

MSA SMarT News

The newsletter of the Sarah Matheson Trust

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Speech & swallowing

From the SMT office

As the year moves on through Spring, we are happy to report the continued expansion of the SMT - both in membership numbers and in the growing awareness of our work. We are delighted also to see *SMarT News* going from strength to strength and really appreciate the input and feedback from our membership. Thank you all.

As you can see from recent editions of *SMarT News* the fundraising efforts of our supporters are increasing apace. We remain grateful to everyone who organises, participates and donates; primarily because it enables our services to continue and allows the Trust to contribute to research. It also raises awareness of MSA which means that more newly diagnosed people have access to information and support at a bewildering and isolating time. Remember that Niki can provide help to promote and publicise your events, so please contact her.

We are pleased to welcome on board another volunteer, Liz Balmford, who responded to Val Fleming's request in the last *SMarT News*. Liz will be helping to collect Gift Aid on all the fundraising donations, which given the increasing volume of fundraising is quite a task. For every £1 donated to the SMT by a UK taxpayer we can claim 28p from the Inland Revenue! This is a really effective way of making your donations go further. So we are indebted to Liz for this valuable help.

Also new on board is Darcy Hare, our latest addition to our Trustees - bringing their number to eleven. All our Trustees have a link to MSA through family and friends. Darcy is Sarah Matheson's niece. She grew up in London, where she lived with Sarah for several years. Darcy ran the London Marathon for SMT in 2004. She currently works as a project officer for the Independent Police Complaints Commission.

The feature in the last edition about brain donation clearly caught people's attention judging by the response both here at the SMT office and at the Queen Square Brain Bank. It was a challenging subject to write about but we have expanded on this experience in bringing you this edition's feature on palliative care. There is a clear move within the palliative care community to extend their skills and services beyond the traditional remit of cancer services. Some of our members are already benefiting from this and we hope that as a result of the article many more members will also have this opportunity.

We look forward to meeting as many of you as possible as we go out and about this year. Invitations to all our Awareness Days will, as usual, be posted to all our local members.

Catherine, Alison & Niki

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

Misconceptions about palliative care abound. To encourage members to use them at the right time, we have asked some palliative care professionals together with some of our members who have used palliative care to share their experience.

Understanding Palliative Care

As you find out about Multiple System Atrophy you may have read or heard the phrase 'palliative care'. If a disease is not curable then palliative treatment will manage and reduce the problems caused by symptoms. Palliative care is a coordinated way to treat an incurable illness in its advanced stage.

If you thought that palliative care is only for people dying with cancer - think again. In the past palliative care has been centred around hospices for people with cancer however there is now an increased awareness of the need for this type of care for other non curable conditions like heart conditions, kidney failure and neurological (brain & nerve) conditions.

If you think that palliative care is only about depressing hospices - think again. While hospices are often central places for hospice care they are increasingly only one part of a variety of palliative services. Day centres and

community care are just two such services. Palliative care is committed to helping people experience pain-free comfortable deaths but they are just as committed to helping people to get as much as they can out of each day so hospices are often vibrant dynamic places.

A progressive illness like MSA fits into the range of services and symptom management that palliative care offers once the advanced stage is reached.

An integral part of health care

Providing palliative care should be an integral part of every health and social care professional's role (NICE, 2004). If palliative care is useful in MSA why doesn't everyone get offered it?

MSA is an unusual condition and not every health professional may be aware that palliative care is appropriate. Some care professionals may also not have had the training and support required to discuss difficult issues such as living with an incurable disease and dying and others may not recognise the advanced stage of MSA so won't know when to refer to palliative care teams. The SMT are working on all these problems by educating health care professionals. Members of palliative care teams are regularly attend the education sessions at our Awareness Days. They add to the discussion amongst the health and social care professionals present - and reinforce

“If you think that palliative care is only about depressing hospices – think again.”

the message we give about the role of palliative care in the longterm management and care of those with MSA.

Palliative care can be very useful in MSA in several ways. Firstly it can focus on managing difficult symptoms such as swallowing or breathing problems.

Secondly, palliative care teams may be able to offer additional care either at home, in hospice day centres or respite care.

Finally, while the primary focus of palliative care is always the person they are treating, palliative care teams recognise that MSA impacts not just on the individual and place great emphasis on supporting the whole network of family and friends.

To dispel misconceptions about palliative care and encourage members to consider using them at the right time we asked a group of professionals in palliative care together with some of our members who have used palliative care to give us their views.

“Palliative care can focus on managing difficult symptoms such as swallowing or breathing problems.”

Q What are palliative care services?

