

**STANDING ADVISORY COMMITTEE ON NEUROSURGERY FOR MENTAL
DISORDER (NMD) SERVICES IN SCOTLAND
REPORT OF VISIT TO NMD SERVICE PROVIDERS
WEDNESDAY, 2 OCTOBER 2002, NINEWELLS HOSPITAL, DUNDEE**

This report has been prepared for the NMD service providers and the Scottish Executive. A copy is with the Minister and Deputy Ministers for Health and Community Care and is available to all with an interest via the Mental Health and Well Being Support Group website – www.show.scot.nhs.uk/mhwbsg.

The SAC:

- Dr Andrew Fraser, Deputy Chief Medical Officer, Scottish Executive Health Department - Chair
- Ms Hilary Patrick, Honorary Fellow, Faculty of Law, the University of Edinburgh
- Dr Cameron Stark, Consultant in Public Health Medicine, Highland NHS Board

In attendance:

- Dr John Loudon, Principal Medical Officer, Scottish Executive Health Department - Adviser
- Mrs Nan Whetton, Community Care Division, Scottish Executive Health Department - Secretariat

The NMD service providers:

- Dr Rob Durham, Senior Lecturer in Clinical Psychology, Department of Psychiatry, Tayside University Hospitals NHS Trust
- Mr Sam Eljamel, Consultant Neurosurgeon and Clinical Leader, Head of Surgical Neurology, Tayside University Hospitals NHS Trust
- Dr June Gilchrist, Consultant Neuropsychologist, Tayside Primary Care NHS Trust
- Mr Mike Lyall, Medical Director, Tayside University Hospitals NHS Trust
- Professor Keith Matthews, Professor of Psychiatry, Dundee University, Ninewells Hospital
- Dr Bill Mutch, Medical Director, Tayside Primary Care NHS Trust
- Dr Linda Treliving, Consultant Psychiatrist in Psychotherapy, Tayside Primary Care NHS Trust (member of Ethics Committee)
- Ms June Wood, Charge Nurse, Carseview Centre, Tayside Primary Care NHS Trust

Two former patients and a carer also participated in the visit to provide their perspectives.

1. Background

In 1996 the CRAG Working Group on Mental Illness published its report (*Neurosurgery for Mental Disorder*) on neurosurgical service provision in Scotland for the treatment of chronic mental disorder. The report approved the continuation of the service provided from Ninewells Hospital, Dundee, which remains the only service provider in Scotland. Further recommendations were that reports on the service be published and that a Standing Advisory Committee (SAC) be established to review the activity, assess the relevance and fitness for

purpose and processes of referrals for the NMD service and provide support to the service providers. These recommendations have been delivered.

The first report on the NMD service covering 1990 to December 2000 prepared by Professor Keith Matthews and Mr Sam Eljamel was published in December 2001. (Available on *related guidance and reports page* of www.show.scot.nhs.uk/mhwbsg.)

A Standing Advisory Committee (SAC) was appointed also in December 2001 and this report sets out its findings following its first visit to the NMD service providers on 2 October 2002.

2. NMD

The term “neurosurgery for mental disorder” covers surgical procedures for the destruction of brain tissue for the purposes of alleviating specific mental disorders. These are carried out by a stereo-tactic or other method capable of making an accurate placement of the lesion. For those with intractable Obsessive Compulsive Disorder (OCD) and affective disorders (for example major depressive illness), NMD may offer a treatment option when all other interventions can be shown to have been tried and failed. The procedure itself is not usually considered to be curative, and more often it offers at best a window of opportunity which may allow the patient to benefit from other forms of treatment - psychological, social, rehabilitative and pharmacological. It is important that these treatments are provided timeously and consistently as the window may only last up to 2 years.

NMD is currently performed in 2 centres in the UK, Dundee and in Cardiff. Professor Keith Matthews leads the clinical service at Dundee with neurosurgical commitment from Mr Sam Eljamel. Drs Rob Durham, Linda Treliving and June Gilchrist provide input to the assessment process and to post-operative assessment and the design of rehabilitation programmes.

The Mental Welfare Commission for Scotland has a statutory duty to assess independently all patients liable to detention under mental health legislation who are referred for consideration for NMD. Following the CRAG report, the Commission adopted informal arrangements to extend this role to all patients. In each case a Commission medical officer and 2 lay Commissioners each certify that the patient understands all aspects of the proposed treatment, the potential outcomes and that they are making an informed consent to the procedure.

The Report of the Neurosurgery Working Group of the Royal College of Psychiatrists, published in 2002, supports NMD as a treatment option in the UK. (The NMD service at Ninewells is mentioned in the report but Professor Matthews indicated to the SAC that he was disappointed at the level of detail included and lack of prior consultation on this.)

