impact on your nutritional intake, a dietician can help advise you on this.

Managing constipation Firstly you need to ensure you are drinking enough fluid. Aim for at least 8-10 cups/glasses a day. Increasing the fibre can also help ease constipation. Try to include wholemeal bread, wholegrain cereals, fruit and vegetables every day.

Managing your weight If you find you are losing weight and having problems putting weight back on, ask to be referred to a Dietician. The Dietician can advise you on how to include high calorie foods in your diet. You may also benefit from

Can I take Viagra?

Erectile dysfunction is often the presenting symptoms of multiple system atrophy and many men with the condition must have taken this medication before the cause of their ED became more apparent. One of the contra indications to taking Viagra has always been if you taking medications containing nitrates for other indications. The reason for this is that the two medications tend to interact and produce extreme lowering of the blood pressure particularly on standing.

We did a small study in six men with multiple system atrophy looking at the effect of Viagra on their blood pressure control. Three who already had symptoms of postural hypertension had marked worsening of their low blood pressure with Viagra, whereas those with normal blood pressure control did not. The advice from this, therefore, is that you should have your blood pressure checked lying and standing before being given a prescription for Viagra if you have MSA. Obviously you need to be aware of the symptoms of developing low blood pressure on standing if you are using the medication – these are light headiness and dizziness and, in its most severe form, blacking out. Interestingly the three men who did experience extreme lowering of their blood pressure with Viagra were still able to develop good erections using the medication, which goes to show that hypotension is not the cause of the erectile dysfunction in MSA.

Prof C Fowler

nutritional supplement drinks. These can boost nutritional intake. Some can be high in sugar, so not recommended for people experiencing low blood pressure. The Dietician will advise on the most suitable types of nutritional supplements for you. *Mrs E Segaran*

Q Can a gastrostomy (PEG) tube help?

■ A gastrostomy is a feeding tube, which is inserted directly in to the stomach. It is a successful way of providing good quality nutrition. It is often termed PEG; this refers to the way it is inserted. Gastrostomy feeding can be helpful in many ways. If swallowing is problematic you may find it takes a long time to eat and drink or that certain types of foods are harder to swallow than others. This can lead to you eating and / or drinking less, which may lead to weight loss, dehydration and a lack of energy. A gastrostomy can help by providing good quality liquid nutrition. The extra calories and fluid help to build up energy levels and strength.

It can also have the additional benefits of helping manage symptoms such as constipation, urine infection and low blood pressure.

Your dietician will be able to provide more practical and written information on gastrostomy feeding and how it may work for you. *Mrs E Segaran*

Q Do many people with MSA have a gastrostomy (PEG) tube?

■ When the swallowing mechanism is affected in MSA, and despite input from Speech and Language Therapists, maintaining adequate nutrition can be problematic. There may also be a tendency for fluids and food to "go down the wrong way" (that is, into the wind-pipe). The latter can lead to chest infections. In this situation, the placement of a PEG feeding system can be a huge benefit. A number of my patients with MSA have commented what a big difference this system can make and how much it can improve their quality of life. A PEG doesn't prevent the intake of food and drink by the normal route, but it does mean that adequate caloric intake can be maintained.

Because endoscopists expert at inserting the PEG tube are now widely available in the UK, our threshold to insert this system has probably fallen over the years, although it is still not indicated in everyone with MSA. *Dr D Burn*

Q I'm taking lots of tablets, how do I find out if I need them all?

■ It is not possible to answer such a general question - some of your medicines are probably essential, and

you are likely to become very unwell if you stop taking them, while others may be of less proven benefit and will help some people and not others. The only advice I can offer is to make a list of all the medicines you are taking, and ask your pharmacist.

Q How do I find out if I am entitled to benefits?

■ There are a variety of ways of finding out about benefits. Probably the most convenient is to call the free phone number 0800 88 22 00. This is a Benefits Enquiry Line for people with disabilities. They will give general advice on benefits available, send appropriate forms and even in some cases help you to fill them in.

For more personal advice suited to your particular circumstances contact your local Citizens Advice Bureau, or ask at your local town hall offices, look in local telephone directory or local library for details of any benefits/welfare rights services in your area.