■ Palliative care should work in partnership with existing services, be available on the basis of need and available to all patients. The range of services on offer may vary slightly from region to region but will include symptom control, psychological and emotional support, spiritual support, and social support (including benefit advice and liaising with social services for support at home). *Mark Perrin*

■ Palliative care services are provided by multidisciplinary teams of professionals and may include:

- In-patient units offer admissions for symptom control, respite care and for terminal care. Admissions tend to be short term for the management of symptoms or fixed respite periods.
- Community palliative care teams offer advice to generalist healthcare professionals such as district nurses or GPs and offer support to patients and their relatives with monitoring and management of symptoms and have knowledge of their local area with regard to available services including voluntary organisations.
- Hospice at home teams can offer crisis intervention at home to prevent admission to acute hospitals. This may be while awaiting admission to a palliative care unit or while awaiting the provision of more permanent packages of care at home. Periods of respite at home may also be offered by hospice at home teams or by volunteer sitters, allowing carers to have some periods of time for shopping/visiting friends/ attending appointments etc.
- Day hospices provide the opportunity to attend, usually one day a week, for access to hospice services and therapeutic activities, either individually or as part of a group.

The palliative care nurses from the local hospice visited my husband at home, assessed his needs, decided on the best action to take to relieve his symptoms and liaised with his GP. They also offered emotional support and bereavement counselling at the appropriate time.

We were also offered 'hospice at home' and Crossroads for Carers who both offered much needed help to sit with my husband at night.

Margaret Smith

- Complementary therapies offer relaxation and reduction of anxiety through therapeutic massage, aromatherapy massage, reiki, reflexology and can be offered to inpatients, outpatients and relatives.
- Bereavement teams offer support to relatives following the death of a loved one. *Melanie Carthy*

Q What is palliative care?

■ Randall Jones, Clinical Nurse Specialist on the Palliative Care Team, St Mary's Hospital, London feels that it is the care of patients with an advanced progressive illness. Involving the management of physical, psychological, social and spiritual problems, by offering support in helping people achieve the best quality of life.

■ The staff at St Giles Hospice, Lichfield added that “the goal of palliative care is to optimise the quality of life for both the patient and their family.”

■ In addition Mark Perrin, Clinical Nurse Specialist, Compton Hospice, Wolverhampton stated that palliative

care should incorporate the following principles:

- Affirms life and regards dying as a normal process
- Neither hastens or postpones death
- Focus on quality of life
- Holistic/whole person approach
- Care of the patient and also those who matter to that person
- Respect for patient autonomy and choice
- Emphasis on open, sensitive and honest communication

Q Can palliative care help conditions like MSA?

■ Palliative care specialists, through working in partnership with general healthcare professionals can offer helpful advice on a number of symptoms. They can offer expert advice on the assessment and management of pain, dizziness, bowel and bladder problems, swallowing and breathing difficulties, mood changes and fatigue.

They can also act as a referral point to other specialist services such as occupational therapy, speech and language therapy and physiotherapy. Advice can also be given on financial benefits, respite care and hospice referrals. *Randall Jones*

■ This may include liaising with other health care professionals, including specialist neurology nurses, in the management of symptoms and co-ordination of care within the community. *Melanie Carthy*

Q I thought hospices were only for people with cancer.

■ Many adults receiving hospice care

Continued overleaf

I feel that *continuity* with the many health professionals that become involved was a very important part of the care and enabled good communication between us as changes in the disease happened. Concerns were able to be voiced and taken seriously with both of us being able to be involved in the timing of any decisions made.

Gill Sugden

will have cancer, although increasingly people with other life threatening conditions including neurological patients are supported. *Mark Perrin*

■ Like all palliative care services there is a concerted movement within hospices to be more open to dealing with medical conditions other than cancer. Where appropriate, neurological patients should be able to gain equal access to all the services a hospice offers. *Randall Jones*

Q Which symptoms can they help manage?

■ Common symptoms are pain, fatigue, anxiety, depression, reduced mobility, and increased dependence in the management of activities of daily living. *Melanie Carthy*

■ In MSA, 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, pain control, emotional support (to both the patient and their loved ones), addressing social issues and providing spiritual care. *Mark Perrin*

Q I imagine hospices are sad places, am I right?

■ Some people imagine hospices to be sad places and are often surprised on their first visit. Hospices attempt to make a patients stay as relaxed as possible for both the patient and their family. There is often a lot of staff and volunteers on hand to talk and share with and to help address any needs.

We were informed of various services which could be accessed whether for symptom control or arranging respite care. This gave reassurance at a difficult time and indeed we did take up the option of day hospital respite care, one day a week, at the local hospice which, contrary to some peoples' perception, was a place of much chatter and laughter.

Gill Sugden

Although there are times when there is sadness, there is also a lot of laughter to be heard. *Mark Perrin*

“Palliative care workers aim to look at the patient and their family as a unit, who should be offered any support that is necessary and appropriate.”

Q Can my family be included?

■ Palliative care workers recognise that caring for someone with a serious illness can have a great effect on a relative's physical, financial and psychological well-being. They aim to look at the patient and their family as a unit, who should be offered any support that is necessary and appropriate. *Randall Jones*

■ Families can benefit from respite care for their relative either as an in-patient admission, day hospice attendance or hospice at home services. This support will allow them to continue to care for their relative at

home. Complementary therapies can be offered to help reduce stress and anxiety. Often simply knowing that there is someone they can speak to with any concerns can be enormous comfort. *Melanie Carthy*

Q Most of the time I cope well but sometimes I feel worried about the future and even frightened. Could palliative care make a difference?

