Home Enteral Nutrition (HEN) Project

Development
of a
Best Practice Model
for
Service Delivery of HEN

Phase II
Best Practice Model & Recommendations

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Austin & Repatriation Medical Centre

Southern Health Care Network

Bendigo HEALTH CARE GROUP

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Glossary of Terms

ACHS	Australian Council of Health Care Standards
AIDS	Acquired Immunodeficiency Syndrome
AuSPEN	Australian Society for Parenteral and Enteral Nutrition
DAA	Dietitians Association of Australia
DHS	Department of Human Services (Victorian Government)
EDS	Effective Discharge Strategy
EQuIP	Evaluation and Quality Improvement Program
GP	General Practitioner
HACC	Home And Community Care
HEN	Home Enteral Nutrition
HITH	Hospital In The Home
HIV	Human Immuno-deficiency Virus
PAC	Post Acute Care
PHACS	Primary Health And Community Support
RDNS	Royal District Nursing Service
SIG	Special Interest Group
VACS	Victorian Ambulatory Classification System

Executive Summary

The use of home enteral nutrition (HEN) is increasing both nationally and internationally. This increase has instigated recent examination of the quality of care delivered to this client group. In 1996 a Ministerial Working Party was formed in Victoria to review the provision of HEN. The outcome of this review has been the implementation of an innovative state-wide funding initiative for HEN. Since 1997, HEN clients managed in the public health care sector in Victoria have received subsidised formula and equipment under the Victorian Government Department of Human Services HEN Pilot Program.

This project has been funded through the HEN Pilot Program. The aim of the project was to develop a service delivery model, and corresponding recommendations, for the implementation of best practice guidelines for HEN in Victoria. In the first phase of the project research was undertaken to profile existing HEN service systems in metropolitan and rural Victoria and to identify gaps in service systems from a customer and service provider perspective. This information was attained through a series of interviews with dietitians from HEN funded health care facilities, a questionnaire to dietitians, state-wide, and interviews with HEN clients. Results and discussion pertaining to the first phase of the project can be found in the document entitled: 'Development of a Best Practice Model for Service Delivery of HEN, Phase I Research Report'.

This document describes a proposal for best practice management of HEN in Victoria. Results from our research have been used to determine characteristics of service systems seen as integral to implementation of best practice guidelines: the AuSPEN 'Clinical Practice Guidelines for HEN in Australia' (Appendix 1).

In developing this model consideration has been given to current health care reforms and future directions of health care policy and planning. A strong consumer focus has been taken that recognises the shifting emphasis of health care delivery from the acute sector to the provision of responsive and accessible services at a local level. The service structures that have been recommended for implementation of quality HEN services have attempted to incorporate existing service providers and programs, from both the acute and community settings, in order to ensure continuity of care for the client throughout their episode of HEN.

A number of key features that were seen as central for best practice have been integrated into our model. These include:

- Team approach involving acute and community sectors.
- Clear roles and responsibilities of team members, enabling flexibility for interchange of functions.
- Central coordination of the HEN team to facilitate continuity of care across both health care sectors.
- Availability of domiciliary services for non-ambulatory clients.
- Equitable client access to HEN supplies.
- 24-hour HEN support.
- Cental point of contact for HEN clients.
- Reduced reliance on acute care services with increased utilisation of community based services.

The proposed model is presented in terms of the service system structures and processes required for best practice. Below is a summary of the key best practice recommendations made throughout the succeeding document.

Recommendations

Recommendation 1 – Dietetic HEN Coordinator

Each HEN funded health care facility allocate a dietetic HEN coordinator/s to undertake clinical, administrative and coordination functions.
(Section 4.1)

Recommendation 2 – Domiciliary Services

Dietetic HEN coordinators undertake a domiciliary role in order to:

- Facilitate continuity of care.
- Enable appropriate management of HEN clients in the community.

(Section 4.1)

Recommendation 3 – HEN Stomal Therapist

Each Health Care Network or Region have a community based stomal therapist with specialist expertise in the management of HEN.
(Section 4.3)

Recommendation 4 – General Practitioners

General Practitioners be supported through education programs and resources as primary care physicians for management of HEN clients.
(Section 4.4)

Recommendation 5 – Replacement of Gastrostomy Tubes

An expert panel be formed to review and develop policies for replacement of gastrostomy tubes in the community.
(Section 5.4.2)

Recommendation 6 – 24-hour HEN Support

Each Health Care Network / Region establish policies and procedures for 24-hour support of HEN emergencies.
(Section 6.1)

Recommendation 7 – Supply of Product

HEN clients be ensured of easy and equitable access to subsidised HEN supplies. The option of home delivery of supplies should be incorporated into all HEN supply systems. There should be an agreed standard for provision of supplies and services across the state.
(Section 6.2)

Recommendation 8 – Professional Development Resources
Further investigation be undertaken into the options for development of multi-disciplinary short courses and supporting resources for HEN.
(Section 7)

Recommendation 9 – Information Management
Standardised tools be developed to assist information management (assessment, data collection, documentation and communication).
(Section 8)

Recommendation 10 – Performance Measures
Performance measures for HEN be developed, with corresponding tools for measurement.
(Section 9)

Recommendation 11 – State-wide Coordination
A state-wide coordinator, with intimate knowledge of HEN services, be appointed to oversee the delivery of HEN in Victoria. This position should be funded through the HEN Pilot Program.
(Section 10)

Recommendation 12 – HEN Special Interest Group
A multi-disciplinary HEN Special Interest Group be formed, under the auspice of an appropriate professional body (eg AuSPEN, DAA), to support the state-wide HEN coordinator and facilitate development of supporting resources for HEN.
(Section 10)

Recommendation 13 – Purchaser / Provider Arrangements
Investigation be undertaken into purchaser / provider arrangements for provision of:
- Dietetic HEN coordinators.
- Regional HEN stomal therapists.

(Section 11)

1. Introduction

1.1 Background

Enteral nutrition is a feeding modality used to support individuals who are unable to manage adequate nutrition via the oral route as a result of impaired ingestion, digestion or absorption of nutrients. Enteral nutrition is commonly used in clients with neurological disorders, gastrointestinal disorders, cancer, cystic fibrosis and HIV/AIDS. It involves delivery of a nutritionally complete formula directly into the intestinal tract via a feeding tube. In the shorter term enteral nutrition is usually delivered via a naso-gastric or naso-jejunal tube. For longer-term nutritional therapy a gastrostomy or jejunostomy feeding tube is usually inserted.

Home enteral nutrition (HEN), as the name implies, is the use of enteral nutrition therapy in the home setting. HEN support allows enterally fed hospital clients, who are otherwise medically stable, to be discharged to the community. There are many benefits to the provision of enteral nutrition in the home. It enables improved quality of life and increased independence for the client by return to their home environment. The cost benefits to the health care system can be significant. Timely introduction of HEN can result in reduced length of hospital stay, the transfer of care to the community enabling more efficient and effective use of hospital beds. In addition, the increased acceptance and use of enteral nutrition in the home setting has obviated much of the former need for long term care in health care institutions.

The use of HEN is increasing both nationally and internationally. In line with the national and international trends, the number of HEN clients managed throughout Victoria continues to increase each year (Elia 1995; DHS July 1997). As a result, the management of HEN in Victoria has recently received considerable attention. In 1996 a Ministerial Working Party was formed to review the provision of HEN in Victoria (Appendix 2). A major outcome from this review was the introduction of the HEN Pilot Program. This program is the first state-wide initiative to assist in the provision of HEN through subsidisation of HEN formula and equipment. The Pilot Program entitles recipients of HEN, managed under the public health care system, to subsidised HEN supplies (formula and equipment).

The research undertaken by the Ministerial Working Party identified an apparent disparity between institutions in their management of HEN clients (DHS July 1997 p.8). Coinciding with this insight was the development of the Clinical Practice Guidelines for Home Enteral Nutrition in Australia (Appendix 1). It was proposed that the introduction and adoption of these clinical practice guidelines would "greatly assist in consistency of best practice in HEN therapy throughout Australia" (DHS July 1997, p.8). As such it was recommended by the Ministerial Working Party that the provision of HEN in Victoria should be based on this framework.

Following the release of these recommendations the ensuing issue of implementation was raised. The rapid growth in the use of home enteral nutrition presents a challenge for health care providers in this era of finite health care resources. The question of how to deliver quality care for this client group in the most efficient, and cost effective manner, was the impetus behind the this research project. The aim of the project was to identify and define best practice in service delivery for HEN in Victoria.

In the first phase of the project, research was undertaken to profile current service systems in place for managing HEN in Victoria and to identify gaps in existing structures. This information was attained through a series of interviews with dietetic managers from HEN funded health care facilities, a questionnaire to dietitians state-wide and interviews with HEN clients managed by the Health Care Networks / Regions involved in the project. The key findings from this research are described below.

1.2 Key Research Findings

The results of our research supported the initial finding of the Ministerial Working Party; delivery of HEN services is managed in a variety of different ways across Victoria. At the time of our research there was no standardised infrastructure in Victoria to support a generic system for provision of HEN services. A number of gaps were consistently highlighted as factors limiting optimal provision of HEN services. The main issues raised by HEN clients and dietitians are outlined below.

HEN Clients:
- Limited domiciliary services for the management of HEN.
- Varying access to multi-disciplinary expertise for the management of HEN, particularly with regard to the management of tubing and stomal issues.
- Multiplicity of contacts with regard to HEN.
- Inequitable access to supply of HEN products.
- Lack of 24-hour support service for HEN.

Dietitians:
- Limited domiciliary services for the management of HEN.
- Varying access to multi-disciplinary expertise for the management of HEN, particularly with regard to the management of tubing and stomal issues.
- Coordination of care.
- Inequitable access to supply of HEN products.
- Lack of 24-hour support service for HEN.
- Lack of definition of roles and responsibilities of professionals involved in the management of HEN.

A number of the perceived issues were common to both HEN clients and dietitians. These are described in more detail below.

Limited domiciliary services for the management of HEN
At the time of our research it appeared that few areas had the capacity to provide a domiciliary service for the purpose of managing their HEN client group. This apparent gap in service structures presented a number of logistical barriers to meeting standards of care for HEN. In the initial phase of establishing HEN, clients may be discharged prior to receiving adequate education regarding management of their HEN. This situation seems to becoming increasingly common with the pressure to decrease hospital length of stay. The capacity to conduct a home visit in this situation is necessary if the client is to be adequately skilled such that they can manage independently.

