

GMNA's objective is the relief and support of people in Greater Manchester who have neurological conditions, and of their carers. It aims to be a representative and credible channel of communication between commissioners, providers and users, and to encourage users and carers to make their views known.

This newsletter is a summary of highlights from our Open Day which took place on 20th November 2009. This was the second time we had held an event like this in partnership with the Neurosciences Centre at Salford Royal Hospital. It was an opportunity for service users and carers to learn about some of the latest developments in neurological treatment & care. The day was well attended by users & carers, health & social care professionals and Voluntary Sector organisations. As well as presentations, there was also a chance for people to ask questions and make comments about services in general as well as about the day itself. All comments have been shared with our colleagues at the hospital and we will use them to inform this year's event planned for 19th November 2010.

The Greater Manchester Neurosciences Centre (GMNC) is based at Salford Royal Foundation Trust. It provides specialist neurology and neurosurgical services for the whole of Greater Manchester's 3.2 million population. In addition it provides general neurology clinics for Salford residents. Spinal surgery, behavioural medicine (neuropsychology) and acute neurorehabilitation services are also based here. GMNC also houses the new Stroke service for Gtr M'cr.

A Strategy for seizures and epilepsy

Rajiv Mohanraj

Consultant Neurologist

Epilepsy is the most common serious neuro condition and Rajiv Mohanraj explained about the changes in the Epilepsy services at the Neurosciences Centre which will include the Epilepsy Surgery Programme, Video Telemetry and other research developments. The team are looking to the future with expansion of the service and looking to ways to increase capacity to keep up with demand.

QR 1, 2 & 3

National Service Framework for Long-term Neurological Conditions

The NSF was developed to raise standards of treatment, care and support for people with long-term neurological conditions.

It does this through 11 Quality Requirements.

- QR1** A person centred service
- QR2** Early recognition, prompt diagnosis & treatment
- QR3** Emergency & acute management
- QR4** Early & Specialist rehabilitation
- QR5** Community Rehabilitation & Support
- QR6** Vocational Rehabilitation
- QR7** Equipment & accommodation
- QR8** Personal care & support
- QR9** Palliative Care
- QR10** Support for family and carers
- QR11** Care during admission to hospital or other health & social care settings

Highlighted QRs are most relevant to hospital treatment & care

Quality Care in Sub-arachnoid haemorrhage

Louise Dulhanty, Specialist Nurse

Specialist nurse Louise Dulhanty presented a comprehensive overview of the patient pathway for sub-arachnoid haemorrhage (SAH) on behalf of the neurovascular service. This highlighted nationally acclaimed aspects of the service – neurovascular surgical ward rounds, the personalized service of the SAH specialist nurse, telephone follow-up access, information provision and access to psychology. Work is being done to reduce time of transfer to the centre (though the average wait is just one day) and to improve access to rehabilitation.

QR 1, 2, 3, 4 & 5

Measuring Patient Satisfaction in Multiple Sclerosis Clinic

Alison Bradford & Fran Jackson, Specialist Nurses

All 700 patients with MS who are prescribed disease-modifying drug treatments (DMDs) are under the care of the MS clinic at Salford Royal Hospital. The team wanted to look at patient satisfaction with information received before their first appointment (n=42) and with the support they received after their first injection (n=32). Patient satisfaction was high when appropriate information and support (particularly by the MS Specialist Nurse) was provided prior to assessment in the DMT clinic. Very high levels of satisfaction (92%) were recorded for all patients after commencing treatment.

QR 1

Motor Neurone Disease (MND) – John Ealing

A challenge for the MND team has been addressing palliative care issues to bring timely care and understanding for their patient group. The team see up to 90 new patients a year with this incurable illness and highlight the need for: early involvement of palliative care services; joint working between neurology, neuro-rehabilitation and palliative care and delivery of end-of-life care by the right person. They have developed a network of interested professionals across Greater Manchester to improve communication between all relevant teams.