■ Definitely. Many of the services offered by palliative care could help. Especially the support of a palliative care nurse giving time to listen as concerns or fears are voiced. Similarly attendance at a day hospice offers support not only from staff but also from patients as well as the security of regular contact with all the hospice offers. Complementary therapy can help with relief of anxiety and give a feeling of well-being. *Melanie Carthy*

Q What is a palliative care nurse?

■ A palliative care nurse is a registered nurse, who has undergone further specialist training and education in the area of palliative care. These nurses will be able to provide advice and support regarding any physical symptoms that may occur as a result of MSA, offer the time and opportunity for patients and their families to talk about their feelings and anxieties, discuss any difficulties at home, advise/apply for relevant benefits and link in with all other available palliative care services and existing health/social care services. *Mark Perrin*

■ They are sometimes called Macmillan nurses or Marie Curie nurses (these professionals can care for anyone

The palliative care and support offered by the local hospice was invaluable. When I could no longer take care of my husband he was nursed there. The care given was the best and I was at liberty to spend as much time with him as we wished. As I had cared for him throughout his illness, I was allowed to continue my involvement, which I wanted to do. Indeed it was encouraged. It became a home from home. *Judy Bara*

Community Care workers provided by Social Services gave practical day-to-day help with hygiene and dressing. District Nurses also provided much needed practical help around the clock. The same Community Care workers and District Nurses had been visiting for some time before they were needed for palliative care which meant their involvement at this difficult time was made easier for all of us because they had become familiar faces. These services meant that Steve would stay at home, in familiar surroundings, with his family around him. *Margaret Smith*

We learnt about the hospice by chance, as it was through a suggestion and recommendation by a district nurse. She felt that I needed a break, to which my husband wholeheartedly agreed, and she recommended the hospice. As a result, my husband went into respite care on a regular basis, where he was in the hands of skilled professionals – an enormous relief to us. *Judy Bara*

with a progressive life threatening illness, not only cancer). *Randall Jones*

Q Can I get help at home?

■ Yes. Community palliative care services are available to patients in their homes and as stated earlier, they aim to work in close partnership with your GP and district nursing teams to supply support and advice. *Randall Jones*

Q How can I get referred?

■ In many cases a GP or district nurse is the main point for referrals to palliative care services in the community.

Many hospitals also have palliative care teams who are willing to meet with patients and their carers whilst they are in hospital and can refer onto community colleagues as appropriate. *Randall Jones*

National Council for Palliative Care

Lucy Sutton, Palliative Care Policy Lead from the National Council for Palliative Care is interested in engaging with groups like the Sarah Matheson Trust

“Of 534,423 deaths per year only 25% are cancer related with 19% related to heart disease, 14% related to respiratory disease and 11% strokes and related disorders. However about 95% of patients who receive care in the UK from hospices and Specialist Palliative Care providers have cancer. It is estimated that about two thirds of people dying from causes other than cancer would benefit from some palliative care. With this in mind the policy unit of the National Council for Palliative Care is setting up groups to look at these areas - one of these is specifically looking at neurological conditions.”

The National Council for Palliative Care is the umbrella organisation for all those who are involved in providing, commissioning and using hospice and palliative care services in England, Wales & Northern Ireland. It promotes the extension and improvement of palliative care services regardless of diagnosis in all health and social care settings and across all sectors to government, national and local policy makers.

“Often simply knowing that there is someone to speak to with any concerns can be an enormous comfort”

■ At St Giles Hospice patients and relatives can also self refer. We expect patients to be informed of their diagnosis; we don't make contact if we are aware that the patient has not been informed of the referral. *Melanie Carthy*

My husband passed away over two years ago now and I am still involved with the hospice. I think that speaks for itself. *Judy Bara*

We are grateful to the following Nurse Specialists and the Palliative Care Teams where they work for contributing to this article:

*Melanie Carthy
Clinical Nurse Specialist,
Community Team, St Giles
Hospice, Lichfield*

*Randall Jones
Clinical Nurse Specialist,
Palliative Care Team, St Mary's
Hospital, London*

*Mark Perrin
Clinical Nurse Specialist,
Compton Hospice,
Wolverhampton*

Our thanks also go to the following carers who contributed:

*Judy Bara, Essex
Margaret Smith, Staffordshire
Gill Sugden, Yorkshire*

NNIPPS Update

NNIPPS: Natural History and Neuroprotection in Progressive Supranuclear Palsy and Multiple Systems Atrophy – a double-blind, placebo-controlled Clinical Trial of the Efficacy and Safety of Riluzole (200mg/day) versus placebo in PSP and MSA.

The NNIPPS Trial has now been completed across France, Germany and the UK. We would like to thank all those people who have put enormous amounts of time and energy into taking part.

Thanks to your willingness to undergo all the extra visits and tests and to complete all our rather tedious questionnaires, we now have a huge amount of information about MSA and PSP to work with. This includes information gathered from regular neurological examinations, MRI scans, genetic blood tests, neuropathology sampling, neuropsychological tests, health economics questionnaires and quality of life questionnaires. We have

teams of researchers with expertise in each of these areas who will co-ordinate access to the data for researchers and ensure that the information is used in the best possible way to improve our knowledge and understanding of MSA and PSP.