A view put forward by both HEN clients and dietitians proposed that the ability to conduct a home visit in the initial phase was something that would benefit all HEN clients. It was suggested that more effective client education could be achieved in the home environment. Further support was received for a domiciliary service with the opinion that more accurate assessments can be made in the home, enabling development of care plans that better meet the needs of the individual.

Similarly the lack of domiciliary services for management of HEN presents issues for reviewing HEN clients. Many clients, particularly non-ambulatory clients, have great difficulty in attending the hospital for review of their HEN. Consequently those clients living in an area not serviced by a domiciliary team can only be reviewed by telephone.

Varying access to multi-disciplinary expertise for the management of HEN, particularly with regard to the management of tubing and stomal issues.

It is recommended that HEN clients are best managed by a multi-disciplinary team, however in practice this did not always seem to be occurring. Very few organisations had a specific team established to manage HEN either through provision of an outpatient clinic or as a domiciliary service. Management was commonly reported to be left to a single professional, often the dietitian. Alternatively a variety of professionals might be involved, however this was often managed in an uncoordinated manner. This lack of centralised coordination was seen to result in poor communication and a disjointed and inefficient plan of care for the HEN client.

An aspect of care that has raised particular difficulties for many organisations managing HEN clients was with regard to the management of stoma and tubing issues. There was an apparent gap in many existing service structures in terms of access to professionals with expertise in these areas. This can result in untimely or poor management of tubing or stoma sites. These aspects of care require access to professionals with specific training or extensive practical experience in this area of enteral nutrition therapy.

Coordination of care and multiplicity of contacts

An issue raised by many of the HEN clients interviewed was the multiplicity of contacts associated with the management of their HEN. A single point of contact to either manage or coordinate management was perceived as a better alternative. Similarly it would seem from a professional's perspective that centralised coordination has the potential to facilitate a more streamlined service for HEN.

Inequitable access to supply of HEN products

An issue raised by HEN clients and professionals alike was equity of access to HEN supplies for clients. Access difficulties can occur for non-ambulatory clients, for clients with no means of transport and for clients who live in geographically isolated areas. Access restricted to business hours was also a limitation of many supply systems.

Home delivery of HEN supplies offers a solution to overcome this issue, however it was not a service generically integrated into supply structures at the time of our research.

Lack of 24-hour support service for HEN

An area of concern raised by a number of HEN clients interviewed was the lack of a specific 24-hour contact for HEN. The main concern for clients was the scenario of their enteral tube falling

out. At the time of our research it seemed that hospital emergency departments were the only points of contact in this situation. However there is a feeling of dissatisfaction or lack of confidence, amongst HEN clients interviewed, in the ability of these services to adequately manage issues associated with HEN. This suggests that new options or modification of existing systems might need to be explored for managing such situations.

Lack of definition of roles and responsibilities of professionals involved in the management of HEN

Our research revealed an apparent lack of clearly defined roles and responsibilities of the various professionals that might be involved in the management of HEN. Variability in the profile of service providers in different areas was considered to contribute to this situation. It was proposed during our research that clearly defined professional responsibilities would facilitate more streamlined and cost effective care.

It was apparent from our research that concomitant to the need for clarification of professional roles and responsibilities is the perceived need for allocation of adequate resources for service provision. Ensuring client access to appropriate service providers is integral to attaining and maintaining best practice standards for HEN.

In addition to the perceived gaps in existing service systems a number of auxiliary resources for supporting best practice were also raised by dietitians. Commitment to ongoing review and development of state-wide policies and procedures was seen to be important for standardisation and streamlining of HEN services. Support in the development and maintenance of professional expertise was also highlighted as a key requirement for best practice.

1.3 Best Practice

The concept of best practice in delivery of health care services has been adopted from reforms undertaken in commercial industry over the last couple of decades. In the National Allied Health Best Practice Industry Report, Crompton and Robinson (1997) note that “successful business places a major emphasis on continuous improvement and customer service through use of integrated strategies which have been developed with the full involvement of the workforce. The overall aim is to improve both cost and quality.” Concurring with this philosophy is the belief that an emphasis on best practice in public health care will allow better management of the health budget while simultaneously increasing the focus on public health and quality care (Crompton & Robinson 1997).

The overall aim of this project was to develop a model of best practice for the service delivery of HEN in Victoria. The AuSPEN Clinical Practice Guidelines (Appendix 1) and the recommendations from the Ministerial Working Party HEN (Appendix 2) provide best practice standards of care. These standards of care provided the performance indicators against which to benchmark and evaluate the efficiency and effectiveness of existing service delivery systems. Analysis of the service delivery profiles and key findings obtained from our research (as outlined in Section 1.2) have been used to define the elements of HEN service systems, that we believe, are intrinsic to the delivery of best practice HEN services in Victoria. This document describes our proposed model of best practice for the management of HEN in Victoria.

2. A Model of Best Practice

In developing this model of best practice for delivery of HEN services in Victorian many factors have been taken into account. The issues and gaps in service systems, identified in our research, have been addressed. Attention has been given to aligning the model with existing standards of care for HEN and health care quality frameworks. The model attempts to integrate existing health care services while taking into account health care reforms and future directions of health care policy and planning. The philosophy and principles behind the model are discussed below, followed by an outline of the scope and structure of the model.

2.1 Philosophy and Principles of the Model

"Best practice dictates that the central goal of any organisation must be to meet the needs of its customers" (Crompton & Robinson 1997). The philosophy of customer focus has been central in the development of this model. HEN clients and their carers have been considered the primary customers of HEN services. The needs of other key stakeholders in HEN, both internal and external to the health care facility operating the HEN service, have also been taken into account in the development of this model.

In this era of finite health care resources, sustainable health care services are dependent on the implementation of cost containment measures. As such, in focusing on the development of a model that delivers a quality service to HEN customers, careful consideration has concurrently been given to the economic viability of options.

As mentioned in the introduction, the Clinical Practice Guidelines for HEN in Australia (Appendix 1) have been developed with the aim of achieving "better health outcomes by improving the practice of health professionals involved in the care of patients requiring HEN". These guidelines have formed the standards of care, upon which the model has been based.

In line with the recommendations of the Clinical Practice Guidelines for HEN in Australia (Appendix 1), our model of service delivery revolves around a team approach. Nutrition support teams operating within hospitals have been shown to increase cost-effectiveness of enteral nutrition support. In addition, at the time of our research, no specific training courses existed that skilled or qualified any one professional discipline to manage HEN, in isolation of other disciplines. This fact, in conjunction with proposed cost containment factors, formed the rationale for taking a team approach in our model.

The direction of health care reforms has also been taken into consideration in the development of this model. In recent times much attention has been given to the structure of the public health care system; in particular hospitals have been the focus of significant change. As described in a recent Primary Health and Community Support System (PHACS) discussion paper, hospitals are evolving into facilities that focus mainly on the care of the seriously ill. New drugs, technology and changes in medical practice have significantly reduced the lengths of stay required for many conditions. Some acute and chronic conditions are now treated entirely outside the hospital environment. Patients who have passed the acute stage of their condition are encouraged to complete their recovery in a community setting (DHS May 1998, p.26). The provision of enteral nutrition support is one such treatment modality that can be transferred from the hospital setting to the community with the provision of HEN services.

As a result of this changing role of hospitals, public health and community sector services are also undergoing reform and development, in order to support this reorientation of care from the acute sector to the community sector. The desired outcome of these reforms is to reduce the utilisation of hospital resources through strengthening of local service systems. The aim is to improve the access, quality and responsiveness of local service systems. In order to achieve this, and ensure continuity of care, service providers from both health care sectors will be required to form strategic partnerships.

Complimentary to this reform process is the Department of Human Services initiative addressing Effective Discharge Strategies (EDS), (DHS December 1998). This project is being undertaken at the time of writing through various hospitals across the state. The aim of these EDS projects is to design and implement strategies for discharge consistent with standards for the continuum of care, as defined in The Australian Council on Healthcare Standards, Evaluation and Quality Improvement Program (EQuIP), (ACHS 1998).

Our model for provision of HEN services has embraced this philosophy of providing quality services at a local level, which are responsive and accessible. The model consists of service providers from both the acute and community settings to ensure continuity of care for the client throughout their episode of HEN. Initial care is required from the acute sector which, after discharge, is transferred predominantly to locally accessible services. However links with the acute sector are maintained. Discharge procedures have been recommended to conform to those of the EDS projects.

The ultimate aim of the model is to provide flexible services that can be moulded to meet the individual needs of each HEN client.

2.2 Scope of the Model

Victorian Public Health Care Sector

With this research being funded through the Victorian Government Department of Human Services' HEN Pilot Program, the development of this model has focused on the provision of HEN in the public health care system in Victoria. As such the model has not addressed Commonwealth or privately funded health care facilities, that might also manage enterally fed clients at home, or in supported accommodation. Residential aged care centres presently receive funding for supply of enteral nutrition formula and equipment through Commonwealth Government funding. The private health care sector at the time of our report does not have any subsidy available for provision of HEN supplies or service provision.

While a needs assessment of these health care providers and facilities has not been undertaken, it is, however, envisaged that the structure of the model could be transferred to the private health care sector and to residential aged care facilities. This could be managed by purchase of public HEN services or by replacement of the professionals nominated in the model with private or commercial providers. The interventions required, and the involvement from various professional disciplines, for best practice management of long term, enterally fed clients should be the same across all health care sectors.

Paediatric and Disease Specific Sub-groups

The profile of HEN clients managed in Victoria is varied in terms of age and the disease state which necessitates the use of HEN. As such, many sub-groups can be formed. Many of these sub-groups have specific requirements particular to their disease state or their age. Paediatric clients have different needs to that of adults. Particular conditions such as Cystic Fibrosis, Cerebral Palsy or HIV/AIDS, are examples of sub-groups that have requirements specific to the respective disease state.

The AuSPEN Clinical Practice Guidelines (Appendix 1) are standards of care that are generic in their application. They do not address the specific requirements of particular sub-groups of HEN clients. The aim of the model is to define the process and structure of a HEN service system that will enable the AuSPEN standards of care to be implemented. As such the model we have developed outlines a structure of service delivery that should encompass the generic requirements of all HEN clients. It does not propose to address additional requirements specific to particular sub-groups of HEN clients. These requirements need to be detailed through more specific research and development of disease or age specific clinical pathways.

