Lothian Stroke MCN
Community Service Development Subgroup

Friday 25th January 2013

MINUTES

Present:

Sheena Borthwick	Speech & language therapy clinical stroke lead for Lothian, WGH
Rosi Capper	Regional manager for Community Stroke Services, CHSS
Paddy Corscadden	Intermediate Care Service team leader, Edinburgh CHP & Council
Catherine Evans	Patient involvement co-ordinator, Midlothian CHP
Linda Gibson	Occupational therapist, Firrhill (ECSS)
David Gillespie	Consultant clinical neuropsychologist
Heather & Ken Goodare	Carer & patient representatives
Hannah Macrae	Health development officer for older people, Edinburgh Leisure
Morag Medwin (minutes)	Stroke MCN co-ordinator
Mark Smith (chair)	Consultant physiotherapist
Rhona Smyth	Lead occupational therapist, AAH & Liberton

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1. Welcome and apologies for absence

Apologies – Pauline Halliday, Michelle Brogan, John Brown, Jane Shiels, Audrey Bruce

Welcome: Sheena Borthwick and Catherine Evans
Introductions were made around the table, with Sheena and Catherine welcomed to the group.

2. Minutes of the meeting of 21 September 2012

Changes to items 7.1 and 7.3 have been requested (by email) and a final amended minute will be circulated to the group. **MM**

3. Stroke Pathway Developments

3.1 Edinburgh Community Stroke Service (ECSS)

Linda Gibson briefly outlined the expansion of the service from its starting point in 2008. From April 2012 it is now a full time service with Change Fund monies and now has occupation therapists (since April), physiotherapists (since June) and speech and language therapists (since Sept/Oct). An update on the spread and referral routes into the service was tabled for the group – from April to December 2012. There is an ECSS "Action Group" consisting of representatives from each profession, support staff and clients to further improve the service.

She noted that demand was greater in the north, and possibly because there is no neuro-rehab outpatient service in this area. The south of the city has this provision at AAH. The majority of referrals are from the stroke liaison nurses, and occur at many stages post-discharge, and often occurs once the patients have been home for a time and their rehabilitation goals have changed. The service can now take those over 65 years, and some referrals are from over 80s.

Clients have the opportunity to attend one to two sessions per week for a limited time (max of 12 months), and will often rely on peer support groups

following their discharge from the service, and may arrange regular get-togethers.

There have been some clients who have moved on from the service and have established their own cluster of peer support, and meet regularly. Rosi Capper noted that some of these then interact with the CHSS Communication Support Service's (ex-VSS) Outreach Co-ordinator to provide additional ad hoc support when necessary. This model is working well, and will be encouraged for other clients leaving the ECSS. She is keen that their 'back to work support group' is promoted to these groups.

3.2 Midlothian stroke pathway group

Mark welcomed Catherine to the group, following her absence for a year, and reminded members that she had written a report on the stroke service in Midlothian from a service user's perspective. This had been a driver in the development of community stroke services there, and a single standardised pathway has now been developed.

3.3 East Lothian

Mark noted that he is in discussion with Sheena Wight, OT Lead E&ML, and a working group is being convened to address the development/clarification of the community stroke pathway in East Lothian.

3.4 West Lothian

Mark noted that he is in contact with Susan Brown, lead OT in West Lothian and the re-enablement developments she is involved in. A stroke specific working group involving the WL CHCP change-funded Intermediate care Services and CRABIS is being convened. Pat Donald is continuing as AHP Lead in West Lothian and will support this work.

3.5 AHP stroke pathway group

This group has been established to increase partnership working with hospital-based therapists. They are involved in developing the high-level pathway model that is indicative of the stages post-discharge. It's planned that this pathway will be made available on the MCN website, and will be searchable to locate particular services.

Catherine suggested that perhaps a simplified document could be made available to patients at discharge to outline what services are available, and referral routes into these.

3.6 Physical fitness training after stroke (pan-Lothian)

Hannah briefly updated the Edinburgh Leisure service and activity data on referrals into their service will be available shortly. She noted that there are currently five Edinburgh Leisure staff undertaking the Exercise After Stroke (REPS 4) qualification and this will be completed in April. There is currently only one instructor providing 1-1 sessions and four circuit sessions – with approximately 40 people per month accessing the services. She was asked if the classes were multi-conditional classes. However there are difficulties with this as the instructors need to be additionally trained in other conditions.