Most centres who took part in the trial have agreed to continue to see participants in an 'open label' study, whereby people who completed the NNIPPS trial are offered active Riluzole medication until the results are available.

We will not know whether Riluzole has benefited people until late this year, as it will take time to enter all the data and conduct the analysis. As soon as we

have the results, we will of course inform people through the newsletter. Those people taking part in the study will be contacted by their trial centre. Until then, we have a supply of Riluzole medication which has been provided by the pharmaceutical company, Aventis, which participants are able to take through the 'open label' study until the results are known.

We are very excited at the prospect of having the trial results through soon and again would like to thank all those who took part, as well as their families and carers who also contributed their time and energy to the study. We will also keep you informed through the newsletter of information relating to research projects using the NNIPPS data in the future.

Caroline Murphy

NNIPPS Trial Co-ordinator, UK

Personal experiences of health and illness:

DIPEX Website

The Department of Primary Healthcare at the University of Oxford have a research team that carry out research into the experience of health and illness from the perspective of the patient. DIPEX is a charity that funds this research team and also produces a website that reflects its findings and invites further interactive research with patients.

The site does have health inform-

ation and possible treatment options for conditions including a few neurological disorders but this is not what makes the site unique (after all there are an ever increasing number of sites offering this).

The strength of the site lies in the video, audio and written interviews of real people who discuss the actual experience of illness. Rather than concentrating solely on just the health implications it addresses the effects on relationships, work and daily life making it very comprehensive.

You can add your own experiences onto the site and ask them to do a focus on your condition. The other important aspect of the site is in providing this information to health care professionals. This site offers an excellent way of seeing things from a patient perspective which could have a terrific impact on the way managers provide health services in the future.

Please let us know what you think.

www.dipex.org

Follow-up Questions from the Brain Bank Article (SMarT News Issue 17)

After reading the feature article on brain donation in the last issue of SMarT News, we received these questions from members. We are grateful to Susan Stoneham for answering them on behalf of the team at the Queen Square Brain Bank for Neurological Disorders.

Q. How long does it take to get a result (the diagnosis) following brain donation?

A. We aim to provide a definitive diagnosis six months after receipt of the brain.

Q. How will I find out what the result is?

A. If a definitive diagnosis has been requested by the next-of-kin (this is done by ticking the appropriate box on the Queen Square Brain Bank's (QSBB) post-mortem consent

form) then the QSBB's Nurse Specialist will contact the next-of-kin offering support and explanation of the results, usually by telephone. A letter is then sent out to the next-of-kin offering the opportunity for them to discuss the report with the nurse specialist. If requested, the QSBB's administrator will send the neuropathology report to the patient's hospital consultant or GP. The next-of-kin is given the opportunity to stay in touch with the QSBB regarding diagnostic findings and research if they wish.

If any members have further queries or would like information on brain donation please contact Susan Stoneham, Secretary/Administrator on Tel: 020 7837 8370 or email: s.stoneham@ion.ucl.ac.uk

“Right to Care” Campaign

This campaign has been set up by a group of organisations who are seeking for all nursing and personal care to be free for individuals funded from general taxation. At the moment many people pay for some aspects of their care and there is much confusion about who should be funding what. Often long term care is funded by individuals and their families, this brings financial burdens at what are undoubtedly difficult times for any family.

Scotland introduced state-funded personal care from July 2002 through a series of grants and allowances for people receiving care. Following pressure from the RTC campaign, NI introduced free nursing care in October 2002 and funding for free personal care is being looked at. Wales is also looking again at funding for personal care. England is currently way behind.

For further information on this campaign and the organisations behind it, log onto the following website: www.righttocare.org.uk or call 01273 234822 for more information.

“Back me up” campaign

This is a campaign spearheaded by Carers UK. Essentially it recognises the need of most carers for emergency back up support.

Carers UK are calling for the following:

- Investing in the right solutions through a carer emergency scheme and better services.
- Giving carers the back up they need to live normal lives through professional help
- Ensuring carers are better informed of their rights through information, technology, case management and carer’s rights.

A carer emergency scheme would work in the following way: carers would register and, with help, draw up their emergency plan. The plan would be held by the scheme who would man a 24 hour response line. In an emergency, you would call the Scheme. An operator would look at your plan and make arrangements for replacement care.

For further information, visit the following website: www.carersuk.org/backmeup

Tips and hints

The Cinema Exhibitors’ Association Card

This is a national card that can be used to verify that the holder is entitled to one free ticket for a person accompanying them to the cinema.

To apply for the card, you will need to meet one or more of the following criteria:

- Be in receipt of the disability living allowance or attendance allowance.
- Be a registered blind person.
- Be a holder of a disabled person’s rail card.