Hospital Size and Location

As clearly highlighted in our research, there are many different structures in place for managing HEN clients across Victoria. The logistics of managing HEN differs between rural and metropolitan areas. There are also different logistical issues facing larger versus smaller health care facilities in their management of HEN. There are obvious difficulties and issues in attempting to develop a model of service delivery that can address these logistical variances. However the model developed is based on broad level structures with a focus on flexible options for integration into metropolitan and rural areas. These structures and options should similarly be adaptable to both large and small health care facilities.

2.3 The Model in Summary

The development of this best practice model has been structured on a conceptual framework, the Donabedian model (Donabedian 1969). This quality framework for health care is based on three facets of care: structure, process and outcomes. The three components of this framework, and the way they interrelate, are outlined, overleaf, in Figure 1.

Within this framework the questions relating to the ‘what, when, where, who and how’ of HEN services are answered. In the sections that follow throughout this document, the model is broken down into smaller components and gradually reconstructed.

Section 3.0 describes the process, or interventions, that should occur from the point that HEN is initiated to the time it is ceased. We have defined this time frame as an episode of care for HEN. Within an episode we have defined various phases in which certain processes or interventions should occur in terms of when and where they occur. The AuSPEN Clinical Practice Guidelines (Appendix 1) provide the basis for the processes defined in our model.

A key aim of our model is to define the structure or resources required for implementation of the process. Section 4.0 describes the service providers and supporting resources required throughout the whole HEN episode of care.

Section 5.0 integrates Sections 3.0 and 4.0. Here the service providers involved in each phase of a HEN episode of care are nominated, and their roles and responsibilities in implementing the processes or interventions are defined.

Sections 6.0 to 11.0 discuss other structural aspects of the model relating to indirect patient support services, supporting resources and funding requirements. Section 12.0 outlines recommendations for future directions.

Key Features of the Model

The best practice model, proposed as a result of our research, has a number of key feature:

- Team approach involving acute and community sectors.
- Clear roles and responsibilities of team members enabling flexibility for interchange of functions.
- Central coordination of the HEN team to facilitate continuity of care across both health care sectors.
- Availability of domiciliary services for non-ambulatory clients.
- Equitable access to HEN supplies.
- 24-hour HEN support.
- Cental point of contact for HEN clients.
- Focus on flexible and accessible, local HEN services.
- Reduced reliance on acute care services with increased utilisation of community based services.

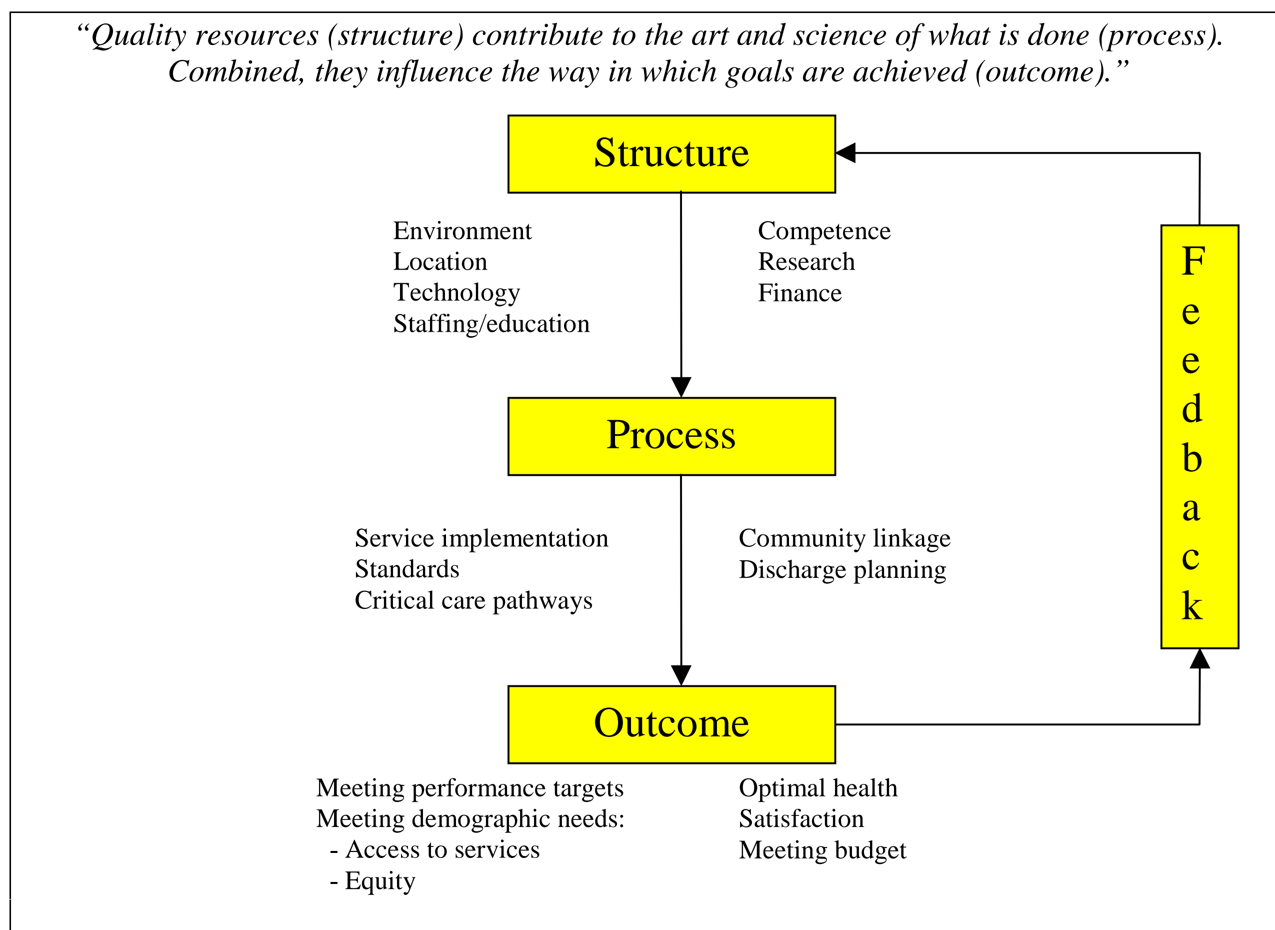


Figure 1 Donabedian Model (Donabedian 1969)

3. Interventions

HEN can be viewed as an episode of care for an individual client. The time frame of this episode might be any length of time from a matter of weeks, months or years. Regardless of the time frame there are a number of phases through which each client must pass. We have defined four distinct phases, as depicted below in Figure 2.

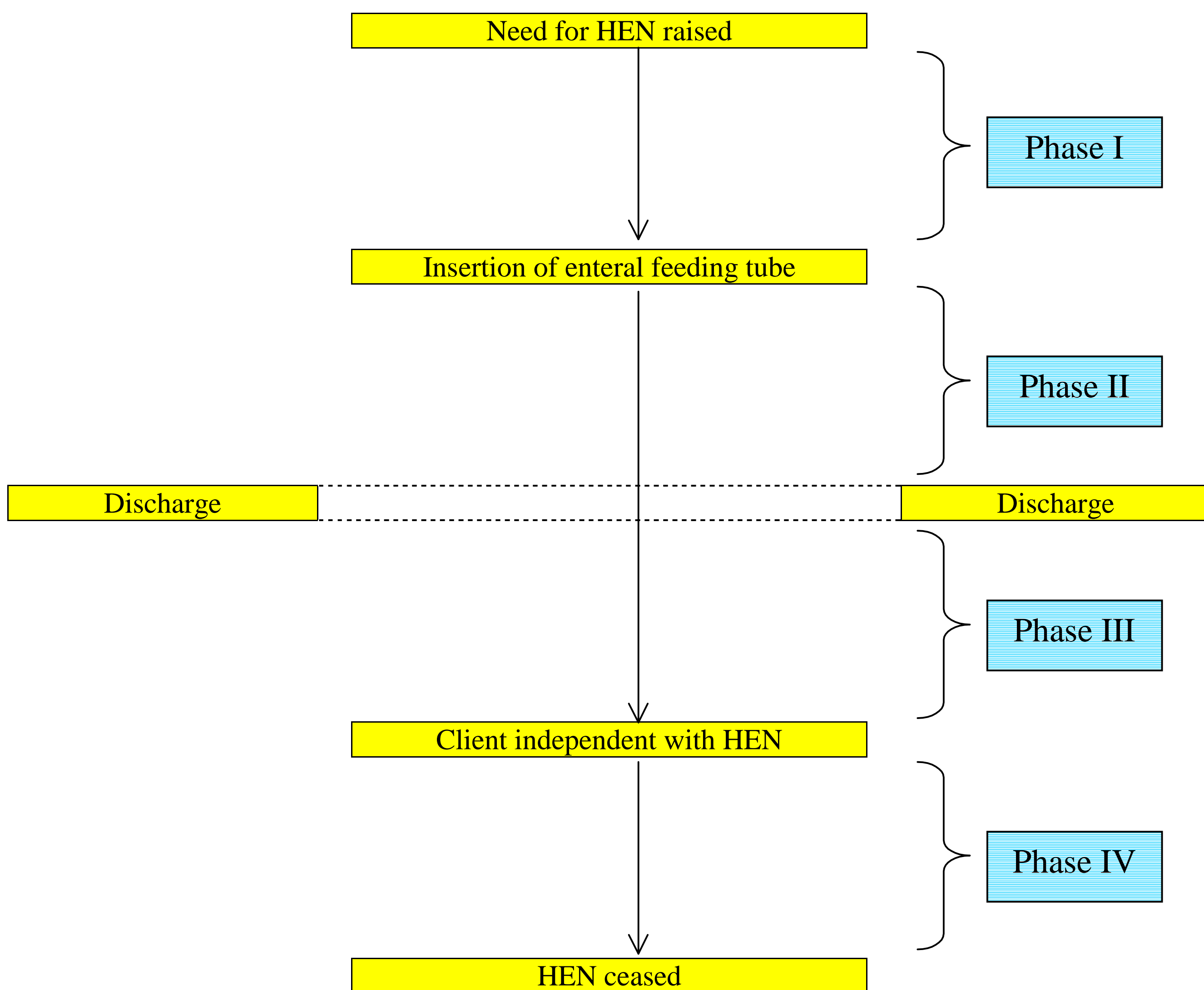


Figure 2 Four Phases of the Model

In each of these four phases certain processes must occur. The AuSPEN 'Clinical Practice Guidelines for HEN in Australia' (1997) are a set of standards outlining a minimum level of practice necessary to assure safe and effective HEN. We have incorporated these into our model with some additions and modifications based on our research. What follows is a summary of the processes we propose should occur at each Phase in order to achieve best practice.