It is important NOT to assume you are not entitled to benefits if you consider you already have a reasonable income or can still work. Some benefits, such as Incapacity benefit

Disability Living and Attendance Allowance are not means tested. IF IN DOUBT, APPLY. You have nothing to lose. *Mrs J Besant*

■ Disability Alliance has a helpline 020 7247 8763. DIAL UK has 150 disability advice centres throughout the UK run by, and for, disabled people 01302 310123. *Mr J Bucknall*

Q I'm worried about being able to afford the extra help and equipment especially as I am not working.

■ For any equipment required immediately on discharge from hospital there should be no charge.

When Social Services assess your needs and agree with you about any care and equipment you might need they will also ask you to give

I find tablets hard to swallow, can I crush them?

Many tablets can be crushed before taking, but they may taste pretty unpleasant! Certain types of medicines should never be crushed or chewed. This often depends on the coating of the tablet. Tablets with a "modified release" formulation, sometimes identifiable by letters such as M/R, SR, LA or XL at the end of the name should never be crushed. This is because the medicine is designed to be released slowly over a prolonged period and crushing may release the full dose too quickly. Similarly enteric coated tablets, (usually labelled EC) are designed not to be released in the stomach, crushing destroys the coating and the drug may cause serious stomach problems. Another type of drug which should never be crushed is the "nitrates" which are normally prescribed for angina. Remember many tablets are available as liquid preparations - again the best advice is to ask your pharmacist. *Ms T Dyson*

information regarding your finances. You may be asked to make a contribution based on your income, not on how much the care costs. If you are in receipt of Income Support or on a low income there is usually no charge.

Mrs J Besant

■ Make sure that you get the correct information in writing; this is part of the community care assessment and is a duty that is to be carried out by local authorities when requested by a person with longterm illness or disability. There are many charities that now make grants to people in these situations. A local citizen's advice bureau will have a list of charities that may offer one off grants. *Mr J Bucknall*

Q I am caring for my partner who has MSA and wonder if I should give up work?

■ There are many factors to consider, and it has to be a very personal decision. The sorts of things you need to consider are, do you enjoy your work? Is it possible and acceptable to you both, for your partner to be satisfactorily cared for by other carers? Is the income from working much higher than any extra income from benefits? Although Income Support payments are relatively low, the fact that it means you are eligible for help with housing costs and health costs can be very beneficial.

When Social Services assess for care needs they also have to consider the carer's needs, and cannot expect you to give up work if you do not wish to.

Financially it is possible to earn up to £77 per week and still receive Carers Allowance. *Mrs J Besant*

Q What benefits can carers claim?

■ Carers Allowance (CA) can be paid if caring for someone in receipt of Attendance Allowance or Disability Living Allowance middle rate care component, for at least 35 hours per week. It can also be paid to someone who is also receiving DLA or AA, but

I am disabled; do I have to pay car tax?

■ You are only exempt from paying car tax if you are awarded the higher mobility component of Disability Living Allowance, or war pensioner's mobility supplement. You should automatically be sent a VED exemption form. If you cannot drive you can nominate another person's vehicle to be exempt if it is used for your transport needs. *Mrs J Besant*

■ A really useful help sheet and further information can be obtained from <http://www.dialdoncaster.co.uk/factsheet/roadtax.htm>. A simple form needs to be filled in and returned which enables a refund.

CA is not usually paid if in receipt of another benefit such as Maternity Allowance, Retirement pension. This is called the overlapping benefits rule and you cannot receive more than the allowance of the highest paid benefit. It can however still be worth claiming, as if eligible for Income Support or Pension Credit, an extra Carers Premium is added. Extra Carers Allowance may be paid if they have an adult dependent and dependent children.

If a carer gives up working, credits for National Insurance can be paid.

It is possible to work and receive Carers Allowance if earnings after tax and National Insurance are not more than £77 per week.

Carers with low income may be eligible for Income Support, which then gives help with Housing and other costs. In certain cases help with mortgage interest can be paid earlier than the usual waiting period of 39 weeks. *Mrs J Besant*

Q What is a Night Sitter?

■ A night sitter is a person, usually paid, to give care to a person with a disability who needs help or a watchful 'eye' through the night.

There can be different levels of care, from someone who sleeps at the accommodation, and is on call if required, or to make a very anxious person feel safe, to someone who is expected to remain awake throughout the night to give a high level of personal care.

