

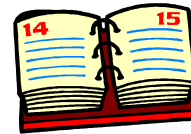
**MOTOR NEURONE
DISEASE
ASSOCIATION**

**WEST SUSSEX - NORTH BRANCH
NEWSLETTER**

January 2005

HAPPY NEW YEAR

Diary Dates



Branch Meetings

Tuesday 15th February

Speaker, **Don Weller**, on
'Grandma's Bygones'.
Antique items that will arouse your
curiosity as to their purpose

*Handcross Park School
8pm*

AGM

Tuesday 19th April

Simon Brett, writer of novels, plays
and serials and performer on the radio
programme "*Quote, Unquote*", will be our
speaker. All are welcome. Bring family and
friends to this special event. The
formalities will be short and there will be
wine and cheese.

*The Parish Hall, Handcross
8pm*



Fundraising

Monday 11th April
Quiz in the City



The Barracuda Bar

A warm welcome to
KATE POTTINGER
who became our new Regional Care
Adviser on 4th January 2005 replacing
Marcia Eason

IMPORTANT NEWS

*For branch meetings in 2005, the venue is to change to
a more suitable location in Handcross Park School.
Please see the rear of the Branch Card for a map
showing details of how to get there.*

Fighting
Motor Neurone Disease



*Our Thumbs Up symbol represents David
Niven's last defiant gesture. It remains
our symbol of hope.*

Report of October branch meeting

Around 20 people attended the extremely interesting talk given by Peter Ford, the Managing Director of West Sussex Deaf and Hard of Hearing Association. Peter retired early from 36 years of banking and helped set up the Association 10 years ago. Benefiting from his expertise and enthusiasm, it has blossomed and now has a high-profile shop at 5a Hazelgrove Road, Haywards Heath and is expanding in other parts of West Sussex. We were told that the aim of the Association is to provide help and support for the 1 in 5 deaf and hard of hearing people in West Sussex. There are three categories of deafness:

- 'Deaf without speech' relate to people who were born deaf. As speech is learned by copying sounds, they were unable to do this. Some are proud of their deafness and value its exclusivity.
- 'Deaf with speech' is when deafness comes on after speech has been learned. The language can be dated depending when deafness occurred but communication is easier.
- 'Hard of hearing' is a degree of hearing loss and is sometimes not recognised by the sufferer. The main signs are having the TV or radio louder than normal, complaining that people mumble or mutter and frequently requesting people to repeat what they said.

We were shown a communication cycle which demonstrated how problems with communication can lead to social withdrawal, depression and loss of confidence. The task was to break into the cycle and reverse its process. Peter emphasised that this is possible.

Peter counselled a visit to the doctor and stressed the danger of getting 'hooked into' advertising from private hearing-loss manufacturers and salesmen because some are out to make money even when the problem could simply be excess ear wax or an ear infection which are easily dealt with. If the doctor believes it necessary he will refer the patient to an ENT specialist. This would also involve a hearing test at the Audiology Department and a hearing aid might be provided. There is a long waiting time between doctor and hearing aid - it can be 2 to 3 years - but a hearing test can be obtained at the Association's shop in Haywards Heath. Here they can also supply specialised equipment and hearing aid batteries as well as arrange Social Services assessments. They aim to promote deaf awareness, encourage the development of new services and act as a link to help improve communications.

Peter's talk certainly made us more aware of the difficulties encountered by deaf people and we came away determined to be more considerate of their problems in the future.

Report of December branch meeting

At a festive meeting with mince pies, sausage rolls and tables decorated with lovely Christmas candle flower arrangements, members were treated to a fascinating talk about aromatherapy by **Jo Cherry** who had brought books and various essential oils by way of illustration. She told us that aromatherapy is a form of herbalism but, instead of being taken internally, the essential oils of the plants are rubbed into the skin, put in bath or burned over a candle. Plants were used for medicine, ceremonies and perfume by the Egyptians and Chinese hundreds of years B.C. The essential oil (*essential* in the sense of being *most important!*) is the working part of the flower or plant. Costs of oils vary from around £3 per 10 ml for the cheapest lavender up to £20 or £30 for rose which is expensive because it takes millions of petals to make a small bottle of oil. Jo told us that 3 or 4 different oils can be mixed using only about 5 drops in a carrier oil such as almond oil, sunflower oil or grapeseed oil. They can be bought from a good quality chemist and are sold in brown glass bottles to help preserve them as they deteriorate in warmth and light. She let us try some on the backs of our hands and explained that the smell changes as it warms up with body heat. She warned that some oils should be used with caution. For example, clary sage, which has relaxing and soporific properties, works so well that it should not be used if you need to drive or be alert. Care needs to be taken in pregnancy as some oils can be harmful and, for babies and children, the dilution must be greater. Jo also demonstrated a shoulder massage and told us that there is no wrong way to massage. She said that, if it is being enjoyed and not hurting, it is being done correctly!



Staff at Varian Medical Systems hand over a cheque for £2500 to Nick Cottom.