Note: AuSPEN Guidelines (Appendix 1) are denoted in *italic* in the summary tables that follow.

3.1 Phase I (Pre-HEN)

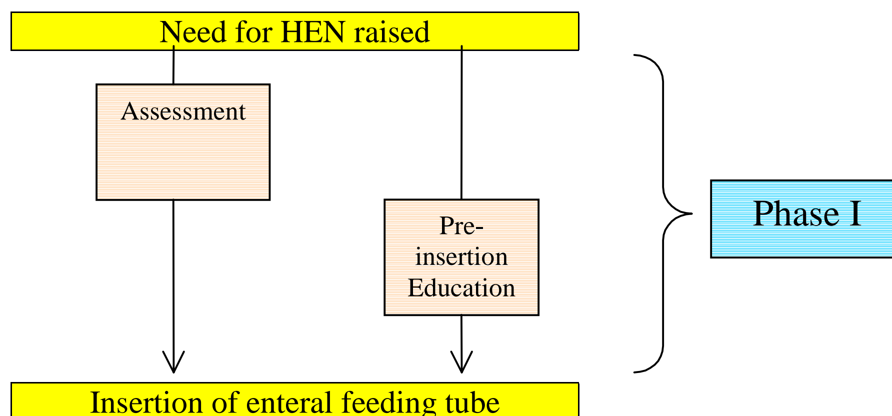
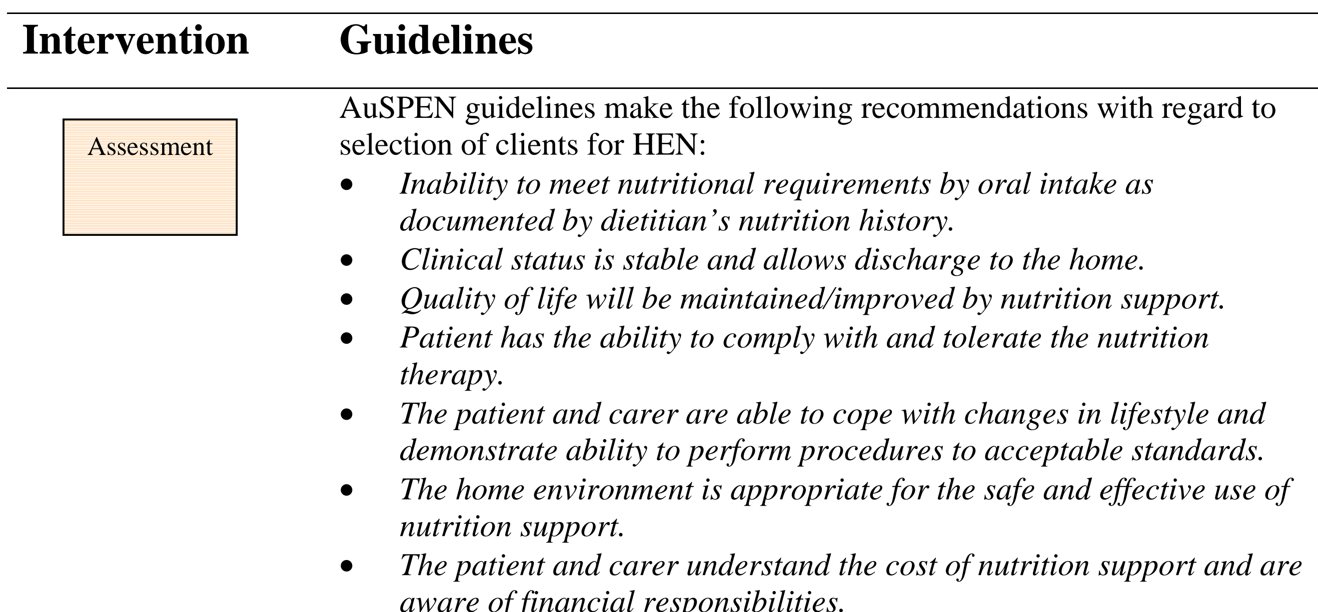


Figure 3 Processes for Phase I

Phase I (initiation of HEN) occurs between the time the need for enteral nutrition is raised and the time that an enteral feeding tube is inserted for the purpose of feeding in the home environment. The processes that should occur are depicted in Figure 3 above. In this phase the client must be assessed for their eligibility to be able to manage HEN. We believe there needs to be some education integrated into this assessment process. In order for the client's ability to cope with HEN to be appropriately assessed, the client must have some knowledge of the implications this therapy will have on their lifestyle.

Once deemed appropriate for HEN, the client and/or their carer should also receive some broad education about HEN in preparation for the insertion of the tube. In our research, a number of HEN clients noted that their initial experiences with HEN were quite distressing. In retrospect, they felt they had been poorly informed about HEN. As a result they found the adjustment more difficult than they otherwise might, had they had the opportunity to learn more about HEN before hand.

Table 1 below outlines the components to each of these processes.



Intervention	Guidelines
Assessment	AuSPEN guidelines make the following recommendations with regard to selection of clients for HEN: • *Inability to meet nutritional requirements by oral intake as documented by dietitian's nutrition history.* • *Clinical status is stable and allows discharge to the home.* • *Quality of life will be maintained/improved by nutrition support.* • *Patient has the ability to comply with and tolerate the nutrition therapy.* • *The patient and carer are able to cope with changes in lifestyle and demonstrate ability to perform procedures to acceptable standards.* • *The home environment is appropriate for the safe and effective use of nutrition support.* • *The patient and carer understand the cost of nutrition support and are aware of financial responsibilities.*

	The selection of the most appropriate route of administration for HEN will take into account the expected duration of the support, the conscious state and clinical condition of the patient. Possible routes include: • *Naso-gastric* • *Naso-duodenal* • *Naso-jejunal* • *Gastrostomy* • *Jejunostomy*
Pre-insertion education	The HEN client and/or carer should be informed of: • What HEN entails. • What an enteral tube looks like. • How and when formula can be administered. • Supply and cost implications. • Follow-up support. • Support groups.

Table 1 Intervention Guidelines for Phase I

3.2 Phase II (Initiation of HEN) & Phase III (Post Discharge)

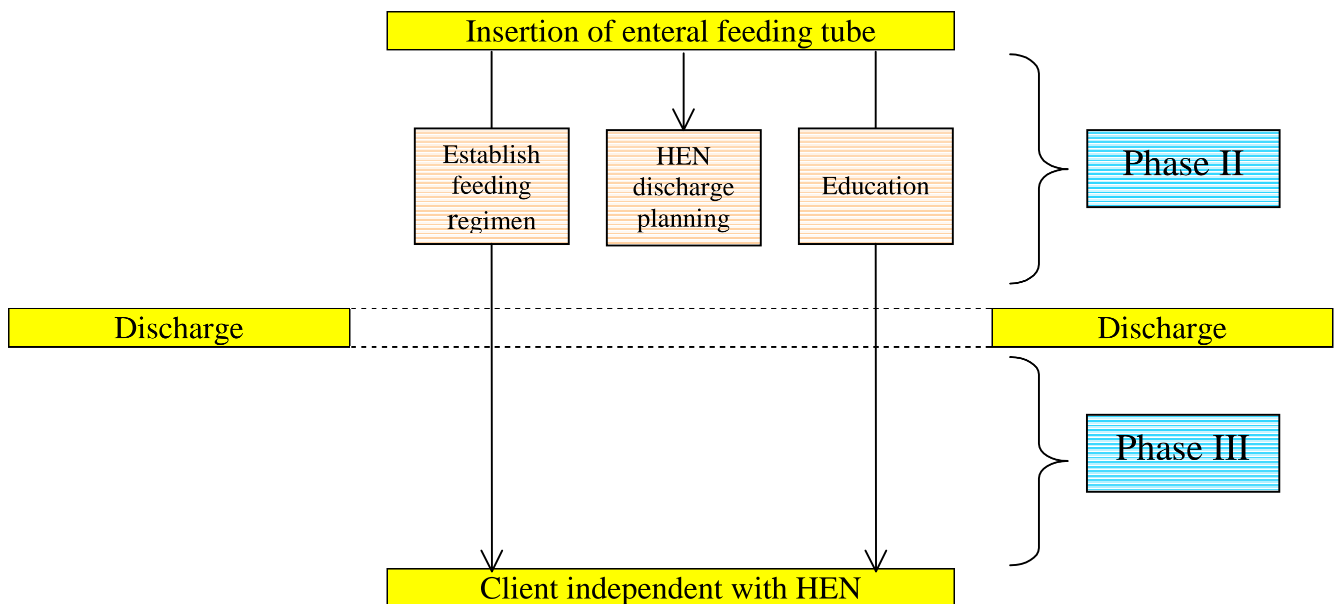


Figure 4 Processes for Phases II and III

Phases II and III occur between the time the enteral tube is inserted (with the view to use in the home environment) and where the HEN client is able to independently manage their HEN. Dividing these two phases is the point of discharge. Phase II, the initiation of HEN, occurs in the

hospital environment. Phase III occurs post discharge, in the home environment. The timing of discharge from the insertion of the tube can vary considerably with each individual client. A client's admission can range from an extended period of time to just an overnight stay, depending on the complexity and stability of the client's medical condition. At the extreme a client may have an enteral tube inserted as a day procedure.

Regardless of the timing of discharge, certain processes or interventions must occur, once the enteral tube is inserted, to enable the client, or their carer, to manage their HEN independently. These processes are generally initiated in the hospital setting however they might need to be carried over into the home environment depending on the timing of discharge. In the case of an extended hospital admission the client might be able to manage their HEN quite independently by the time they are discharged from hospital. However, with the ever-increasing pressure to decrease hospital length of stay, the situation might arise where it is not possible to adequately complete these interventions in the hospital environment, owing to the timing of discharge. As such, these interventions might be initiated in the hospital environment and completed in the client's home. Alternatively, they might need to be undertaken predominantly in the home environment.