It is important that if employing a night sitter that a clear contract is

agreed which states just what is expected of them and for what they are being paid. *Mrs J Besant*

■ The Parkinson's Disease Society's welfare and employments right service has 16 factsheets on welfare benefits for people with Parkinson's and their families and carers. These are available free of charge to SMT members on 020 7932 1340. *Mr J Bucknall*

Q The neurologist has referred me to the local Hospice – what will happen there?

■ Many people think that Hospices care only for those who have cancer and are approaching the end of their illness. This however is not the case. Hospices also cater for patients who have incurable, progressive illnesses, including different neurological illnesses. The focus of Hospice care is to help people achieve the best possible quality of life. Staff are highly trained to give advice, support and care to patients with a variety of different symptoms, as well as providing emotional support, not just to the patient but also to family and friends.

Hospices often provide a variety of different specialist services. Many patients who are referred to a Hospice will access only some of these services and many never actually need to be admitted to an inpatient unit.

A large number of Hospices have a specialist inpatient unit with a limited number of beds. If a patient is experiencing a number of different symptoms that are proving difficult to control, it may be suggested that they be admitted for a short period of time for

symptom control. Alternatively, most Hospices offer an ongoing programme of Respite admission. This is usually admission for one week, which is pre-arranged in advance. This would enable the individual to be looked after whilst enabling their carer / family to have a break. Hospices are also often able to provide inpatient care when someone is coming towards the end of their illness.

Day Units are also available at many Hospices, usually allowing individuals to attend for one or two days per week. These Units not only provide the opportunity for individuals to get out and meet with other people, they also provide a warm, friendly and safe environment.

Specialist physiotherapists and occupational therapists, who are trained in helping people with progressive illnesses such as MSA, are often available to assess and advise on a range of mobility issues.

Teams of palliative care specialist nurses (often known as Home Care or Macmillan), who visit people in their own homes, are often based at a Hospice or work very closely with Hospices. These nurses will be able to provide advice and support regarding any physical symptoms that may occur as a result of a patient's illness, offer the time and opportunity to talk about their feelings and anxieties and help to discover ways of coping with their situation. They will also be able to advise and apply for any relevant benefits that a patient or carer may be entitled to. The specialist nurse will work very closely with a patient's G.P. and all other members of the primary health care team.

If further emotional support is needed, or more specialist financial advice necessary, many Hospices have a team of counsellors / social workers on hand to provide assistance.

It is now becoming more common for Hospices to incorporate a Hospice at Home Team to provide round-the-clock care to those who are approaching

How can I take part in research?

Tell your specialist that you are interested knowing about any research they do. Keep reading the Research Update in SMarT News. The European MSA Study Group website (www.emsa-sg.org) also gives details of forthcoming trials. *Alison & Catherine*

the end of their illness and wish to remain at home. The aim is to provide the best possible care through working in partnership with all other community services.

Hospice care can be provided at home, in a specialist Hospice or at a Hospice Day Centre. A Hospice does not take over a patient's care but aims to work alongside all other professionals involved in their care. *Mr M Perrin*

Will the Hospice nurses know about MSA?

As MSA is becoming more widely known about, so more nurses are becoming aware of the condition. Hospice nurses are highly skilled in caring for patients with progressive illnesses and most will have cared for patients with a variety of neurological illnesses, including MSA. *Mr M Perrin*

What symptoms can the Hospice help manage?

Hospice nurses and doctors will work alongside the GP and neurologist to assist in the management of any symptoms that may develop. This would include trying to manage postural hypotension, resolving and preventing constipation, trying to address any sleep problems and breathing difficulties, trying to promote urinary management, providing dietary advice, trying to address difficulties caused by reduced mobility, providing pain control and also emotional support to both the patient and their loved ones. *Mr M Perrin*

What kind of research is happening?

Research is occurring on several fronts:

Diagnostic Many patients with MSA only have the diagnosis made quite late in the day, and others will never have the diagnosis made. Making a diagnosis is important to help guide treatment options. It is important also to let patients and relatives know a likely prognosis, if they want it, to help make decisions on the future. Finally, the correct diagnosis is vital if we are to progress in terms of research to enable us to perform high quality studies that may hopefully lead to improved treatments in MSA; it is no good finding that a treatment helps in a trial only to find out later that the subjects had actually different diagnosis.