For further information, including how to apply write to The Card Network, Technology Centre, Rossmore Business Park, Ellesmere Port, Cheshire CH65 3EN
Telephone: 0151 348 8020
Minicom/Text phone: 0151 356 7113
Website: www.ceacard.co.uk; email: info@ceacard.co.uk

Unsolicited mail to bereaved families

Continuing to receive junk mail for someone close who has died can be very distressing. The Bereavement Register offers a free service which should help stop junk mail being received.

You can register for this service by writing to:
The Bereavement Register, Freepost SEA8240,
Sevenoaks, TN13 1YR
Telephone: 01732 460000 and ask for The Bereavement Register Helpline
Website: www.the-bereavement-register.org.uk

Volunteers Week 2005

Did you know that 2005 is the Year of the Volunteer? Research carried out by the Community Service volunteers shows that volunteers reap health benefits from the volunteering they do.

Volunteering improves health and fitness, helps individual volunteers lose weight, reduces consumption of chocolate, cigarettes & alcohol. National Volunteers week for 2005 is 1st – 7th June.

More information about volunteers’ week can be found at www.volunteersweek.org.uk

Help from local volunteer agencies

More and more people are getting involved in local communities as volunteers – there may well be local services that can support you with volunteers.

For details of your local volunteer bureau contact Volunteering England, Regents Wharf, 8 All Saints Street, London N1 9RL

Tel: 0845 305 6979

Website: www.navb.org.uk

Email: information@volunteeringengland.org

Did you know...

If you are registered disabled you can use directory enquiry services for FREE!

Dial 195 to register for this free access.

London Marathon 2005 On Sunday 17th April nine runners completed the 25th London Marathon for SMT. This year's runners were: Susan Bourke (6.38), Allan Comette (4.49), Clare Dixon (6.12), Christine Fergusson, Hayley Lemas (4.0), Joseph Rham (4.14), Mark Steel (4.07), Nick Webster (3.52) and Stuart Yoxall (4.26). Well done all!

Post Marathon Event

We were overwhelmed by the support we had at our first post London Marathon event. The afternoon, at the Red Lion in the centre of the West End, proved to be a real success with the runners, their friends, families and members of the Sarah Matheson Trust all joining in the celebration.

As the Marathon runners joined us from the finishing line wearing their medals and smiles, they all got a great round of applause not just from the SMT crowd but from everyone in the pub. Five of the runners made it to the pub: Hayley Lemas, Mark Steele,



(top left) (clockwise from left) Mark Steel, Mike Evans, Nick Webster, Hayley Lemas; (bottom left) The Stone family with Mark Steel; (above) Susan Bourke with her Dad, John

Christine Ferguson, Nick Webb and Susan Bourke to enjoy the occasion, the food and the well deserved drinks! It was wonderful to be able to meet together afterwards and thank the marathon runners for their magnificent efforts to raise funds for SMT. It was also fun to share the experience of the

day – either as a runner or spectator, as well as to meet other people connected with MSA.

We look forward to keeping up the momentum and building upon the success of this year's event, in 2006. Thank you again for all your support.

Michael Evans, Trustee

Fundraising events across the UK & beyond

Wembley Collection

Allan Comette once again proved to be a star and collected £247 for SMT at a boxing match held at Wembley. Redevelopment of the Wembley Arena site means we may not have as many opportunities to collect this year – this one was offered the day before but Allan turned up trumps for us. Those of you who have kindly offered to help if available will be contacted for any future events offered.

Christmas Gifts

The McLennan family and friends decided this year to donate the money they would have spent on Christmas gifts to SMT. We received a generous total of £360.

Concert

St Mary's Singers of Swaffham Bulbeck donated £340 from their annual concert given by the singers and

musicians to raise funds for St Mary's Church and the SMT. Rhiddian Jones was a former member of the St Mary's Singers.



Brian Dunning cutting his cake

60th Birthday Celebration

Friends and family helping Brian Dunning to celebrate his 60th Birthday donated over £375 to SMT in lieu of gifts.

Snowdon Marathon

On 31st October 2004 Paul Humphris

completed the Snowdon Marathon raising £460 for SMT in memory of David Humphris.

Flora Light Challenge

Anna & Sarah Folan completed the challenge for SMT and have raised in excess of £200 for SMT in memory of Patrick Folan.

Forthcoming events

- *SMT Family Picnic – Battersea Park, Sunday 7th August*

This year the SMT team are moving the annual get-together to Battersea Park and invite you to bring a picnic and join us. There are lots of facilities in the park to keep a range of age groups amused, the rest of us have an opportunity to sit and chat in the glorious surroundings of a London park. More details of where we will be gathering are available on request from the SMT office.



- *First SMT Nottinghamshire*

- Sponsored Walk – September 11th 2005*

Hugh Matheson will be leading walkers raising funds in this new event – guiding the route and talking about what they will be seeing as they walk through Thoresby Park, Nr Ollerton in Nottinghamshire where they will see some of the few surviving parts of the ancient woodland of Sherwood Forest. Walkers will be invited to gather from 10.45 with the main party of walkers setting off at 11.30 to reach the advertised and mapped lunch stop at 12.30. The less mobile will find plenty of interest within close reach of the car park. It is planned that there will be some kind of gathering at the end of the walk where walkers and non-walkers will be able to congregate together. Further details will be published in the Summer edition of SMarT News and sponsorship packs will be available from the SMT office.