Given the variability in the timing of discharge, and the subsequent variability in the length of phases II and III, HEN service systems must be designed to ensure interventions can be carried out in a seamless manner in either phase, that is in the hospital or at home. Broadly these processes involve establishment of the feeding regimen, HEN discharge planning and education of the client. Table 2 details the processes that should occur across these two phases.

Interventions	**Guidelines**
Establish feeding regimen	The client must have their nutritional requirements assessed and the feeding regimen established. AuSPEN guidelines suggest the following with regard to selection of formula and timing of feeds for HEN: • *The selection of formula will be based on a balance between the clinical requirements, mode of delivery tolerance, long-term cost and availability.* • *The formula will be appropriate for the disease process and be adjusted according to metabolic requirements.* • *Formula will meet estimated nutritional and fluid requirements, with consideration for other sources of fluid/restrictions.* • *The cost implications of type and quantity of feeds and the availability of government subsidies for HEN should be considered in the selection process.* • *Rate and timing of administration of solutions shall be based on patient tolerance and home routine.*
HEN discharge planning	The following aspects of care need to be arranged at the time of discharge: • Supply of HEN products • Coordination of home supports • Documentation • Follow-up arrangements

The client should receive education and written information on all aspects of HEN care.

The AuSPEN guidelines state the following:
Upon discharge from hospital the patient/carer will know:

- *How the function of GIT has changed and the reason for enteral nutrition.*
- *How to manage the delivery system: pump or gravity drip or syringe*
- *The principles of hygiene*
- *How to prevent and recognise complications such as infection, aspiration and mechanical complications such as occlusion or misplacement of the tube.*
- *How to irrigate a blocked tube.*
- *How to change malfunctioning parts of the tube.*
- *Storage, hang-time and means of provision of feeds*
- *Names of personnel to contact 24/hours per day*
- *Follow-up arrangements*

The patient/carer will be able to:

- *Check tube position*
- *Prepare feed ready for administration*
- *Connect feed to feed tube*
- *Program feeding pump*
- *Administer a bolus feed down the tube*
- *Administer medication down the tube*
- *Disconnect feed and flush water down the tube*

In addition the client receive education regarding:

- Feeding regimen
- Oral intake and/or mouth care
- Care of stoma (if applicable)

Table 2 Intervention Guidelines for Phases II and III.

3.3 Phase IV (Ongoing Management)

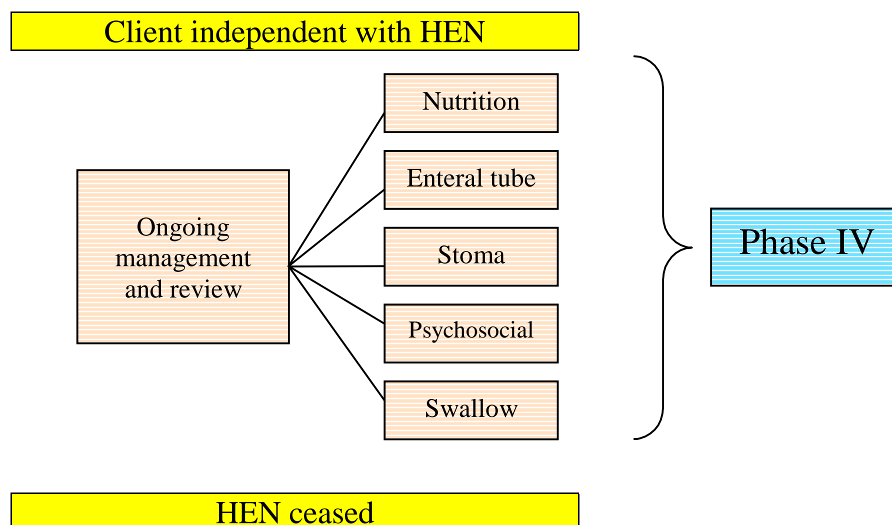


Figure 5 Processes for Phase IV

A client enters phase IV (ongoing management) once deemed competent to manage their HEN independently. However, while able to manage independently, they will still continue to require the interventions of service providers up until the time where their HEN ceases (end of phase IV). The interventions in this phase will be more intermittent and less intensive than in the previous two phases. The ongoing management can be divided into five key areas of management, nutrition, enteral tube, stoma, psychosocial issues and swallow. The recommended interventions are listed below in Table 3

Interventions	Guidelines
Ongoing management and review	The AuSPEN guidelines state: Patients receiving HEN feeding shall be reviewed by the nutrition support team a*fter the first 3 months of initial treatment. After this review at no longer than 6 monthly intervals.* *The patient will be monitored for effectiveness of therapy, adverse effects and clinical changes. Routine monitoring should include:* • *Continued need for HEN* • *Nutrient intake* • *Review of current medications* • *Signs of intolerance to feeds* • *Weight changes* • *Biochemical, haematological data* • *Adjustment to therapy* • *Psychosocial problems* • *Changes in home environment* In addition the client should routinely: • Have their enteral tube and stoma site (if applicable) reviewed. • Have their swallow reviewed if dysphagic

Table 3 Intervention Guidelines for Phase IV

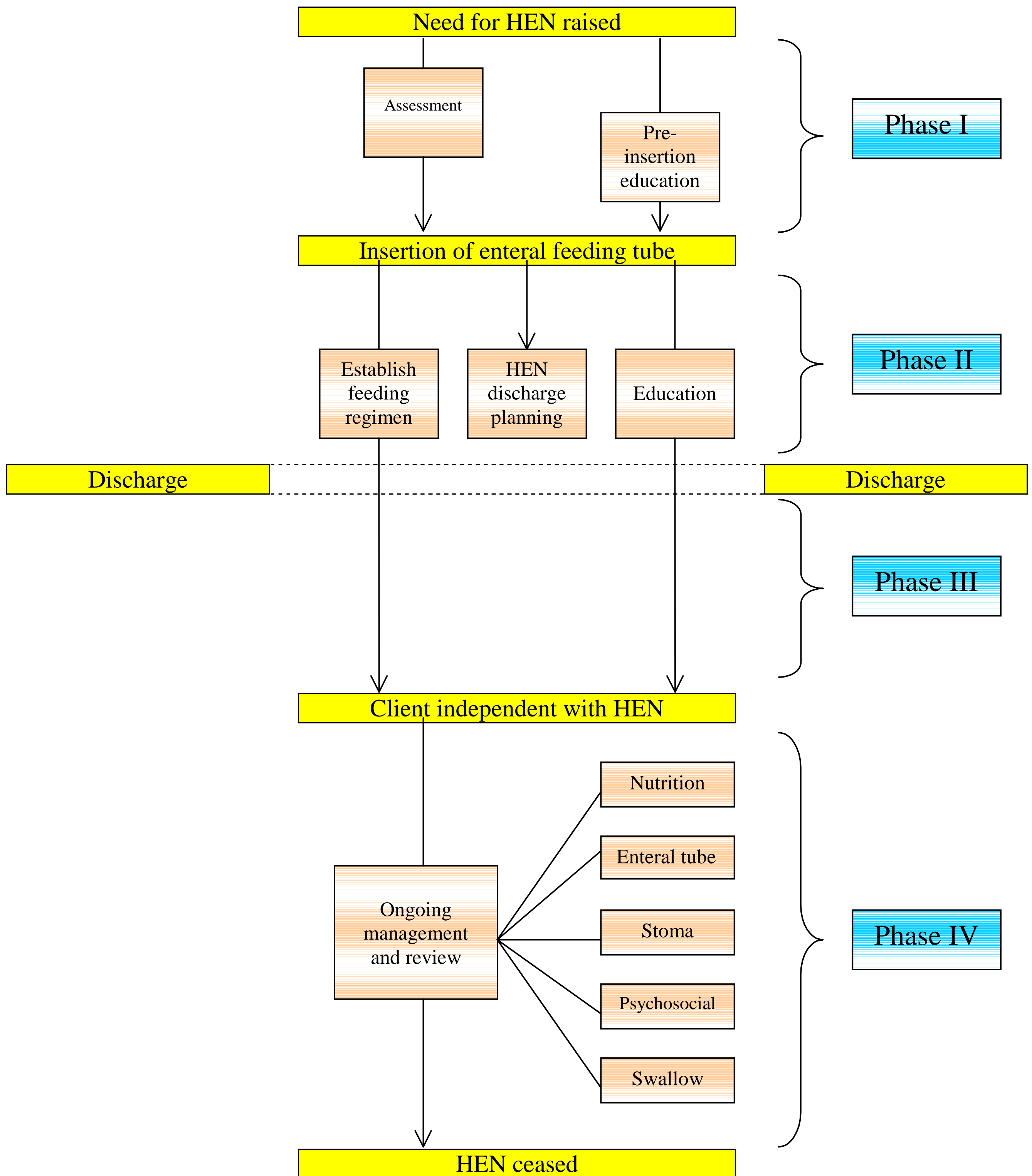


Figure 6 Processes in the Four Phases of the Model

4. Service Providers

Implementation of the processes or interventions outlined in the previous section requires the expertise of a multi-disciplinary team of health professionals. This is the recommendation made by AuSPEN in their Clinical Practice Guidelines (Appendix 1). Presently no specific training courses or qualifications are in existence that skill or qualify any one professional discipline to manage HEN clients in isolation of other disciplines.

In collating information obtained from our interviews it seemed that there was considerable variation in the profile of professionals involved in the management of HEN between Health Care Networks or Regions. However a number of key professionals were generically perceived to be central to the management of HEN, namely nutrition professionals, stomal therapists or nursing professionals and medical professionals. Other professionals such as speech pathologists and social workers also have involvement in the management of HEN, however their expertise is not necessarily required in all cases.

In addition to the professional skill base required for HEN, auxiliary services are also required to support the provision of HEN for clients. Integral to HEN is the provision of HEN supplies. Similarly access to 24-hour support services is essential to provision of best practice HEN services.