Underlying cause of MSA Neuro-imaging is improving our understanding of the brain areas involved in MSA and studies such as PET scanning are important as they not only show where the damage is occurring, but also at areas of the brain where one may look for early signs of improvement in future drug trials.

Treating symptoms Various blood pressure studies are starting now involving novel medications. These include pyridostigmine, nicotine gum (yes, really!) and the intravenous compound L-NMMA. *Dr T Young*

Do you think that a cure will be found for MSA?

If the mechanisms involved in the nerve damage in MSA can be more fully understood then a cure may be possible in the future. A more likely scenario is that better treatments will be introduced to help both length and quality of life. This is by no means a negative view, as very few diseases in medicine can be "cured", but most can be treated with better results than in MSA. We already are improving the treatment of blood pressure falls on standing-one of the major initial problems in MSA, and many of the early bladder symptoms. Parkinsonian treatments are available

any many with MSA may benefit, at least initially, with these. However, better control of the cerebellar symptoms remains a real challenge; if treatments could be developed for his aspect of MSA then a major hurdle would have been crossed. *Dr T Young*

■ Very recently animal models mimicking MSA have become available. This opens the door to novel therapies being tested and I remain optimistic that cure or at least effective treatment (such as we have for Diabetes) will be available in the near future. *Dr R Chaudhuri*

■ Undoubtedly one day a treatment will be found to slow down, stop or even prevent the process underlying nerve cell death and dysfunction in MSA. This is clearly the best hope for future generations. There is an increasing amount of research directed at this but really a major breakthrough is probably some way away. *Prof N Quinn*

Contributors to *Ask the experts*

Mrs Jill Besant, Welfare Rights Adviser, National Hospital for Neurology and Neurosurgery – London

Mr John Bucknall, Advice and Information Worker, Parkinson's Disease Society

Dr David Burn, Consultant Neurologist and Reader in Movement Disorders, Regional Neuroscience Centre – Newcastle-upon-Tyne

Dr Ray Chaudhuri, Consultant Neurologist, King's College Hospital – London

Miss Trish Dyson, Principal Pharmacist, National Hospital for Neurology and Neurosurgery – London

Professor Clare Fowler, Consultant Uro-neurologist, National Hospital for Neurology and Neurosurgery – London

Professor John Hodges, Professor of Behavioural Neurology, Addenbrookes Hospital – Cambridge

Dr Graeme Macphee, Consultant Physician, Medicine for the Elderly and Movement Disorders Clinic, Southern General Hospital – Glasgow

Mr Mark Perrin, Clinical Nurse Specialist – Palliative Care, Compton Hospice – Wolverhampton

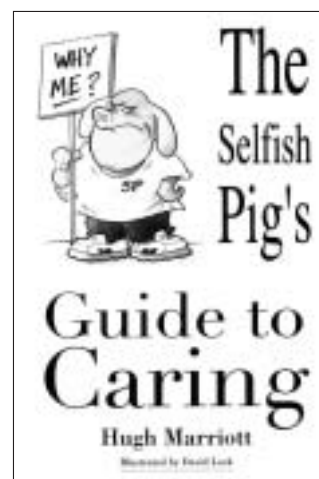
Professor Niall Quinn, Professor of Clinical Neurology, National Hospital for Neurology and Neurosurgery – London

Mrs Ella Segaran, Senior Dietician, National Hospital for Neurology and Neurosurgery – London

Dr Tim Young, Sarah Matheson Trust, Clinical Research Fellow, National Hospital for Neurology and Neurosurgery – London

Selfish Pigs

The Selfish Pig's Guide to Caring – recommended in *Caring*, the Carers UK Magazine. This is a frank and informative book. It covers everything from sex and incontinence to dealing with friends and bureaucracy, but is written in a relaxed style making it easy for carers to read, letting them pick it up and put it down as time permits. We have a copy available for loan if anyone would like to read it.



Carers Award 2003



Nominations are invited for the third Sarah Matheson Trust Carers Awards. Nominations can be for anybody that helps you, or anyone who makes a difference in your life. This could be your partner, a family member or a friend. Think about who goes out of their way to make your life easier. This could be your hairdresser, home help or physiotherapist.

Let Alison or Catherine know who you want to nominate and why. You can do this by letter or telephone. Everyone nominated will receive a certificate and a small token of appreciation and of course they will get a mention in the next *SMarT News*. Closing date for nominations is 1st June.

