

Taking Control

People with neurological conditions don't get adequate information about their condition or their treatment. This is the conclusion of an internet survey of over 1000 people with a neurological condition carried out by the Neurological Alliance, Ask About Medicines and the ABPI. Having access to high-quality information allows people to navigate their way through complex, fluctuating conditions and inadequate services. Information empowers people to make informed choices and reduces fear and isolation. The survey shows many people are not getting the information they need. **48%** leave their initial diagnostic appointment without understanding their diagnosis. **Nearly 70%** do not receive any advice about where to seek information about their condition when first diagnosed.

The information that people with neurological conditions value most highly is that from patient support organisations and from on-going relationships with specialist doctors and nurses. **Only 11%** of respondents ranked information from GPs as very useful.

Over 40% do not have the name and phone number for a specialist team who they can call to ask questions about their condition or treatment. Specialist nurses are a fantastic source of information but **only 40%** of those surveyed had seen a specialist nurse in the last year. The internet is also valued as an information source but many participants said they don't know where to begin looking for reliable on-line information. Others do not know how to use the internet and rely on written or broadcast information. In a world awash with information people with neurological conditions need advice on finding and judging the quality of information about their conditions and their medicines.

The conclusions of the survey were that: As a minimum people with neurological conditions should be able to expect:

1. To be treated by health professionals who attach priority to giving information to patients.
2. To leave their diagnostic appointment with a minimum 'information prescription' of:
 - Adequate information about their condition and treatment
 - Copy of Ask About Medicines guide '*Finding and using Information about Health and Medicines*'
 - Copy of the Neurological Alliance pamphlet '*Getting the Best from Neurological Services*'
 - Contact details for a specialist team
 - Contact details for patient support group
 - Date for follow-up appointment when there will be opportunity to discuss their condition and treatment in greater detail
3. To have a single, well-informed and accessible point of contact for on-going information about their condition and treatment.

At the end of February 2008 the campaign group will hold a summit to address these three targets. The summit will involve people with long-term neurological conditions, health professionals, commissioners, managers and policy makers. Ann Keen MP, Parliamentary Under-Secretary of State for Health has been asked to provide leadership on this vital issue.

Quotations to savour

When Ann Keen MP addressed the Neurological Alliance AGM on 27th November 2007, she made 3 important points.

To quote her exactly:

1. "My duty is to make sure the workforce is right."

2. "Specialist nurses are absolutely critical."
3. "Short-term cutting of specialist nurse posts must not happen."
WBNA agrees whole-heartedly!

Hydro Pool and Gym Boost

Five Directors have stepped forward to form the Board and drive the formation of the Social Enterprise needed to provide much needed specialist hydrotherapy and specialist power-assisted gym services in Newbury/Thatcham. A detailed business plan is being assembled in parallel with the legal structure of the Enterprise being established. Negotiations for suitable land have restarted, with some challenging issues believed to be resolvable. Greenham Common Trust remains committed to seeing how to assist this major local community project. The Board will identify stakeholders and, in order to secure their commitment, will offer them the opportunity to secure a share in the enterprise. This ongoing involvement from stakeholders will be key to the long-term success of the specialist pool and gym therapy services. For further details contact John on 01635 33582 or johnmholtbsc@aol.com.

Pain Conference

WBNA is grateful to the Greenham Common Trust for awarding £1500 to support a conference on neurological pain. We plan to work with neurological specialists in this field and to hold the conference later in 2008. Please look out for more details.

Dates for your diary

A free one-day conference, *Excellence and Innovation in Care of People with Neurological Conditions*, is being hosted by South Central SHA on 7th February at Milton Hill Training Venue, Steventon Oxon. For more details contact sue.overton@southcentral.nhs.uk.

Phoenix Choir Charity Concert 7:30pm
Saturday 1st March St Nicolas Church.
Norman Morris, conductor of the Reading Phoenix Choir, has kindly donated this performance to the Alzheimer's Society West Berkshire to support *Singing for the Brain*, a social therapeutic activity designed to help people with dementia and their companions. These weekly sessions help with confidence, coordination and communication and spread happiness through the joy of singing. It all started in Newbury in early 2003 and so we celebrate the 5th Birthday with one of the best amateur choirs in Britain hoping to raise awareness of good self-help for dementia. Tickets from Corn Exchange 01635 522733 or www.cornexchangenew.com (£10 and £8).

This year the Neurological Alliance will be a supporter of Carers Week (9-15th June). The theme this year will be '*Carers can't afford to be ill*'. WBNA hope to become involved with Carers Week locally and to raise the profile of people affected by a neurological condition.

Once again we have been invited to make a collection at the Newbury Racecourse to help raise funds. In 2007 we collected £1337.50 through the generosity of race-goers. In 2008 we will be collecting on May 17th so please keep the date free and come and join us.

Our next Open Meeting will be March 6th at 1.45 for 2.00 pm at St Joseph's Church Hall, Newbury with a speaker from the Health Commission. Further Open Meetings in 2008 are on May 8th, July 10th, November 13th. Free admission includes tea and biscuits.

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