3. Organisation of the NMD service

The NMD service is provided jointly by Tayside Primary Care NHS Trust, Tayside University Hospitals NHS Trust and Dundee University. There is no identified local service or programme budget. An income flow is received by the Primary Care Trust from other health boards and authorities, linked to individual referrals and has amounted to an average of £100,000 per annum. Tayside University Hospitals NHS Trust receives a proportion to cover the costs arising from the neurosurgical intervention. The remainder is retained by the

Primary Care Trust, but not separately accounted for. This lack of an identifiable budget for the NMD service hampers service planning or development.

To deal with problems highlighted in this report, Professor Matthews has submitted a Business Case to Tayside Primary Care NHS Trust and NHS Tayside. It contains proposals for a nurse practitioner to work with referring units to help ensure quality aftercare to support the specialist NMD work; and for secretarial support which in addition to facilitating the organisation of services around an individual patient, would allow data entry to support detailed analysis of clinical outcome. As at March 2003, Tayside NHS Board is still considering this submission.

- **The SAC recommends that NHS Tayside reach an early decision on the Business Case to support the NMD service.**

4. Consent

Currently the stated position of the Dundee service is that it will not offer NMD to patients who are incapable of providing informed consent to the procedure. Professor Matthews and Mr Eljamel are aware that this issue is being addressed under the provisions of the Mental Health (Care and Treatment) (Scotland) Bill. This would allow treatment in such cases, but only where the patient did not object, the treatment was approved by an independent medical practitioner, and with the prior approval of the Court of Session. Such a measure would permit surgery on patients unable to give consent but would not of course interfere with the discretion of practitioners not to carry out such procedures.

5. Referrals

Referrals to the NMD service at Dundee are from centres throughout the UK and Ireland. Referrals are for NMD and/or specialist assessment where NMD is one of a range of care options. Some referrals prove inappropriate for NMD as a treatment option. From the updated table of activity tabled on the day of the SAC visit, around 80 formal referrals were received between January 1990 and December 2001. (However it is difficult to give a definitive number because of the referrals received that are referred on to more appropriate care options by the NMD team following assessment at several stages.) During that same period 33 NMD procedures were performed (bilateral anterior capsulotomy, bilateral anterior cingulotomy and vagus nerve stimulator implant).

The recent closure of the service in London (due to retirement of key staff) has had little impact on the referral rate to the Dundee service so far. Any increased referral activity would necessitate an increase in the service's capacity for assessment and treatment. The pattern of referral from across Scotland bears no relationship to population density.

- **The SAC recommends that a health board referral map be prepared. The outcome would inform equity of referring organisations and clinical teams and also assist the NMD service planning process.**

6. Assessment

Assessment is multi-disciplinary. Each referral is assessed on its own merits with consideration of the extent and quality of previous treatments playing a major part in any treatment decision. Experience has shown that the quality and consistency of previous psychological interventions given prior to referral varies, causing benchmarking difficulties when following a strict assessment protocol.

Physical health is also a key consideration, particularly for older patients. In every case alternatives to NMD are explored.

In each case where NMD is not considered appropriate a written report is produced for the referring clinician/authority setting out the reasons behind the decision and suggesting alternative care options. Where relevant, comment will be offered on the quality of previous treatments.

For those proceeding to NMD the length of time between referral and surgery is determined by the adequacy of previous treatments and patient's response to further treatments. There is minimal delay between the decision to proceed to surgery and the procedure itself.

Both Drs Durham and Gilchrist stated to the SAC that their input to this service is either under funded or provided on a shoestring. They both questioned their ability to cope should the level of referrals increase.

- **The SAC recommends that NHS Tayside gives early attention to the capacity and burden placed on those involved in the assessment process of the NMD service.**

7. Procedure

The NMD service offers anterior cingulotomy for resistant depressive disorder. For obsessive-compulsive disorder, the NMD service providers consider anterior capsulotomy and anterior cingulotomy to offer the current best-established treatment options. One vagus nerve stimulation procedure was also performed in 2001 - a potentially 'non-destructive' alternative to ablative neurosurgery.

8. Follow-up process

Acute follow up in-patient care is provided by the Tayside Primary Care NHS Trust and can last for around 6 weeks following surgery. Six-month and 12-month follow-up appointments with Professor Matthews are also included in the care package. However, in addition to the proficiency with which the intervention is carried out the success of the procedure is very dependent on the quality of post-operative care provided locally by the referring unit. This was reported as varying from poor to excellent. Professor Matthews continues to manage elements of ongoing care for those where the local delivery of care is considered problematic and retains an advisory/consultancy role for all NMD patients.

As previously mentioned, the Business Case submitted to Tayside Primary Care NHS Trust includes proposals for the appointment of a link nurse to the NMD service to work with referring units to help ensure quality aftercare. The SAC looks forward to the outcome of this Business Case application.

