

ABI NMCN

Acquired Brain Injury – National Managed Clinical Network

Newsletter No. 2

Welcome to the second MCN newsletter

The MCN is beginning to pick up pace. The steering group had its second meeting on the 23rd of May and 3 of the 4 work groups have been established and have met at least once. The groups have started to discuss their programme of work and this will be progressed over the next few months.

This newsletter contains brief updates from each group

If you have any information that you think will help with any of the work streams I would be happy to hear from you, particularly for the Patient & Family Information group (see page 2)

If you would like to receive the newsletter directly please email me and I will add you to the mailing list.

Chris Flannery (MCN Manager) 31st May 2007

Standards Group (next meeting 8.6.07)

The aim of this group is to 'Promote the adoption of recognised standards of care'

Core group members:

Dr Alan Carson Consultant Neuropsychiatrist (Lothian)
Mr Douglas Gentleman Consultant in Brain Injury Rehabilitation (Tayside)
Ms Bette Locke Rehab Team Manager (Forth Valley)
Dr Lance Sloan Consultant in Rehabilitation (Fife)
Ms Chris Flannery

Mapping group

This group will map the services for patients with acquired brain injury in Scotland

Core Group members:

Mr Laurence Dunn Consultant Neurosurgeon (GG&C)
Prof Tom McMillan Neuropsychologist
Dr Phil Mackie Public Health Specialist (Lothian)
Dr Brian Pentland Consultant Neurologist (Lothian)
Dr Cameron Stark Public Health Specialist (Highland)
Ms Chris Flannery
(Dr Jacques Kerr [SpR A&E] will join this group)

Patient, Carer & Family Information Group

(Next meeting 25.7.07)

Core group members

- MR Bill Bryden - Carer and Edinburgh Headway
- Ms Shona Forsyth - Neuropaediatric Outreach Nurse, Southern General, Glasgow Ms Pauline Linn - Scotland Development Manager - Headway Scotland
- Ms Ailsa McMillan - Outreach nurse Astley Ainslie Hospital
- Ms Gail Somerville - Specialist Traumatic Brain Injury Occupational therapist - Social Work Department South Lanarkshire
- Ms Chris Flannery - NMCN Manager

Education

This group will be set up shortly. If you are interested in being involved or have carried out any form of educational needs assessment for acquired brain injury we would like to hear from you.

Patient, Carer & Family Information Working Group

The value of information to patients and their families is well recognised and the focus of this group is to ensure that information is easily available and to a high standard.

What has happened so far?

This group, which has met twice, agreed to set specific objectives in order to meet the overall aim described above. It has decided to work in three stages, each stage having a more detailed action plan. The group will aim to involve people as it goes along, co-opting people into the group, consulting other groups and networks and asking for feedback through the newsletter and local contacts. The work will be as evidence based as possible i.e. the guidance or resources that come from this group will not be just because they think it's a good idea - although the experience in the group will be recognised!

Can you help?

To be addressed in the first stage.

What information do patients & families need/want? When do they want it? How should it be presented - in what format?

The group is aiming to collate work that has been done already, which identifies what information patients and families want. If it does not exist then work will have to be undertaken to develop it.

What information exists already?

The group will be contacting hospitals and rehabilitation services to ask what information they provide and if they would share it. Examples will be collected and the group will review the range of information that is available.

For example, in the Emergency Medicine Journal this month, Dr Jacques Kerr et al report on '*A survey of the information given to head injured patients on direct discharge from emergency departments in Scotland*'. The survey, which had a 100% response rate, will be of interest to the MCN.

Can we define good practice?

There are two aspects to this which the group will consider. One is about the quality of the information that is available. There is guidance available about the provision of written information which we will refer to.

For example

<http://www.plainenglish.co.uk/guides.htm>

http://www.doh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4070141

http://www.officefordisability.gov.uk/docs/ODI_FivePrinciples_2007_full.pdf

The other aspect will be to identify good practice when giving information to patient & families.

We will then **test ideas** with patients & families and with professionals, **identifying any gaps**.

Stage 2

This will focus on the information gap and on developing resources that can be used widely.

Stage 3 This stage is likely to focus on developing and auditing a standard for information giving

Mapping services in Scotland

This group has discussed the scope of this piece of work. We want to know what happens in each Health board areas what happens to patients with ABI. We recognise that there is not one pathway - there are several causes of acquired brain injury and the severity/impact is variable, therefore the pathways are many. We have decided to map traumatic brain injury in the first instance and, in order to capture the variable pathways, we will use pen pictures of situations as a basis for discussing the services. (See below)

We hope to visit each Health Board area meeting with a range of people and using a semi-structured interview approach. The results will be collated and sent back to each area for checking before being published in a report that will describe how services are provided in each area. This approach will be piloted initially in Forth Valley.

In addition to the interviews we are also reviewing what information exists already. We have had helpful discussion with STAG - the Scottish Trauma Audit Group, which has substantial data on patients attending A&E with head injury <http://www.staghq.com>. There was also mapping work done in Glasgow which will also be helpful. We hope to start the mapping visits by late June 2007.

Acutely behaviourally disturbed person, who is independently mobile, is confused and disorientated, is unco-operative with ward staff, attempts to leave hospital, and can be aggressive to staff

An individual in a vegetative state/minimally conscious state. Medically stable but requires nursing care for all needs and has been in this state for some weeks.

An individual who is medically stable but has mixed physical and cognitive impairment without major behavioural issues. He requires physical assistance with transfers and all mobility activities and because of mixed cognitive and language difficulties needs supervision in activities of daily

Challenging behaviour that has persisted for several months in a person who is aggressive and violent. They can be unco-operative and lack the capacity to be responsible for their own behaviour

An individual who has no significant impairment and is sufficiently orientated to be allowed home but has persisting cognitive impairment

Interested in Telehealth and its potential?
Check out the new website for the
Scottish Centre for Telehealth

<http://www.sct.scot.nhs.uk/index.html>

Read the latest HDL- 'Strengthening the role of MCNs'
http://www.show.scot.nhs.uk/sehd/mels/HDL2007_21.pdf

Standards for ABI services

The standards group is looking at what guidelines and standards exist already to identifying any that can be adopted or adapted or to be used as a basis of new acquired brain injury service standards. These include

The service standards for the rehabilitation of adults with acquired brain injury (2001)
<http://www.shif.org.uk/Docs/Rehab%20standards.doc>

Standards for specialist inpatient and community rehabilitation services (2002)
<http://www.bsrm.co.uk/ClinicalGuidance/standards.PDF>

The standards should be evidence based and work will be undertaken to identify what evidence is available. The standards also need to be realistic and practical but should be stretching enough to improve services. The variable starting points for services in each Board area is recognised.

The aim of this group is for 'dustfree standards'!

Steering Group

This group met on 23rd of May and will next meet in late September/early October 2007. A list of steering Group members was given in the 1st edition of the newsletter. New members include

Ms Kitty Mason (Planning & Commissioning Officer city of Edinburgh Council) who is representing the Association of Directors of social Work.

Ms Myra Duncan (Director of South East & Tayside Regional Planning Group) who is representing the 3 Scottish Regional Planning Groups.

Contact us

Dr Brian Pentland - NMCN Clinical Lead

Chris Flannery - NMCN Manager

MCN Office Administration Building,

Astley Ainslie Hospital,

Edinburgh EH9 2HN

0131 537 9092

chris.flannery@lpct.scot.nhs.uk



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