Mark updated regarding the pan-Lothian steering group discussions. There has been agreement from representatives of the leisure industry in the four local authority areas that a standardised exercise referral form will be

developed so that the same information will be required irrespective of which locality in Lothian an exercise referral is being made. A working subgroup was convened to take this forward and will be picked up at the next meeting of the pan Lothian group.

He also noted that an application for a Health Foundation grant is being submitted to fund a pilot for a fitness instructor to be based in Ward 101 at RIE. They would meet patients and demonstrate use of equipment with them whilst in hospital, and then introduce them to community gym facilities. Hannah noted that this model currently works well with mental health patients.

Rosi noted that the Ageing Well programme offers a wide range of non-gym activities, and the CSS have developed an outreach worker post to support other such activities with patients.

3.7 Carers project at WGH

Morag and David briefly outlined the proposal for a two-year appointment of a nurse (from national funding) who will train and support carers (next of kin, family and friends) during the hospital phase of the patient's journey following a stroke. This post will be based at WGH, and is anticipated to also provide a service to support linking with care providers that can be accessed on discharge.

4. Community Service Development Subgroup Workplan - future direction of subgroup

Mark led the discussion about the future direction of this group, given that there have been falling attendances, workplan objectives have been achieved, and community services have been developed. Many of the workstreams developed within this group are now firmly established within services, eg: AHP consultant post, ECSS, neuropsychology service, exercise after stroke programme, bridging the gap speech and language therapy services, and lifestyle management programmes.

It was agreed that the networking opportunities provided at the meetings were valuable and effective but that it was important to have a purpose for the meeting. It would be challenging for clinicians to attend a quarterly networking meeting, considering their clinical priorities with patients. The following points were raised in the discussion:

- need to consider how best to provide reports on the progress of the developments that this group has initiated
- what is the future remit of this group, to determine if it should still meet
- if the remit of the group is amended, then the membership may need to be re-assessed
- latterly the group hasn't been making decisions on developments, and it's just been an information giving session, so in these challenging times, it needs a purpose
- there is a need for effective carer/patient representation for ongoing service development
- important for this sort of forum so that carers/patients can raise issues
- where would future national developments (eg. self-directed care legislation and the social care/health integration agenda) be considered for their impact on developing stroke services
- reports will have to be submitted from those CHSS services with

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service level agreements with NHS Lothian, ie liaison nurse service and Community Stroke Services. Where could these reports be submitted? And how often (quarterly, six monthly)?
- what would be the best way to inform the wider services about the community stroke developments that are still ongoing in their local areas?

It was agreed that members will be asked to provide their thoughts on the future of the group, taking into account the above points, when they consider what they want from the group. These will be discussed at the next meeting, which will be scheduled in six months time. **ALL**

5 Update on projects

5.1 Patient & carer feedback

Heather noted several concerns:

- Referral method to the Eye Pavilion. It was agreed that the system is problematic with many delays, and certainly not just for stroke patients. Linda noted that national funding had been made available to RNIB for a liaison worker for visual impairment. However, the person was only in post for a short time before they left and recruitment is taking place again. It is planned that this worker will work with ECSS for some of the week. Mark also agreed to raise this issue with SPMT. **MS**
- Stroke workbook. Heather noted that she had worked with the team to edit the workbook and had been promised a copy, which has not eventuated. Morag will speak to the manager. **MM**
- FOCUS trial. Minutes of previous meetings have noted their concerns with this trial. Heather noted that she and Ken have now met with the university sponsor of clinical trials and she will respond to them. Mark confirmed that them liaising with the university sponsor was the appropriate way forward.
- Home care vs intermediate care. Paddy outlined that intermediate care is a time limited joint service offered by NHS and social care, and providing physio and occupational therapy in the patient's home. He also clarified rules on personal care for people under 65 years.
- Patient/carer representation on the stroke management group. She suggested that there should be representation on the management group. Morag noted that there had been previous discussion on this and will raise it again at the next SPMT (stroke pathway management team). **MM**

Post-meeting note: (minuted note from SPMT on 5th Feb 2013)
The group reconsidered the request to have patient/carer representation and decided that the group did not offer the best opportunity for making use of such a resource, both because of the high proportion of confidential matters that are discussed and because of the preferable alternative options for involving patient and carer representatives. This decision will be passed on.