Interaction of a number of stakeholders is therefore required for the provision of a HEN service. If HEN services are to operate efficiently and effectively these interactions need to be well coordinated. To facilitate this process we have a proposed central coordination position in our model to oversee the integration of the clinical and administrative components of HEN services. Figure 7 depicts the key stakeholders in our model of best practice in HEN service systems

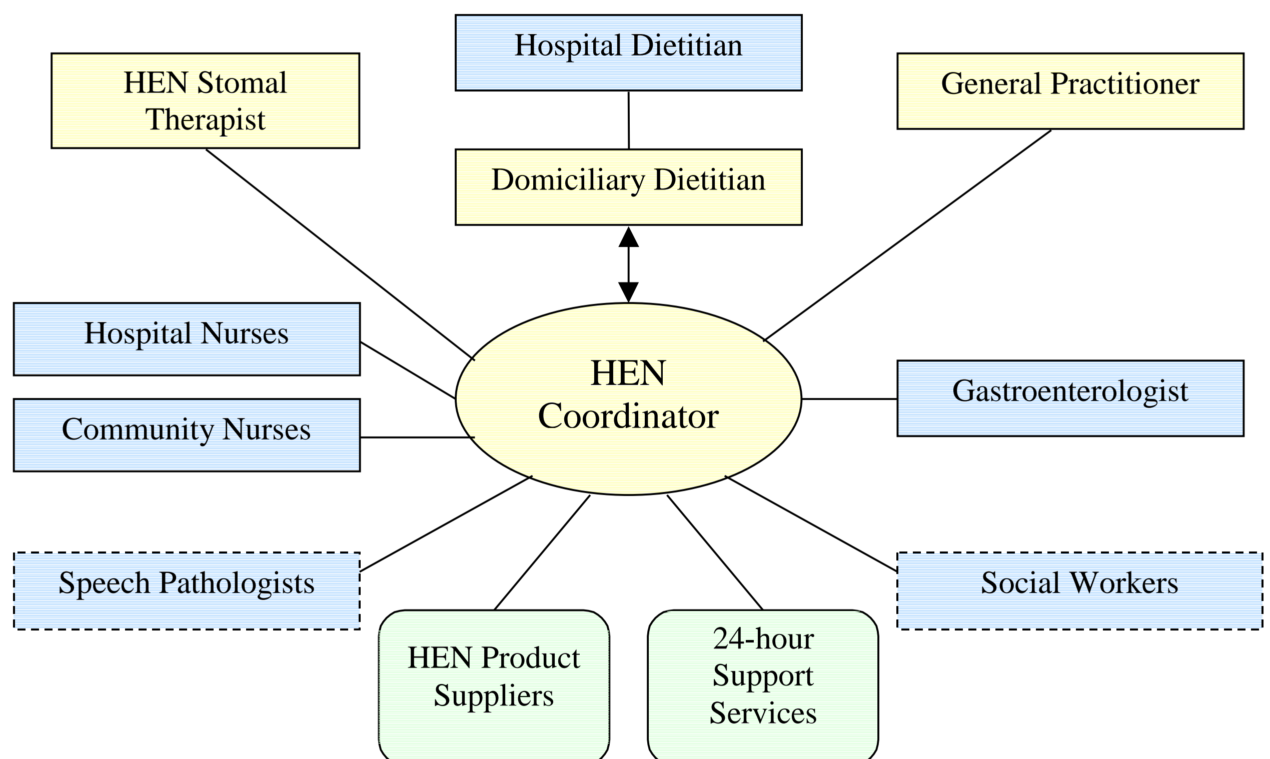


Figure 7 Service Providers

What follows is a more detailed description of these stakeholders and the rationale behind their selection for the model. Section 5.0 will expand on the discussion in this section by specifying the key professionals involved in each phase of the model and their roles and responsibilities in terms of the processes discussed previously in Section 3.0.

4.1 HEN Coordinator

Our research indicated that a variety of professionals might potentially be involved in any individual HEN client's management. However there was frequently no formalised process in place for communication between professionals, or for the overall management of the HEN client. In many instances there was no professional designated to coordinate this management. This was seen to result in a disjointed and inefficient approach to the management of a client's HEN.

In some cases coordination of services falls to the client or carer. Without any formalised team structure or lines of communication between professionals accessing support can be difficult for the client. The multiplicity of contacts for HEN clients, created by this situation, was clearly perceived to be an issue for clients.

The increasing HEN population is likely to compound the situation described above. We believe that centralised coordination would overcome many of these issues through streamlining service delivery and increasing cost efficiency. As such at the core of this model is the concept of a HEN coordinator. In our model each public HEN funded health care facility has a designated HEN coordinator.

Potentially the HEN coordinator might have involvement in a client's HEN throughout all phases of their HEN episode. The HEN coordinator's potential involvement in each of the phases and their associated roles and responsibilities will be discussed in detail in Section 5.0. Below is an outline of the broad functions that the HEN coordinator will undertake.

4.1.1 Functions of the HEN Coordinator

The HEN coordinator has a number of key functions in addition to a coordination role. They will undertake a clinical role in the management of HEN clients and also have responsibilities associated with the administrative side of HEN management.

Coordination

As a coordinator this person will be responsible for coordinating the clinical management of the HEN client population associated with the respective funded hospital. The HEN coordinator will be the primary contact for all professionals involved in the care of HEN clients both internal and external to the funded hospital and will coordinate their involvement with the client both during the hospital admission and post discharge. The aim of this position is to ensure continuity of care in the management of HEN between the hospital setting and the community. The HEN coordinator will facilitate this by establishing clear lines of communication and care plans with the key stakeholders in HEN from both health care sectors.

At the individual client level the coordinator will effectively act as a case manager to coordinate the HEN aspect of a client's care.

Clinical

The HEN coordinator will also have a hands-on role in the management of HEN clients. In order to coordinate the client's care appropriately the HEN coordinator requires an intimate understanding of the clinical management of the client. As such the most cost-effective use of resources is for the HEN coordinator to have a clinical role, as appropriate to their professional discipline. This set-up is more likely to enable the coordinator to make appropriate decisions with regard to overall coordination of a client's HEN management.

Administrative

An administrative component is also incorporated into this position. Since October 1997 public HEN clients in Victoria have been eligible for a financial subsidy of their enteral feeding supplies (formula and equipment). To date the funding has been delegated to public hospitals or health care networks in annual block grants. The philosophy behind this model of funding is that the linking of clinical decision making with budget accountability should facilitate best practice service provision (DHS July 1997, p.30). In line with this view we believe the clinical coordination of HEN should be linked to financial responsibility. In this context the HEN coordinator would be based at, or closely affiliated with, the organisation holding the HEN budget.

This financial responsibility involves considerable administration. As described above, the funding is for the purpose of subsidising the provision of HEN products to clients. As such management of this budget is accompanied by responsibility for overseeing the provision of HEN supplies. In addition a database has been developed as part of the funding program to assist in the management of both the administrative and clinical components of HEN. The HEN coordinator would be responsible for the day to day administration associated with these responsibilities. The ultimate responsibility for management of the HEN budget would be negotiated with the manager under whom the HEN coordinator functioned.

4.1.2 Domiciliary Service

The ability to conduct home visits is an integral component to the position of coordinator. Access to domiciliary services was a gap in current systems that was clearly highlighted in our research by both dietetic service providers and HEN clients. While a few health care facilities were noted to operate a domiciliary service for HEN, this was not common place at the time of our research.

The capacity to undertake home visits is important from a clinical perspective and a coordination perspective. In the clinical role of the HEN coordinator our model proposes that a home based assessment in the initial discharge phase is necessary for best practice to ensure client is adequately equipped to manage their HEN independently and to ensure appropriate design of the individual's care plan. Secondly a domiciliary service is required for face to face review of many clients, most particularly for the non-ambulatory HEN client group.

The domiciliary component is also important from a coordination perspective. The coordinator will act as an interface between the hospital setting and the community setting. The HEN coordinator will often need to liaise in person with these two health care sectors.

4.1.4 Which Profession?

In the majority of HEN funded health care facilities in Victoria, the accountability for the HEN budget lies with the Nutrition and Dietetics Department. As described above, concomitant to the management of the HEN budget is the responsibility of overseeing the system of supplying HEN products to clients. The Nutrition and Dietetics Department of HEN funded health care facilities are also responsible for maintaining ongoing clinical and administrative data on all their HEN clients, through a specifically designed database.

Given the role Nutrition and Dietetics Departments presently undertake in the running of the HEN funding program, our model has a placed a dietitian in the role of HEN coordinator. Should the current funding arrangement change, it would be recommended that the clinical coordination role becomes the responsibility of the subsequent department or manager of the funding.

The position of HEN coordinator will be referred to as the dietetic HEN coordinator from this point forward.

Recommendation 1

Each HEN funded health care facility allocate a dietetic HEN coordinator/s to undertake clinical, administrative and coordination functions.

Recommendation 2

Dietetic HEN coordinators undertake a domiciliary role in order to:

- Facilitate continuity of care
- Enable appropriate management of HEN clients in the community

4.2 Dietetic Professionals

Dietitians are generally involved in all phases of a client's HEN episode. In the majority of situations the HEN client would have first contact with a dietitian in a hospital prior to, or at the time of their enteral tube insertion. This hospital dietitian might then continue to manage the client once discharged. Other dietitians might be involved if the client is transferred to an intermediary institution, such as a rehabilitation facility, prior to discharge home. In addition, depending on their availability and the client's circumstances, a community dietitian could also be involved after discharge from the hospital.

In our model two dietitians are generally involved in a client's HEN episode, the 'unit' dietitian and the dietetic HEN coordinator. This will be discussed in more detail in Section 5.0, however in summary the hospital dietitian, under whose unit of care the client fell, would be involved initially. As discussed in Section 4.1.4, a dietitian has been designated to fill the HEN coordinator position in our model. With a dietitian in this role the nutritional management of the client is handed over to the dietetic HEN coordinator at some point around the client's discharge. From this point forth the dietetic HEN coordinator becomes the primary contact for the client. As noted above the options for the timing of the dietetic HEN coordinator's involvement in various circumstances will be discussed in Section 5.2.

4.2.1 'Unit' Dietitian

The label 'unit' dietitian is used to describe the dietitian who is initially involved with the HEN client. In the majority of circumstances this will be a hospital-based dietitian, the hospital being the place where enteral tubes are generally inserted. This dietitian will be involved in establishing the client on HEN in the initial phases.

4.2.2 Dietetic HEN Coordinator

Dietitians who are presently involved in HEN come from a variety of different work-sites. The results from the dietitian questionnaire indicated that the majority of respondents who are presently involved in the management of HEN worked in a public hospital. Other areas were Home And Community Care positions (HACC), aged care facilities and rehabilitation centres.