Thoresby Hall (a Warner hotel & spa)

- *Great North Run September 2005*

On the 18th September Helen & Simon Parker will be running in the Great North Run for SMT and When You Wish Upon a Star, the charity that fulfils the wishes of children with life threatening illness. Anyone else planning to run please let us know so that we can help you with your fundraising efforts – including an online sponsorship facility.

- *Everest Trek October 2005*

Clive Grove and Andrew Griggs will be organising the group of 9 who set off to walk to the foothills of Everest in the beginning of October. Clive reports that

Fundraising Football Competition

Until recently I used to play football; badly. Indeed there were those who would dispute my description, but I turned up and drank my fair share. Our team is called Chesham Thursday FC: 6-a-side on a Monday night and occasional 11-a-side fixtures with similar veterans' teams.

When I was diagnosed with MSA, about a year ago, I asked my team-mates if I could continue to play. They agreed I should while I felt comfortable with it. I continued to make little impact on the pitch and stopped playing (but continued drinking) when I considered it unsafe.



Courtesy of the Bucks Examiner

Trevor Munns

I started planning a sponsored walk that was to be in aid of the SMT, but time seems to pass quicker now and before I knew it, it was too late in the year. Then in February, some of "the Thursday" who had volunteered themselves for the walk proposed a fundraising event this spring. I was speechless that people were willing to put so much thought and effort on my behalf. "Gosh" I said.

The event we settled on was a 6-a-side football competition with an attached family fun day. The aim is to provide enjoyment for the maximum number of people, while maximising revenue to the Trust and spreading information about MSA as widely as possible (we are sending or handing out hundreds of flyers about MSA and the SMT). By asking old friends to help, or enter a team or donate a raffle prize I am taking the opportunity to tell them of my condition without casually dropping the 'degenerative neurological disorder' bombshell into a conversation.

So a football competition it is. Up to 30 veteran's teams (over age 35) if we are lucky and 10 under-14s teams (the age group I used to coach)... with a bar and barbeque and band and bouncy castle and beat the goalie and a balloon race and a raffle and soccer skills workshop and a carom competition and maybe some theatrical events and maybe a footballing celebrity and much, much more. And to top it all, Alison says there should be one or more people from the Trust!

It is all happening on Saturday 18th June starting at about mid-day until about 6pm (play 1pm until 5 pm ish). The venue is at the Chesham (Buckinghamshire) Campus of Amersham & Wycombe College, at the top of Nashleigh Hill (Lycrome Road, Chesham HP5 3LA) on the road to Berkhamstead. There are due to be some road closures in Chesham town centre that day so it would be best to approach from the A41 at Berkhamstead if possible (between Junction 20 M25 and Aylesbury). Do come. **Trevor Munns**

For more details contact Stephen Young (07748653942), Pat Drew (07798566822), Ken Smith (07952185978) or Trevor Munns (01494727003)

"We are planning to start fund raising proper around June when the weather is warm and so that a trek over freezing glaciers to Everest will seem even more awesome!! Everyone now has their flights booked and so we depart on the 8th October". Anyone wishing to sponsor them in this mammoth effort can do so by contacting Clive on 01202

826449 or clive@cgrove.fslife.co.uk

To find out more look at the trek website at www.etsplc.com/everest.asp.

We will publish any reports and photographs in the Summer edition of SMarT News. Please let us know of any fundraising events taking place so that we can let the Sarah Matheson Trust membership know.

A 'Health Hotel' in Tenerife

As my husband Geoffrey's MSA progressed we found ourselves unable to take the holidays we had enjoyed so much in the past. Also, since our darling daughter lives in Tenerife, it had also become impossible to visit her as Geoffrey could no longer cope with stairs or with the lack of facilities in an ordinary home/bathroom.

Happily, we found the answer and have had two visits and are planning a third to the Mar y Sol (www.marysol.org) hotel in Los Cristianos, Tenerife. This hotel is described as a "health hotel" and is organised around disabled people and anyone with restricted mobility. The rooms, including the bathrooms, are spacious, allowing good wheelchair access, with walk-in showers and any equipment required (e.g. raised toilet seats, wheelchairs, bath lifts, etc. etc.) can be hired from LeRo, a company based in the hotel (www.lero.net).

Literally, any equipment you can think of can be hired from them for your stay and will be in your room when you arrive. LeRo will also arrange for your transfer via a specially adapted coach or minibus.

The low season at Mar y Sol is from 1st May to 30th October and would strongly recommend that period as the time to visit as, lovely as it is to break up the winter, the prices almost double between 1st November and 30th April!

The only criticism we have of this hotel is the food which we considered very poor plus the restaurant itself lacks

any atmosphere and reminds you of a canteen! Of course, there are numerous restaurants in the area and eating out need not be expensive. As many tables are outside the restaurant, this does help to make them accessible to all.