New leaflets from Carers UK

Taking a Break details the various kinds of support that can be offered to carers who feel they need some time off.

Coming out of Hospital covers planning a hospital discharge and includes the new rights that help carers under the Community Care Act 2003 (Delayed Discharges etc.). Both these leaflets are available free of charge from Carers UK, 20-25 Glasshouse Yard, London EC1A 4JT. 0808 808 7777

Carers Allowance on Line

Carers can now claim this benefit online at this website: www.dwp.gov.uk/lifeevent/benefits/carers_allowance.asp

Tips & hints

Moving in bed

Turning over and getting comfortable in bed has been made much easier since our District Nurse gave us a "glide sheet". This sheet helps movement around in bed and is more comfortable than silky pyjamas or sheets.

Stephen & Margaret Smith, Stoke-on-Trent

Exemption from VAT

If you are purchasing anything or having adaptations done to the home, e.g. rails or ramps or bed and bath equipment you may be entitled to exemption from VAT. This exemption is applied by the supplier or builder and the VAT element of the bill is deducted at source. Further information can be obtained from the HM Customs and Excise site at <http://www.hmce.gov.uk/business/vat/disabilityfaqs.htm>

Hedgehog, Kent

Quality of Life in MSA

The study: Recap This is an update on the progress of our Quality of Life in MSA study. As you may remember we are developing questionnaires to assess the quality of life in both patients with MSA and their carers, and how quality of life changes as the disease progresses.

Progress A number of you completed the original lengthy questionnaires and from these answers we developed a shortened questionnaire. The data are presently being analysed and we anticipate that the results will soon be helping in the understanding and treatment of your disease.

An extra special thank you goes out to those of you who have offered to

partake in further parts of our study. By now many of you may have received our shortened follow up questionnaire. This further stage aims to establish the scientific properties of the questionnaires we are developing.

Overall Development This work is taking a long time because the scientific development of questionnaires has a lot of stages and the analysis of the data is quite complicated. It is because of this effort that we can say that the final MSA questionnaires will be reliable and valid measures for the assessment not only of the quality of life of MSA patients and carers, but also of how it changes throughout the progression of MSA.

And Finally! Thank you again to everyone who has helped so far with

this study and to those who have telephoned with information regarding their MSA and how this could be incorporated into the questionnaires. It is always good to speak with you. Your comments, suggestions and questionnaire answers have been invaluable.

Niall Brady, Dr. Caroline Selai and Dr. Anette Schrag, Institute of Neurology, Queen Square, London, WC1N 3BG

Proposed trial of GDNF infusion into the brain in patients with MSA An initial study, in Bristol, of continuously infusing a growth factor for dopamine neurons called glial-derived neurotrophic factor (GDNF) into the brain of patients with

Fundraising

Wembley Arena Charity

Collections Thanks to Allan Commette we have been accepted as one of the charities which will be given the opportunity to collect outside Wembley Arena before and after a concert. We would like to hear from anyone who will be able to give up a few hours one evening – we have no dates yet but will keep you informed. *Please contact Alison if you may be available*

London Marathon 2004 This year's marathon will take place on Sunday 18th April. Running for us this year, fitness permitting, will be Allan Commette, Faye Stammers, Darcy Hare, Nicola Webb, Chris Marsden, Pam Parsons, Paul Hatfield, Miguel Bracamontes. We may well also have other independent runners who will donate to the SMT who haven't used Amanda and Chris's organisational skills in setting up sponsorship. If you are watching the marathon on TV, look out for the SMT logo on the t-shirts of our runners. We'll let you know how they all ran, and the total raised, in later editions of SMarT News.

Fun Walk – Sunday 12th September 2004 JA date for your diaries! Once again Hampton Court has

graciously agreed to host our Fun Walk for the third year running. We will have two walks, a long one and a shorter chair friendly one, and the event will culminate in a picnic lunch.



Entry for the walk and picnic is by donation to the SMT on the day although

sponsored walkers are welcome and sponsorship packs will be available from Alison nearer the event. All members and their families and friends are welcome to register for the event.

Pyrénées to Paris – July 2003

The grand total raised by Peter for this event was over £25,000.