The position of dietetic HEN coordinator could potentially be filled from any of these sites, the main contingency being that they are closely affiliated with the health care facility managing the HEN funding.

Our model recommends that each funded health care facility has a dietetic HEN coordinator. There will be instances where more than one dietetic HEN coordinator for each HEN funded health care facility might be appropriate. Such situations might be:

- **Where a health care facility manages a large number of HEN clients.**
- **Where a health care facility manages a subset of the HEN clients that require specialist nutrition input for a particular disease state (eg Cystic Fibrosis, HIV).**
  In this situation the dietitian responsible for the nutritional management of this client group would be also be responsible for the coordination of HEN clients in this sub-group.
- **Where clients live geographically distant from the funding health care facility.**
  In this situation coordination might be managed by a chosen professional at the local level, with liaison with the coordinator from the funding health care facility.

In many health care facilities, a number of dietitians might be involved with establishing clients on HEN. However as described above, once discharged the clinical management of HEN clients becomes the responsibility of the dietetic HEN coordinator. We propose this set-up would ultimately provide a number of benefits. It would:

- Facilitate development of expertise in the area of HEN through increased involvement with clients and other health professionals. The sharing of experiences with other dietetic HEN coordinators will also foster learning. The dietetic HEN coordinators will be used as a resource to provide professional development to other dietitians and other professionals.
- Facilitate development of skills in case management.
- Facilitates more streamlined management of HEN within Nutrition Departments, the dietetics profession as a whole and between other health professionals.
- Ultimately provide a more efficient and effective service for clients.

While a criticism of this model might be that it denies some dietitians the opportunity to work in HEN we would argue that if the positions were rotated it would actually create opportunities to gain more extensive experience in the area of HEN than is presently available.

4.3 Nursing Professionals

The nursing profession also has a key role to play in the management of HEN. In the initial phase where a client is being established on HEN, nurses at the ward level are involved in the client's management. Some health care facilities have the services of a stomal therapist available for the management of HEN clients. As such these professionals might also be involved during a client's hospital admission or during an outpatient visit. The other nursing groups frequently involved in the care of HEN, are community based nursing professionals, namely Royal District Nursing Service (RDNS). Enteral formula and equipment companies, one in particular, were noted to offer the services of a stomal therapist for follow-up of HEN clients.

The specific roles and responsibilities of nursing professionals will be discussed in Section 5.0. However an area that was quite clearly perceived to require the expertise of the nursing profession was with regard to stomal and enteral tubing care. Our research highlighted an apparent gap in the access to nursing professionals with specific expertise in the management of enteral stoma sites and tubing, particularly once a client has been discharged from hospital.

Our model proposes input from three different groups of nursing professionals over a client's whole HEN episode. In the initial phases during the hospital admission (Phase II) ward nurses will be predominantly involved. After discharge (Phase III) Royal District Nursing Services will be involved until the client is deemed independent with HEN. Ongoing management (Phase IV) of stoma and tubing issues will be dealt with by a network or regional HEN stomal therapist.

4.3.1 Ward Nurse

The ward nurse is the name used to describe the nursing staff responsible for a client's care during a hospital admission. This nurse/s will be responsible for the actual administration of the client's enteral nutrition post tube insertion. Initial care of the stoma site (if applicable) and enteral feeding tube will also be the responsibility of the ward nurse during the hospital admission. The ward nurse might also be involved in some education of the client, depending on the length of the client's hospital admission.

4.3.2 Royal District Nursing Service (RDNS)

The provision of this aspect of care in our model has taken into consideration existing nursing services by incorporating RDNS. Other community based nursing could as easily be interchanged, however from our research it was apparent that RDNS were the community based nursing service most commonly used to follow up HEN clients managed through the public health care system.

RDNS are often involved with HEN clients in the initial post discharge phase. Many HEN clients interviewed, expressed that they needed and appreciated the reassurance of nursing follow-up in the home with regard to their enteral tube. This might be particularly true if the client has been discharged from hospital before receiving adequate education to ensure their ability to manage independently. Even those clients who have theoretically received 'adequate' education, might need some additional education or reassurance with regard to managing their enteral tube or stoma.

While post discharge nursing follow-up was perceived to be beneficial, this is not arranged for all HEN discharges, particularly if there are no other clinical reasons for nursing support. Our model proposes that all HEN clients should be given the option of nursing follow-up. If the client opts for nursing follow-up, the RDNS assigned to the client will ensure the client or carer is appropriately educated in the management of stoma sites or management of enteral feeding tubes. Once the client is deemed able to manage independently, RDNS would generally withdraw their involvement.

4.3.3 HEN Stomal Therapist

Stomal care and management of enteral tubes is an area that requires a certain level of experience or training to manage appropriately. Difficulty in accessing professionals with expertise in the care of enteral tubes and stomas was a gap identified in our research in a number of places. As such, in order to support both general nursing professionals and other health professionals, our model proposes that a stomal therapist with specialist knowledge in the management of enteral nutrition should be available to service each Health Care Network or Region. This person should have specialist knowledge in:

- Care of stoma sites associated with gastrostomy and jejunostomy tubes
- Enteral tubing types and their care.
- Placement of enteral tubing, particularly naso-gastric tubes
- Replacement of enteral tubing parts.

This proposed stomal therapist would be a domiciliary position with both a hands-on clinical role and a teaching and training role in the network. The stomal therapist would become the primary contact for follow-up of stomal issues once RDNS support has ceased (ie once the client is able to manage their stoma and enteral tubing independently

A community based domiciliary position was chosen in preference to a hospital based position in order to ensure equity of access to HEN clients to the services offered by this professional. In many instances clients on HEN are non-ambulatory or frail elderly and have trouble attending hospitals for follow-up. The ability to address stomal issues in the home is likely to result in more timely and individualised intervention.

A Network or Regional HEN stomal therapist has been chosen as the most economically viable option for provision of this service. This position would have a liaison role with all the HEN

funded health care facilities in the Network or Region. In the situation where a hospital already had a stomal therapist involved in HEN it would be envisaged that the network based stomal therapist and the hospital based stomal therapist would liaise to develop standardised care procedures. Follow-up of the stoma could then occur either in the hospital setting or in the community, depending on the client's preference or the client's ambulatory status.

The proposition of a Network or Regional stomal therapist requires the creation of a new position. There are a number of possible options for implementation of this role. As RDNS are a key group involved in the model, a logistically viable option might be to affilitate the HEN stomal therapist with this service. The HEN stomal therapist would then provide RDNS in the Network or Region with training in stoma and enteral tubing management. The HEN stomal therapist would also be available to assist in more complex cases.

Affiliation of the HEN stomal therapist with RDNS would also work well in rural areas where clients might be geographically isolated from the funding hospital. In these situations RDNS are usually the closest nursing contact. With a regional HEN stomal therapist to resource these nurses, stomal and tubing management would be able to be dealt with in an appropriate manner at the local level by the local RDNS.

Resource implications with regard to creation of this position are discussed further in Section 11.0.

Recommendation 3
Each Health Care Network or Region have a community based stomal therapist with specialist expertise in the management of HEN.

4.4 Medical Professionals

Our research revealed much disparity in the profile of medical professionals that might be involved with HEN clients. Examples of the medical professionals that have been noted to have involvement with HEN clients included gastroenterologists, surgeons, medical professionals (responsible for management of the client's primary condition), general practitioners and emergency department medical professionals.

Medical professionals generally have involvement with HEN clients throughout all phases of a HEN episode. In the initial phases gastroenterologists or surgeons seem to be most commonly responsible for insertion of enteral feeding tubes, namely gastrostomy and jejunostomy tubes.

Ongoing follow-up was found to be managed on a rather ad-hoc basis in many places. Often no formalised structure for the medical review of HEN was in place. A few hospitals with large numbers of HEN clients had established a multi-disciplinary clinic for review of clients that included a medical practitioner, usually a gastroenterologist or a surgeon. However this set-up was not common place at the time of our research. Those hospitals that did have a clinic in place noted a few difficulties with their clinics. One issue was the number of HEN client's who failed to attend. A reason given for this was that clients who already had multiple other medical reviews were reluctant to attend an additional clinic. Access was also a problem for those clients who were non-ambulatory, for those who had no means of transport and for those clients who

lived geographically distant from the hospital. In places that had no formal HEN clinic any of the medical professionals listed earlier were utilised for medical review.

In line with the overall philosophy of our model, and given the fact that few formalised review processes have been established for medical review of HEN, we have chosen to use a model of medical follow-up that would enable more localised medical care of HEN. As such the key medical practitioners used in our model are general practitioners with gastroenterologists providing support from the acute care setting.

4.4.1 General Practitioner (GP)

The GP is usually the client's primary medical contact, generally being the most local and accessible. With regard to HEN, medical follow up might be required in situations such as stomal infections, gastrointestinal disturbances and routine pathology. These are issues that could generally be handled at a local level as opposed to requiring specialist medical attention.

In this role GPs should be have a certain level of knowledge about HEN. This potentially presents issues in that management of HEN is not a care modality that GP have a lot of experience or training in. Few GPs would have multiple clients with HEN. Given the number of HEN clients the average GP would see, the cost effectiveness of conducting generic professional development programs for GPs is questionable. However in order to support GPs as primary care physicians for HEN, the development of appropriate education programs and resources is required.

Recommendation 4
General Practitioners be supported through education programs and resources as primary care physicians for management of HEN clients.

4.4.2 Gastroenterologist

The gastroenterologist, as noted above, is often involved in the initial phases of HEN with placement of enteral tubes. With regard to the ongoing management of HEN clients, once discharged home from hospital, our model nominates the client's GP as the primary contact for the medical management of a client's HEN. However support and involvement from the acute sector will still be required. Access to specialists, such as a gastroenterologist and access to an endoscopy unit, is required for the changing of enteral tubes that require endoscopic removal and replacement. The specialist support of the gastroenterologist is also required for other professionals involved in the management of HEN, particularly in complex cases.

4.5 Other Professionals

Other professionals, whose discipline specific expertise might be required in the management of HEN, are commonly speech pathologists and social workers. These two professionals can have a key role to play with many HEN clients, however their expertise is not necessarily required with all HEN clients. As such, these professionals are not classified as 'key professionals' in our model but rather 'support professionals'. Their involvement would be acquisitioned by referral. These professionals could be sourced from the hospital or community setting depending on the services available in the area.