We can strongly recommend "Sugar & Spice" an Italian restaurant in the admittedly more "brash" area of Las Americas, a steep ramp but quite wheelchair accessible. Another good choice is one of the Little Italy chain at Playa Fanabe where you can watch the sun go down over the sea. There isn't a ramp but a small step that with a kindly waiter's assistance is easily managed. Also, for a treat, try the "Molino Blanco", again steep ramp but well worth a visit. We have also had takeaways delivered to our room to eat out on the terrace which are equally as enjoyable. Nearby is "Rosie's Cantina" – they do not deliver but if there is someone who can pick your meal up and you enjoy Mexican food they are very good. Also for delivery to your room, if you are wheelchair bound, undoubtedly the best Indian food we have ever had anywhere can be ordered from "Tigre Tigre" (www.tigre-tigre.com) (Tel: 922 79 15 16). Of course, if mobility is not a problem, far better to visit the restaurant itself which is between Los Cristianos and Las Americas at El Camison.

This holiday can be booked through Accessible Holidays but I would recommend booking directly with the

hotel and arranging your own flights as this works out a lot cheaper. We booked the flights with Monarch who were most helpful with regard to wheelchair assistance.

I hope this information will be helpful to others in a similar situation as ourselves as I feel the therapeutic benefits of a break in routine are even more important now.

Marion Wooldridge, Cheshunt

A warming tale for all members

I said that I would send you some information on two helpful schemes which some members may not be aware of. Neither of them is means tested and I have recently taken advantage of both.

The first is for home insulation and heating improvements. I had just installed a new central heating boiler and double glazing before I found out about this scheme from Warm Front so did not need help with heating, but they arranged for 10 inches of insulation in the loft as well as cavity wall insulation. The work was carried out professionally and quickly; it did not cost me a penny.

Members may also be eligible for a reduction in council tax if they need an extra room, bathroom, kitchen or extra space to use a wheelchair. I applied to my council tax office and my council tax was lowered by one band.

If you think it might be helpful, you may wish to publish this information in SMarT News. Some members might be unaware of it; I certainly was!

Best wishes, David Lee (Waltham Abbey)

Contact: Warm Front 0800 952 1555

We welcome letters that share news and experiences from all our members. We will publish as many as space permits in each issue of SMarT News.

East Midlands Support Group

The next meeting of the East Midlands Support Group is to be held on Wednesday 27th April, when the guest speaker will be Mr David Richmond. His talk will be about "The Golden Days of Hollywood". The meeting will be held at Holme Pierrpont Hall, Nottingham commencing at 2pm.

On Saturday 21st May the support

group will be having an information stand at the Long Eaton carnival. If anyone in the East Midlands area knows of a summer carnival where it would be possible to have an information stand please contact me.

Ian Jones, Secretary,
i.jones5@ntlworld.com
Tel: 0115 9199294

Discovery Mk2 4 wheel scooter

Excellent condition, 18 months old, one careful owner – now unable to use. Includes swivel seat, basket, owners manual and charger. Cost when new £2250, will accept £800 ono. Buyer must collect (St Albans, Herts.)

For further details contact Chris Dunkerley on 01727 856706

Mercury 4 wheel scooter, 2 speed

Hardly used. Comes with swivel seat and canopy. Cost when new £2500, will accept £700 ono. Buyer must collect (Edinburgh).

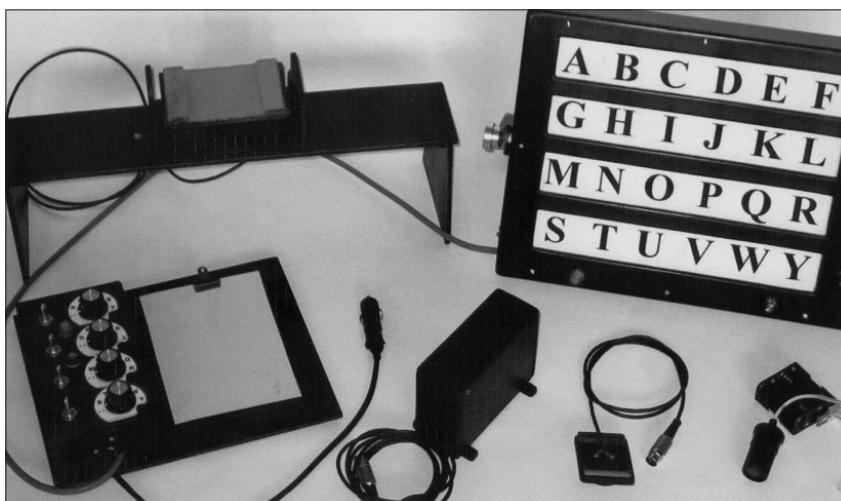
For further details contact Dorothy Newlands on 0131 339 5609

Cruiser 2E electric wheelchair

Good working order - folds to lift into car but not very lightweight. Asking price of £300 – SMT will receive a donation from this sum. Buyer must collect (Wickford, Essex).

For further details contact Jenny Ward on 01268 764034

The SMT recommends that you are assessed by an occupational therapist before obtaining disability equipment. The SMT does not accept responsibility for the safety and suitability of any advertised items.