Half of the proceeds come to SMT, the other half go to the Development Foundation at the National Hospital for Neurology. Those of us who were able to attend the event at the Architectural Association on the 23rd February were treated to a narrated film with the architectural and cycling highlights of his journey. Next year Peter is planning on cycling coast to coast across the USA!

Line Dance Changes to the format of the Line Dance on November 22nd,



arranged by Janet Fear and Mary James, saw the addition of Polly and Edna performing a cheeky cabaret to add to the evening's entertainment! The event raised £615 for the SMT.

Hand Made Cards Two of our members, Doreen Dowling in Surrey and John Fowler in Scotland, are keeping themselves busy and adding to our coffers by producing hand made greetings cards. Any current stock will be visiting our Awareness Days with us – hint!

Other fundraising events Once again the Croft Singers in Sheringham raised £200 for us carol singing. Mary Dickinson held a Bring & Buy in Henley and raised £120 for the SMT. Norman & Lyn Parkyns raised £60 in a pre-moving house book sale. Other more energetic fundraisers include Scott Luckey who raised £630 from the Great North Run and Judith Grainger who raised £309 from the Nottingham Half Marathon. We hope they are now fully recovered from their exertions.

Parkinson's disease has given promising preliminary results.

Researchers in Toronto, Innsbruck and London are now planning a trial of GDNF infusions in patients with the parkinsonian presentation of MSA. Subjects will be randomised to receive active GDNF or placebo infusions for the first six months, and then all patients will receive active GDNF for the next six months. The study protocol, which involves brain surgery to place a catheter tube on both sides of the brain, connected to implanted refillable infusion pumps under the skin in the abdomen, is currently being submitted for Ethics Committee approval.

Patients must be able to walk, and preferably not live too far from London, as 18 hospital visits are planned during one year.

Further information can be obtained from Professor Niall Quinn, Institute of Neurology, Queen Square, London, WC1N 3BG, Tel 0207 837 3611 ext 4253 (Marina, Academic Secretary), Fax 0207 6762175, email n.quinn@ion.ucl.ac.uk

Michael J Fox Research Fellowship awarded to MSA researcher.

Kyoko Tsuboi, PhD, has been awarded the first Michael J Fox Fellowship at the University of California, San Diego. Dr Tsuboi will study the process of cell death in Parkinson's Disease and Multiple System Atrophy. Read more at www.michaeljfox.org/research

Carers UK Research For most people getting stuck in a traffic jam can be inconvenient. However for many carers unexpected events like this can have more serious repercussions when someone else is relying on them. The Government has said that carers should get help with planning for unexpected events, such as the carer suddenly becoming ill. Carers UK need your opinions on what happens to carers when things go wrong. If you would like to take part in this research you can

Living with MSA – part 2

Having read "Living with MSA" in the last *SMarT News* Maureen Watkins realised she too had made changes that others might like to know about.

I live with my husband and dog in Gloucestershire. We both took early retirement – him from a stressful job in the city, myself from Social Services day care (for adults with physical disabilities would you believe!). We planned a move from London with him starting in engineering and me returning to ceramics, an interest that I had studied at Art School 30 odd years before!

I was lucky and got into a superb ceramic course at a nearby college. I had galleries selling my work and thought I'd set up my own studio. All seemed well, when disaster struck. I thought I had RSI but I began to fall and found I needed a stick when walking. I was referred to a neurologist.

Two years on I still did not know what was wrong with me, but I was getting worse. Eventually I was referred to a neurologist in London where I got my diagnosis. I had not heard of MSA and not come across it in my working life. I did not want to know, but of course I could not deny having it and when I was told about life expectancy, well, I had to take note!

I was walking then, admittedly with a walking frame. Now I can barely shuffle, using a wheeled walking frame for support. I am housebound, have a temperamental bladder and a wobbly voice. My co-ordination is poor and I rely totally on my husband to get through each day. But I want to share my useful tips to making life easier.

Anything heavy or awkward to use, went. We bought lightweight saucepans with glass lids (so I could see what was cooking without taking the lids off). A paella pan had large handles so was easy to grab and made an ideal roasting pan. The tall kettle went, and was replaced with a low stable one. Right

from the beginning an Occupational Therapist got involved. She supplied specially adapted cutlery and I bought a "ridged" plate. I knew I would become a messy eater but wanted meals to be as "spill free" as possible. I now raise the plate on a number of cork mats, it looks a little 'Heath Robinson' but it does work! I also use drinking straws for any liquids – including soups.