QR9

Neurological Movement Disorders Group Monty Silverdale and Patsy Cotton

There is a new clinical service for patients with multi-system atrophy (MSA) and progressive supranuclear palsy (PSP) – Manchester is the only centre in the UK to have specialist services for both these groups of patients. A patient satisfaction survey gave 100% scores (25 patients) for the service – highlighting the importance of education, understanding, personalized services and attention to ‘everyday’ problems that are often missed. The talk was illustrated with moving examples of pragmatic solutions and successes.

QR1,8,9

Palliative care – Stephanie Gomm

QR9

As a palliative care consultant Dr Gomm gave an overview of her work in conjunction with the neurosciences departments. Palliative care is traditionally associated with cancer, and accepted there, but many neurological conditions have no cure. Patients with long-term neurological conditions need support throughout their illness and the best care at the end stage of their life. Palliative care can help with pain management, non-invasive ventilation, cognitive (thinking) and communication problems, and around questions of capacity, consent, and advance directives (living wills). At best 30% of patients experience well co-ordinated care from neurology, neuro-rehabilitation and palliative care. She made some suggestions for better joint working, timing of palliative care involvement and development of links.

Dystonia Nurse Service — Diane Ashton

QR 1 & 2

Dystonia affects at least 40,000 people in the UK in various forms, to which there is no cure. Diane explained about the Dystonia Nurse—led Botulinum Toxin Clinic at SRFT which provides just one of the available treatments. In addition, these clinics can offer information, support and advice and develop important links with other specialists caring for Dystonia patients (i.e. Neurophysiology and ENT) and charities such as the Dystonia Society (which also provide volunteers to attend clinics and offer support and advice to newly diagnosed patients).

Update of work between GMNA & Salford Royal Hospital.

GMNA was selected as one of two patient organisations to work with Salford Royal to help improve services and enhance the patient's experience. We were invited to submit a wish list of 3 priorities for consideration. After consultation with our member organisations our wish list asked for; 1. the implementation of the “What You Need To Know” (WYNTK) leaflet; 2. appointment of a Rare Condition Specialist Nurse; 3. Expansion of neuropsychology and counselling services. The WYNTK leaflet has been developed by the national Neuro Alliance to assist service users when they are admitted to a non-specialised setting. Salford Royal have taken this leaflet and adapted it into a WYNTK Passport. It is currently being trialled with Parkinson's patients at the hospital but it will eventually be rolled out to be used by patients with any type of neurological condition or injury. The original WYNTK leaflet can be downloaded from the useful links page on our website www.gmneuro.org.uk.

The appointment of a Rare Condition Specialist nurse is unlikely in this current economic climate, however the Salford Royal team are looking at ways to provide information & support to these patients in other ways (i.e. information packs). The expansion of Neuro-psychology and counselling is still under discussion but, as a result of our issues and concerns, we will be hosting an event around this topic (*further details to follow*).

Stroke – Claire Ardron

The way stroke services are provided for Manchester is changing. Since December 2008, Salford Royal has been taking patients with stroke who would previously have been admitted direct to Trafford General hospital (TGH). They attend Salford for their hyperacute stroke care and then transfer back to TGH for their further care. To the end of July, 109 patients were admitted through this ‘pathfinder’ system. Of the 87 patients with ischaemic stroke (due to blood clot, not bleeding) 15% were given ‘clotbusting’ treatment which they would not have had available under the previous service. The rollout now also includes Wythenshawe hospital and will eventually be extended to other parts of Greater Manchester.

QR 2, 3 & 4

There were 46 attendees at this day, including 23 service users and carers. Overall feedback about the day was very positive and evaluations of the presentations, venue and facilities scored very highly. However there were comments about the presentations which suggested that some speakers spoke too fast, tried to cover too much in the allotted time and assumed too much specialist knowledge of the audience. These comments will be taken on board and passed onto the speakers for this year's event. In addition it was suggested that it would be useful to have an open day looking at a specific themes with a common interest across a wide range of conditions. We have taken this on board and have decided to hold an Open Day to look at Neuropsychology and counselling services in Greater Manchester. We hope to hold this day in June or July this year—details will be circulated nearer the time.

DON'T MISS THIS YEAR'S EVENT PLANNED FOR 19TH NOVEMBER 2010

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