

## **Joint National Nurses Nutritional Group and Parenteral and Enteral Group of the British Dietetic Association Symposium on ‘Working in partnership’**

### **Scottish Home Parenteral Nutrition Managed Clinical Network: coordination and standards**

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Home parenteral nutrition is required by patients with intestinal disease such that they are unable to maintain nutritional status or fluid volume without this treatment. A Managed Clinical Network has been established in Scotland. The aims of this multi-professional group are to ensure equity of access and that patients are managed according to nationally-agreed evidence-based procedures and protocols. The Clinical Standards Board for Scotland has provided support in preparing a quality-assurance framework to which the network must adhere.

#### **Home parenteral nutrition: Clinical standards**

##### **Home parenteral nutrition**

Parenteral nutrition is required when patients are unable to maintain either an adequate nutritional status or fluid and electrolyte status. This situation is largely due to intestinal failure following resection of the small bowel and disorders of the intestinal mucosa which cause malabsorption or stasis within the lumen of the gut. Many episodes of intestinal failure will resolve, and many patients will manage without parenteral nutrition if attention is paid to their fluid and electrolyte imbalances using drug treatment. Those patients who are likely to require parenteral nutrition for months or years would be considered for home parenteral nutrition (HPN). The number of HPN patients can be kept to a minimum. Data from the British Artificial Nutritional Survey (Elia, 2001) suggest that there are ten patients per 1 000 000 of the UK population receiving HPN. In Scotland, however, the prevalence is higher at fourteen patients per 1 000 000 of the population.

HPN has allowed more patients to be discharged from hospital who would otherwise have remained in hospital with increased healthcare costs. Patients receiving this treatment can enjoy a reasonable quality of life, independent of hospital. Fundamental to the success of this treatment is careful training of the patient and, sometimes, the carer. The

purpose of this training using validated catheter care procedures is to avoid catheter-related complications such as infection, central vein thrombosis, mechanical problems and occlusion. Some patients are managed in centres where there is a lack of expertise or experience in the management of the central catheters required for HPN. It is likely, therefore, that these patients may experience a higher incidence of catheter-related complications and consequent admissions to hospital, and thereby require greater healthcare resources. Historically, patients are referred to regional centres where there is expertise in HPN. This type of referral is inconvenient for patients.

##### **A Managed Clinical Network for home parenteral nutrition**

In 1998 the National Health Service in Scotland undertook a review of its acute services. This review was carried out in order to take a critical look at the delivery of acute services, and to involve health professionals and the public in its discussions in order to allow ownership and a sense of involvement. The single most important recommendation of the Acute Services Review (Scottish Executive, 1998) was that managed clinical services should be developed. Scotland's geography and its dispersed population mean

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that it is not feasible that the whole population can have access to all high-quality services within easy travelling distance. It was evident to the authors of the review that 'more systematic and robust mechanisms are needed to monitor the equitable provision of high-quality clinical services throughout Scotland' (Scottish Executive, 1998).

A Managed Clinical Network is defined as linked groups of health professionals and organisations from primary, secondary and tertiary care, working in a coordinated manner, unconstrained by existing professional and Health Board boundaries, to ensure equitable provision of high-quality clinically-effective services throughout Scotland (National Health Service, 1999). The Managed Clinical Network for HPN is a method of delivering the seamless care described in the Acute Services Review (Scottish Executive, 1998). It is not intended to centralise care, but to allow treatment to be delivered as near to the patient's home as possible. It has a defined structure and must work within the specified framework supported by the National Services Division of the Scottish Executive Health Department (National Health Service, 1999). A service agreement exists between Tayside University Hospital NHS Trust and the National Services Division. As such the Trust has agreed to host the network, which included the lead clinician and the network coordinator.

#### *Quality assurance*

The Clinical Standards Board for Scotland (CSBS) was established as a special health board of the National Health Service in Scotland in 1999. The remit of the CSBS is to run a programme of quality assurance and accreditation for clinical services. It is mandatory, therefore, that the network works with the CSBS towards an acceptable quality-assurance framework. The are two key components to this framework:

1. a set of standards;
2. agreed arrangements by which performance against the standards will be audited and monitored, and action taken to implement any recommendations that are agreed in response to findings (Clinical Standards Board for Scotland, 2001b).

#### *Standard setting*

A set of clinical standards was prepared for the network. These standards were prepared using previously-published documents (Wood, 1995; Clinical Standards Board for Scotland, 2001a). The network is expected to demonstrate that arrangements are in place to collect the data required in the monitoring of performance, and to take action as required. Thus, an audit tool has been developed to monitor practice against standards. As the standards are still in draft stage with the CSBS, it is not appropriate to include them at the time of writing the present paper. However, they fall into the standard statements described in Table 1. The standards are set out in the following format:

a standard statement explaining the level of performance to be achieved;

**Table 1.** Draft standard statements for the Scottish Home Parenteral Nutrition (HPN) Managed Clinical Network

There is a named lead clinician for HPN services
The management of patients receiving HPN is multi-professional
All health professionals involved undertake continuing professional development in the subject of artificial nutritional support
The patient and/or carer is involved in decision making at all stages of care from assessment to discharge
All patients will be provided with continuing support after discharge
All patients are provided with appropriate information materials about their diagnosis and treatment
Prospective clinical audit is an integral part of the HPN Managed Clinical Network

a rationale providing the reasons why the standard is considered to be important; criteria stating exactly what must be achieved for the standard to be reached.

The process by which the standards have been developed is important. The network is required to demonstrate that it has involved all the relevant professionals responsible for providing the service to patients. Members of the network were asked to comment on draft copies, and amendments were made as necessary. A revised set of standards has been submitted following the advice of the CSBS, complying with their guidelines for preparation of quality-assurance frameworks (Clinical Standards Board for Scotland, 2001b; Scottish Intercollegiate Guidelines Network, 1995).

It is important for the network to support the teams who wish to manage their patients locally. Centres providing this service are expected to have a multi-professional nutrition team with a named lead consultant in charge and at least a dietitian, specialist nurse and pharmacist.

#### *Audit*

The collection, processing and dissemination of results from audit data are fundamental to the success of the network. This information, along with evidence from the literature, will allow the procedures and protocols to be updated in an attempt to ensure that there is adoption of best practice. Visits by the coordinator to nutrition teams involved in the management of patients receiving HPN have highlighted variations in clinical practice. These variations include the composition, function and level of activity of nutrition teams, the use of evidence-based procedures and protocols, frequency of clinic review and the level of monitoring of the patients. Lack of adequate resources for the effective organisation of a nutrition support team is an issue in several centres, which has implications for their ability to meet the required standards.

#### *Activities*

There are several issues to be addressed by the network. Progress has been made in the preparation of protocols for patient monitoring, such as those for nutritional status and biochemical, including micronutrient, status. Funding is

often a major problem for centres undertaking the management of patients with HPN. This situation results in protracted discussions between primary and secondary care professionals and health boards to agree financial responsibility. The network hopes to help to resolve some of these problems and to facilitate national contracting, which will result in financial savings.

As patient numbers in individual HPN centres are relatively small, participation in the network will allow increased patient numbers which will allow more meaningful research and audit projects to be carried out.

### References

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