- **The SAC recommends that the NMD service providers make explicit their expectations of the referring service at the time of referral. This will serve to raise expectations and delivery of adequate post-operative support on completion of treatment in Dundee – in other words an Integrated Care Pathway, possibly through the Managed Care Network mechanism. NHS Circular HDL(2002)69 *Promoting the Development of Managed Clinical Networks in NHS Scotland* refers (http://www.show.scot.nhs.uk/sehd/mels/HDL2002_69.pdf)**

9. Patients' experiences

The SAC was interested to learn at first hand of the patient's 'experience'. Two former service users presented their personal accounts. Both complimented the care and support they received at all stages. They considered the patient information material both informative and easy to understand. Neither felt that stigma was a dominant issue. The service user most recently treated was particularly appreciative of the after care arranged and paid for by her referring health authority in England.

- **The SAC supports the work to produce an Integrated Care Pathway (ICP) for referring units which will include clarification of the patients' expectations. It looks forward to receiving a copy of both the ICP on completion and the patient's information material.**

10. Advocacy

Experience has shown that it is not unusual for relatives to support patients during the assessment and post-operative recuperation.

- **The SAC recommends that use be made of advocacy services (both local to the patient and within Tayside) for all patients as part of the Integrated Care Pathway.**

11. Outcomes

Professor Matthews advised that detailed post-operative information is obtained from patients but that currently this is not analysed as fully as he would wish. This is due in part to the small number of patients involved, some variability in the data and limited time opportunity to follow up former patients. The difficulty in deciding how and at what points to measure constantly changing progress is also relevant.

This causes difficulty in gauging the overall success or otherwise of the NMD service and procedures followed.

The NMD service providers are aware of the compelling case for a collaborative study with the Cardiff service to review the long-term outcomes of patients treated for depressive disorder. A research application with Cardiff is in preparation.

- **The SAC recommends an ongoing structured evaluation of outcomes, including long-term outcomes and those derived from a service user perspective, as an integral part of the service, ideally on a multi-centre basis; that the costs be included within the care costs; and that this be an integral part of the NMD process and service.**

12. Future of service

The SAC recognises the vulnerability of the current arrangements, not least given Professor Matthews' pivotal role and the heavy clinical workload carried by several key colleagues. The capacity, burden and funding issues identified earlier in the report also refer.

Designating the service as a National Service was discussed in terms that such an arrangement would perhaps better address the after care and outcome evaluation issues. The referral data exercise proposed by the SAC will inform this consideration. The assistance requested in Professor Matthews' Business Case would provide means of inputting this data to allow such analysis.

13. Findings

The SAC was impressed by the commitment of those involved in providing this service. The former patients also spoke highly of the way they were treated throughout the whole process. However, the service appears to run "on a shoestring" with insufficient recognition by the local service managers of the staff resources necessary. There is also a need to develop evaluation of treatment outcomes in order to give weight to the continuation of the service.

14. Recommendations

- **The SAC recommends that NHS Tayside reach an early decision on the Business Case to support the NMD service.** (Section 3)
- **The SAC recommends that a health board referral map be prepared. The outcome would inform equity of referring organisations and clinical teams and also assist the NMD service planning process.** (Section 5)
- **The SAC recommends that NHS Tayside gives early attention to the capacity and burden placed on those involved in the assessment process of the NMD service.** (Section 6)
- **The SAC recommends that the NMD service providers make explicit their expectations of the referring service at the time of referral. This will serve to raise expectations and delivery of adequate post-operative support on completion of treatment in Dundee – in other words an Integrated Care Pathway, possibly through the Managed Care Network mechanism. NHS Circular HDL(2002)69 *Promoting the Development of Managed Clinical Networks in NHS Scotland* refers (http://www.show.scot.nhs.uk/sehd/mels/HDL2002_69.pdf)** (Section 8)

- **The SAC supports the work to produce an Integrated Care Pathway (ICP) for referring units which will include clarification of the patients' expectations. It looks forward to receiving a copy of both the ICP on completion and the patient's information material. (Section 9)**
- **The SAC recommends that use be made of advocacy services (both local to the patient and within Tayside) for all patients as part of the Integrated Care Pathway. (Section 10)**
- **The SAC recommends an ongoing structured evaluation of outcomes, including long-term outcomes and those derived from a service user perspective, as an integral part of the service, ideally on a multi-centre basis; that the costs be included within the care costs; and that this be an integral part of the NMD process and service. (Section 11)**

Finally, the SAC would like to thank all who took part in the visit and, in particular, the former patients and carer, without whom a large part of the picture would have been missing.

Standing Advisory Committee
24 March 2003