MNDA has been nominated as ‘Charity of the Year’ at Varian Medical Systems in remembrance of one of their staff, who supported MNDA because his father had died of MND. Funds raised so far have come from a donation by the company and a football tournament. The next event will be a Dinner Dance and Raffle. The ‘year’ ends in October and we really appreciate the efforts involved.

Challenge in 2005



In December, a dance was held at The Princess Royal Hospital in Haywards Heath, which raised £470 towards the sponsorship required by Anna Tolbom to take part in MNDA’s challenge for 2005. Anna is preparing to ride through tribal lands, rolling hills and rural villages in Rajasthan, India, on horseback to raise money for the MNDA in memory of her partner’s mother whom she refers to as ‘a wonderful woman’ and who lost her life to MND in 2002. Anna needs to raise at least £2,750 in sponsorship and is participating in many fund-raising events. The challenge will take place in October.

=====

MONIES RECEIVED SINCE SEPTEMBER

Tim and Stevie Roberts’ Bridge Drive and Raffle	£1,000
Varian Medical Systems	£2,500
Dance at Princess Royal Hospital	£ 470

National Programme for IT (NPfIT)

Over the next 10 years, modern computer systems will be installed in the NHS.

Once the work has been completed, these systems will connect more than 100,000 doctors, 380,000 nurses and 50,000 other health professionals in England. It will also give England’s 50 million+ patients easier access to their own health and care information with each person having their own electronic NHS Care Record.



There is a leaflet available. If you would like to find out more, visit the NPfIT website www.npfit.nhs.uk.

Grand Prix Official Joint Charity




The MND Association has been selected as one of two charities to benefit from the F1 Grand Prix Ball 2005. The event will take place in Stowe School in Buckingham in July. Year after year it attracts many high calibre celebrities and most of the F1 drivers attend.



The headline act on the night will be a performance by the legendary Lionel Richie with other acts to be confirmed.



This event has been going for seven years and has raised over £2 million for different charities. The other charity to benefit alongside the MNDA is The ABC Trust, which is a charity that supports the street children of Brazil.

Tripscope


Tripscope is the nation-wide travel and transport information service for people with impaired mobility. They offer assistance with information about any aspect of travel, whether planning  journeys involving private motoring or public transport. They will answer any of the whole range of transport-related questions, for example:

- What is the best way for me to get where I have to go?
- Is there transport to take me in my wheelchair?
- Where can I get the help I will need on the journey?
- I have a journey in mind but I'm not even sure if it will be possible.

They can help with the information needed to arrange a journey, whether it is a shopping trip across town, a family visit further afield or a holiday abroad. They can advise on the best way to plan the journey to meet your particular needs and try to locate suitable transport services. They can tell you about local door-to-door services, how to get help at the station, port or airport  or on the train, ferry or plane, and also give accessible  information about toilets, refreshment shops and accommodation.

If you are organising a journey for a whole family or group, Tripscope can provide information about hiring accessible taxis, minibuses or coaches. If you haven't travelled for a long time because of your  disability, or if you have to make a trip to an unfamiliar destination on your own, the  staff know that travelling can be very worrying. They have extensive information and useful travel tips to help plan a journey with confidence and can often suggest alternative ways of travel to make a trip less complicated.

Information alone may not give a disabled or frail elderly person the confidence to make a journey. Because of this, Tripscope does not supply printed lists of information but responds personally to each individual request of advice and information.

They can also help with a range of travel-related questions. For example information about travel insurance, where to hire wheelchairs or scooters, car parking and other  concessions for disabled drivers in the UK and many foreign countries.

Tripscope does not operate transport itself nor make bookings but they do put you in touch with the people who do. Contact the National Helpline on 08457 58 56 41 (local rate). All information staff on the Helpline have a personal understanding of disability which enables them to offer encouragement and reassurance, in addition to the information needed, without which many people might be too nervous or anxious to travel, or believe that their journey is not possible at all.

MOTOR NEURONE DISEASE ASSOCIATION

HELPLINE – 08457 626262
(all calls charged at local rates)

Address: PO Box 246,
NORTHAMPTON, NN1 2PR

Reg. Office: David Niven House
10-15 Notre Dame Mews
NORTHAMPTON, NN1 2BG

Telephone: 01604 250505

Fax: 01604 624726

Reg. Charity No. 294354-Reg. Co. No. 2007023

COMMITTEE



Chairman	Carol Rieley 01444 482387
Vice Chairman	Nick Cottom 01444 453508
Secretary	Vijaya Shetty 01444 453781
Treasurer	Alf Bodimeade 01444 482260
Newsletter	Lorelei Hilson 01444 440148
Committee Member	Tricia Greenfield
Branch Visitors	Carole Lloyd Maureen Stokes Bridget Gosney

Branch Meetings

Meetings are held at Handcross Park School, at
8 pm.

2005 dates are:

15 th February	11 th October
28 th June	6 th December