5.2 Speech & Language Therapy

Sheena outlined the changes to the Speech and Language Therapy (SLT) service in Lothian with them now becoming single system. She briefly explained what this meant – previously there were separate structures in acute and rehab hospitals and also for outpatients in the community. The complete service has now been brought together and she has been appointed the clinical lead for stroke services.

The SLT service recognised and identified that patients fell into four categories: immediate acute, early rehabilitation, continuing rehabilitation and longer term support. It was recognised that patients were often handed on to another therapist even within these stages due to moves from hospital or organisation of services, which made it difficult for seamless treatment. Their aim is now for the clinician who starts with the patient, to attempt to complete a phase in therapy. There will be some exceptions to this, mainly where there are geographical constraints – but the service will continue to uphold their current values of multi-disciplinary working and patient-centred goals.

5.3 CHSS Liaison Nurse Service

There was no report, as Audrey was not at the meeting. It was noted however that the follow-up questionnaire from discharged patients is currently being processed and results will be considered in February.

Post meeting note:

Morag liaised with the nurses to ascertain if the practice of phoning discharged patients within 72 hours of their discharge had been extended to other acute sites, following the June 2012 discussion of the pilot at RIE. Nurses at the acute sites have confirmed they are seeing most patients on the stroke unit before discharge and ensuring they have contact details for a timely visit post-discharge.

5.4 Neuropsychology service

David tabled a report, and it will be circulated with the minutes. Generally, the service is somewhat stretched at the moment as their staff resources are reduced due to sick leave, and referrals are up. Heather asked if there were referrals from carers, and it was confirmed there are significant calls from them.

David noted that he will be taking up a fellowship for one day per week sometime after April, for three years. Backfill will be provided by the funding body for his clinical sessions. The research will involve work with families around the transition from hospital to community services.

5.5 CHSS volunteer service (VSS) – now Communication Support Service

Rosi tabled a quarterly report for the recently re-named Communication Support Service (CSS), and this will be circulated to the group. She reiterated that the service can respond to 1-1 needs, with the appointment of the Outreach Co-ordinator. An invitation was offered for any member of the group, to visit one of the CSS groups.

5.6 CRABIS

There was discussion as to the community stroke service provision in West Lothian and the current position of CRABIS within this. As mentioned above (item 3.4), there is work ongoing to clarify this as the change fund spend in WL has been invested in significant community developments in partnership with St John's Hospital inpatient services and there is a need to ensure that stroke community service provision has been addressed in line with the evidence-based and political drivers.

Paddy Corscadden invited Mark to attend a pan-Lothian OT meeting as

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community services are well represented there, and Mark agreed to take up this offer. **MS**

Sheena advised that she is involved in discussion with West Lothian S< services to build a pan-Lothian single system.

5.7 SSKIA community/Stroke Association

Mark noted that work being done here is with regard to the softer targets from the National Action Plan, specifically around physical activity and advocacy. He is involved in the discussions.

6. Any other business

6.1 Stroke Workbook -- update

Morag advised that the final evaluation of the stroke workbook is currently being done, with patient interviews. The evaluation will be finalised before funding ceases at the end of March 2013. It was confirmed that there is a supply of workbooks available for those already trained to access, but free training places have been exhausted and any further training after the February 2013 training days will be available at a cost. Paddy suggested that a bid be made to the Change Fund programme for further training places if it was agreed that social service staff should be trained to deliver the workbook intervention.

Post-meeting note: Two staff from ECSS have been offered places on the final training days in February.

6.2 Cross-party group (CPG), Scottish Parliament

Mark noted that he is involved in developing a "life after stroke" charter. This work arose from a perceived lack of community stroke services and long term support for stroke survivors nationally. This had been raised by ex service users, charities and the professional bodies for AHPs represented within the CPG. A stroke subgroup of the Heart Disease and Stroke Cross Party Group at Holyrood, chaired by Helen Eadie MSP, is taking on this work and a draft version of the Charter will be presented to NACS for ratification. Mark will feedback on progress but it is anticipated that the Charter will be launched before the next meeting of this group.

7. Dates of future meetings

Agreed that a meeting in six months would be arranged.

Friday 2nd August, 10am – 12 noon, Leith CTC

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