Out went various clothes, especially those with difficult fastenings – no fitted jeans for me! Loose trouser with elasticated waistbands are easier. Tops with buttons were not replaced, neither was a heavy winter coat.

Make up went – I have my eyelashes dyed now. Glasses are hinged and supposedly shatterproof. I invested in a sonic toothbrush – a godsend! Flat and supportive shoes are velcroed or tied with laces. To save struggling to bend down to put them on, I always use a long handled shoe horn. On discovering difficulty putting in earrings with butterfly backs I had a sort out and only kept the hook ones.

Because I cannot bathe every day now I use baby wipes, facial wipes and deodorising wipes. Maintaining a high level of cleanliness is important to me, I think I have solved the washing problem but still have trouble washing my hair.

Right from the early days I have experienced bladder problems so I researched pads. I found "Poise extra" suited me. In addition to them I am supplied huge pads by the Continence Advisor and know I will eventually be catheterised.

If you have the money, invest in a wheeled desk chair for "work". It a boon as I can glide it from one area to another without getting up. A word

Continued on page 12



Sarah Matheson Trust for
Multiple System Atrophy

Information, Support, Education & Research in Multiple System Atrophy and other autonomic disorders.

Providing services to people with MSA, families, carers and professionals.

- Information leaflets and newsletters
- Specialist nurses
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- Regional support meetings
- Training and education sessions
- MSA research
- Communication Aid Loans
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St Mary's Hospital
Praed Street
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020 7886 1520
020 7886 1540 (fax)

www.msaweb.co.uk

The Trust is financed entirely by voluntary donations.

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processor and my computer are invaluable communication aids.

Make sure you receive help from all quarters. I have a visiting chiropodist, hair cutter, beautician, cleaner and odd job help as well as a speech therapist, NHS and social services occupational therapists, a social worker, a physiotherapist and a continence advisor. And of course a dog trainer (I wrote about Sophie last time, I'll update

in a later edition). Sophie is important to us, although quite an expense!

I have used some money on a riser/recliner chair. We hoped for financial assistance but didn't get any.

Now there is an electric wheelchair to consider. All of £5000 plus! How can I manage that? Then there is an electric bed, bedding ... and more ... Oh well, time to start contacting various charities....

What is an MSA Awareness day?

Apart from being one of the favourite parts of Alison & Catherine's jobs, an MSA Awareness Day is a chance to meet many of our members, their families and the health professionals involved in their care.

These days are usually held in a hospital where there is easy access and facilities for members. The day is divided into two halves: a morning session for health and social care professionals updating them on MSA and its management and an afternoon support meeting for people with MSA and their families. The morning session lasts for two-and-a-half hours and is free of charge which enables as many people as possible to attend.

While the afternoon session does have some presentation of information and MSA news, it is a more social event allowing Alison & Catherine to speak to members individually. Once venues and arrangements have been made all our registered members are sent an invitation. This gives members the opportunity to meet other people in a similar situation to themselves which is important in reducing the sense of isolation felt by having an unusual disorder.



Catherine Best, Dr Graeme Macphee, Carol Vennard, Alison Abery at an Awareness Day at the Southern General Hospital in Glasgow.

We aim to get to as many parts of the country as possible as we have members throughout the UK. We rely on the assistance of a local professional to help us book a venue and advertise the event; this tends to be Parkinson's Disease Nurse Specialists. Carol Vennard, the Parkinson's Disease Nurse Specialist at the Southern General Hospital in Glasgow helped us arrange our recent meeting there. As you can see from the smiling faces in the photograph the day was a friendly affair.

If you would like a meeting near you please let us know.

Future Awareness Days

Manchester (May), Ipswich (May), Sheffield (June), Birmingham (July)

In Memory

Donations received with gratitude in memory of:

- | | | |
|---------------------|--------------------|---------------------|
| • Brian Abra | • Pannel Huskisson | • Ellen Revell |
| • Maureen Bell | • John Marshall | • John Stanton |
| • Raymond Catling | • Robert Milton | • Geoffrey Stone |
| • Harold Chapman | • Kenneth Murray | • Geoffrey Turner |
| • Mona Dunkerley | • John Nicholls | • Kenneth Whittaker |
| • Christine Hampson | • Marilyn Qusklay | |