The Chatterbox communication aid

My wife passed away late in 2002, I had been caring for her since 1996. It was thought she was suffering from PSP, however after her death it was found that she in fact had MSA. During the long slow deterioration of her health she began to lose the ability to speak clearly. Her movements became very limited, eventually having movement only in her lower arm and wrist. In spite of her suffering it was her inability to converse with me that caused her the most distress and anger.

After making enquiries into available aids to help us solve this problem it appeared there was nothing within our budget to help. I decided to make something myself, a communication light box. The operation at first proved little slow, but with patience we managed at last to be able to talk to one another.

I later improved on the model and designed the Chatterbox (see photo) which are now available in limited numbers at the cost of the materials only. These units are simple to operate taking only 10 minutes to master.

For more details please contact me on 01444 881444

Ken Chipperfield, Hickstead

In Memory

Donations received with gratitude in memory of:

- Susan Abbott
- Ian Adams
- Trish Adams
- Nancy Ansbro
- Dennis Barker
- David Bran
- Joan Callingham
- Christopher Cordingley
- Bill Curry
- Piers Eggett
- David Eglinton
- Patrick Folan
- Ken Forster
- Albert Glover
- Paul Greensill
- Christine Hampson
- Enid Hill
- Chris Jones
- Paul Latimer
- (Sheila) Wendy Lord
- Sheila Macfarlane
- Peter Male
- William McGinness
- Allen McGinness
- Eileen Moor
- Carole Ann Oakes
- Gilbert Peters
- Evelyn Petty
- Cyril Read
- Ernest Reffold
- Christina Richardson
- Jenny Rollitt
- Jean Rowles
- Roy Russell
- Tony Shaw
- Stephen Smith
- Agnes Stark
- Julie Sutehall
- Malcolm Threlfall
- Stella Trivass
- Raymond Walker
- Gale Watson
- Eddie Whiteside
- Ron Williams
- Maureen Wyatt
- Ray Young

Legacies received from the estates of:

- Mr M Szell
- Mrs SW Lord
- Mrs JH Smith



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
- Telephone advice line
- Regional support meetings
- Training and education sessions
- MSA research
- Communication Aid Loans
- Welfare Gift Scheme

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Christopher Marsden
Hugh Matheson
Peter Murray
Eileen Lady Strathnaver OBE
Lady Harriot Tennant

All correspondence and enquiries to:

Alison Abery (Nurse)
Catherine Best (Nurse)
Nikita Ranade (Administrator)

Sarah Matheson Trust

Pickering Unit
St Mary's Hospital
Praed Street
London W2 1NY
020 7886 1520
020 7886 1540 (fax)

www.msaweb.co.uk

The Trust is financed entirely by voluntary donations.

Registered Charity Number 1062308

Ways to support the SMT and help us to grow

• **Become a regular donor**

Donations by monthly or annual direct debit however small will help us maintain our services. Don't forget to GiftAid any donations to increase the value of your donation by 28%.

• **Become a fundraiser**

Events such as coffee mornings, car boot sales and a wide variety of sponsored events bring us valuable income every year. New ideas always welcome!

• **Use our online**

fundraising/donation facility

We now have the facility for you to use the online fundraising package on www.justgiving.com. You can create your own personalised online sponsorship page to raise money for the SMT for a sporting event (such as a marathon or trek), a personal occasion

(a birthday or anniversary), a sponsored event (such as a spellathon for your school) or maybe in memory of someone who supported the SMT.

• **Contribute to SMaRT News**

Sharing your experiences and tips with other members helps keep it your newsletter.

• **Form a local SMT group**

Linked with the SMT but independently run to provide what the local group wants (e.g. information, mutual support, social contact).

• **Raise awareness about MSA**

Share our information with family, friends and the health professionals you meet.

The SMT staff can offer practical guidance if you are interested in taking part in any of these activities.

Gift Aid It!

Did you know that if you are a UK taxpayer we can increase the value of any donations you make to the SMT by 28%? This could raise the SMT as much as £20,000 extra per year to support our work.

We now include Gift Aid in all the sponsorship forms and fundraising packs. Gift Aid declaration forms are available from the SMT office.

Dates for your diary

- **Guernsey** – 6th July
- **Liverpool** – Glaxo Centre, 13th July
- **Cambridge** – 20th July. Toby Churchill Limited, Over
- **Cornwall** – 8th September
- **Edinburgh** – Scottish Health Services Centre, 12th October

All our members will automatically be notified of any Awareness Days held in their area; an invitation will be forthcoming once the date and details are fixed.

For details of meetings outside your region please contact the SMT office.

Membership Numbers as of May 2005

Current MSA members	672
Past MSA members (since 1997)	416
Other patient members	41
Relatives & carers	300
Professionals	1232
Others	116

Newsletter Mailing: For the eagle eyed amongst you it may have been noted that this edition of *SMaRT News* has arrived by an automatic mailing. This will save us money and hopefully speed up the delivery to you in the future. We would like to assure you that your address details are not held by the mailing company to maintain your privacy. Please continue to advise us of any change of address details.