4.5.1 Speech Pathologist

A speech pathologist becomes an integral member of the HEN team in cases where a client requires enteral nutrition support as a consequence of dysphagia. In this situation, the input from the speech pathologist would be required in the initial phases of assessment and in the latter phases of ongoing management, to determine any changes in the client's swallowing status.

4.5.2 Social Worker

In situations where clients were faced with psychosocial issues that were unable to be dealt with by the other professionals discussed previously, the services of a social worker would be required.

4.6 Support Services

Support services, such as HEN product suppliers, while not having direct clinical involvement with the HEN client, are also integral components to the management of HEN. As with the coordination of clinical services, the dietetic HEN coordinator is primarily responsible for linking the provision of these services with the HEN clients.

The other key support service that is required is access to 24-hour support. Hospital emergency departments presently are the main source of this service.

Support services and their involvement with HEN are discussed at a later stage in Section 6.0. The following section, Section 5.0, discusses the clinical roles and responsibilities of the service providers outlined here, in the context of the various phases of a HEN episode of care.

5. Service Providers - Roles & Responsibilities

5.1 Phase I (Pre-HEN)

In this pre-HEN phase, the need for HEN has been raised and the client's eligibility for HEN is assessed. In addition to assessment, the role of the key professionals in this phase is also to provide the client and their carer with some education and the opportunity to ask questions, in order to prepare them for the tube insertion.

The key professionals involved in this phase of the model are depicted below in Table 4.

Key Professionals	Support Professionals
• 'Unit' dietitian • Gastroenterologist	• Speech Pathologist • Social Worker

Table 4 Professionals Involved in Phase I

5.1.1 Key Professionals – Roles and Responsibilities

'Unit' Dietitian

The 'unit' dietitian will:

- Assess the clients need for HEN on the basis of the client's inability to meet nutritional requirements orally (liaise with speech pathologist as appropriate).
- Will assess the suitability of the client's home environment for HEN in terms of facilities and support. A home visit may need to be arranged if there is concern.
- Discuss with the client how HEN operates and the potential impact on the client's lifestyle.
- Assess the capability of the client and carer to manage HEN.
- Assess the impact of HEN on the client's quality of life (refer to social worker as appropriate).

The suitability of the client for HEN will be determined in consultation with other members of the team. Once deemed suitable the unit dietitian or HEN coordinator will:

- Make a recommendation as to the appropriate enteral feeding route, taking into consideration medical, physical and lifestyle factors.
- Be available to address any questions or concerns the client or carer might have.
- Provide the client and their carer with some basic literature, describing HEN.
- Show the client the tube and the equipment that will be used to administer the formula.
- Inform the client and their carer of support groups.
- Refer to other professionals as appropriate.

Gastroenterologist

The gastroenterologist will assess the suitability of the client for HEN on the basis of:

- The stability of the client's clinical status for discharge home.
- The assessment of other team members (dietitian, speech pathologist, social worker)

If the client is deemed suitable the gastroenterologist will:

- Determine the most suitable enteral feeding route, in consultation with the dietitian and other medical practitioners involved in the client's care.
- Discuss the insertion of the tube from a medical perspective with the client.

5.1.2 Support Professionals – Roles and Responsibilities

Speech Pathologist

The speech pathologist will be involved with clients who have been referred for assessment of dysphagia. In this situation, the speech pathologist will:

- Assess the client's swallow.
- Recommend an appropriate texture modification, if applicable.
- Consult the unit dietitian / HEN dietitian with regard to their assessment and recommendations.

Social Worker

The social worker will be referred HEN clients with psychosocial issues that are unable to be dealt with by other members of the team. The social worker will:

- Assess the client's psychological and financial ability to cope with HEN.

5.2 Phase II (Initiation of HEN)

Phase II (initiation of HEN) commences once the enteral tube (with which the client is to be discharged) has been inserted. This phase occurs in the hospital environment. As discussed in Section 3.2 there are a number of processes that must occur between the time an enteral tube is inserted and the time the client is deemed able to manage independently. These processes broadly include establishment of the feeding regimen, education of the client and their carer and HEN discharge planning.

The professionals commonly involved in this phase of the model are depicted below in Table 5.

Key Professionals	Support Professionals
• 'Unit' dietitian / dietetic HEN coordinator*[1] • Ward nurse / HEN stomal therapist*[2]	• Speech Pathologist • Gastroenterologist • Social Worker

Table 5 Professionals Involved in Phase II

*[1]'Unit' Dietitian / Dietetic HEN Coordinator

The level and timing of involvement of the 'unit' dietitian and the dietetic HEN coordinator can be arranged in a number of combinations to fit various situations. The dietetic HEN coordinator could potentially enter the client's management at a variety of points in a client's HEN episode, ranging from taking on total management of the client's enteral nutrition, from the time the tube is inserted, to becoming involved only once the client has been discharged. The possible options are depicted below in Table 6.

	Education	Discharge	Ongoing Management	Description
Option 1	Unit	Unit	Unit	The unit dietitian is responsible for the education, discharge planning and ongoing management of the client.
Option 2	Unit	Unit	HEN	The unit dietitian educates the client and arranges their discharge with respect to HEN. Once the client is discharged the dietetic HEN coordinator takes over the client's management.
Option 3	Unit	HEN	HEN	The unit dietitian educates the client during the hospital admission but hands the discharge planning over to the dietetic HEN coordinator, who will be responsible for the client's ongoing management.
Option 4	HEN	HEN	HEN	The dietetic HEN coordinator is referred all clients in the hospital for education, discharge and continues to manage this client post discharge.

Unit = 'Unit' Dietitian HEN = Dietetic HEN Coordinator

Table 6 Involvement of the Dietetic HEN Coordinator

The standard options chosen for the model are Options 2 and 3. Variations on this standard option (Options 1, and 4) will occur in certain situations. The rationale for these choices is discussed below.

Standard Options for the Model – Options 2 and 3

The aim of the model is to streamline procedures and increase efficiency. The HEN coordinator position is central to facilitating this. Discharge planning typically requires considerable coordination. As such the dietetic HEN coordinator would ideally be involved at this point (**Option 3**). This enables the number of people involved in coordinating the discharge of a client on HEN to be minimised. Minimisation of the number of people involved is likely to reduce variations in discharge procedures, internal and external to the funded health care facility.

In addition to streamlining and standardising procedures, this would also eliminate duplication of communication. Lines of communication can be established between community-based professionals and the client's HEN coordinator directly, eliminating the need for an intermediary

person in the client's transition from hospital to home. The client is able to meet the person who will be responsible for the ongoing management of their HEN prior to discharge, thereby relieving some potential anxiety of the unknown for the client. Elimination of an intermediary person also allows the client to have involvement in the development of their care plan and discharge arrangements with their dietetic HEN coordinator directly, prior to discharge.

While **Option 3** has potential efficiencies, it may not always be a practical option. This option would work well if the dietetic HEN coordinator was based at the health care facility initiating the HEN, most usually a hospital. However in situations where the dietetic HEN coordinator might operate out of a community based health care facility or another HEN funded health care facility, their involvement in discharge, in person, at the hospital site might not always be logistically feasible. An example of this situation might be where a HACC funded dietitian is delegated responsibility to coordinate HEN clients discharged from a hospital in the service catchment area. While this dietitian might have close affiliation with the HEN funded hospital, they are not necessarily physically on site to oversee the clients discharge. In this situation the dietetic HEN coordinator would have involvement with the clients discharge through liaison with the 'unit' dietitian involved with the HEN client in hospital. The dietetic HEN coordinator would then, most likely, have first physical contact with the HEN client post discharge **(Option 2).**

Another common example where the dietetic HEN coordinator would not be on-site to coordinator discharge is where a client lives geographically distant from the initiating hospital, such as where a client from a rural area was admitted to a metropolitan-based hospital. Here the 'unit' dietitian would commence discharge planning and hand over to the dietetic HEN coordinator most local to the client's place of residence **(Option 2).**

Option 1

As discussed in Section 4.2.2, there will be instances where more than one dietetic HEN coordinator per HEN funded health care facility might be needed. One instance already highlighted is in those health care facilities that manage a very large number of HEN clients. Another scenario where more than one dietetic HEN coordinator might be appropriate is in health care facilities that manage a significant sub-population of HEN clients that require specialised nutritional management. In this situation the specialist 'unit' dietitian would remain responsible for ongoing management of this group. In these hospitals the dietetic HEN coordinator would only be involved with the HEN clients who were initiated under more general medical and surgical units.

Option 4

In hospitals with smaller numbers of HEN clients, or in a hospital with dietitians with little experience or expertise in HEN, the HEN dietitian might be allocated to fully manage any potential HEN clients. Option 4 also depicts the situation that would occur in sole positions and as well as the situation that would occur if the HEN dietitian also managed specific units in addition to their HEN responsibilities.

*[2]Ward Nurse / Stomal Therapist

Our research indicated that not all health care facilities had access to the service of a stomal therapist for the management of HEN clients. As such, in this phase of our model, the ward nurse undertakes nursing education of the client. If a stomal therapist were available they would take on a more dominant role in educating the client.

5.2.1 Key Professionals – Roles and Responsibilities

Following is a description of the roles and responsibilities of the 'unit' dietitian, ward nurse and dietetic HEN coordinator, with regard to implementing the interventions required in phase II (establishment of the feeding regimen, education of the client / carer and HEN discharge planning). If these processes are unable to be completed during the initiation phase (II), in hospital, they will be continued, as discussed in Section 5.3, by the dietetic HEN coordinator and RDNS in the client's home (phase III).

'Unit' Dietitian

The 'unit' dietitian will have involvement with the establishment of the client's feeding regimen. With regard to this process the 'unit' dietitian will:

- Assess the client's nutritional requirements and determine the formula type and volume.
- Determine the timing and method of formula administration.
- Liaise with ward nursing staff regarding initiation of the feeding regimen.
- Monitor and adjust the feeding regimen as clinically indicated.
- Document the enteral feeding plan and instructions in the client's medical history.

The unit dietitian also plays a key role in educating the client and carer with regard to HEN. The unit dietitian will be responsible for formally educating the client and carer, however during a client's admission it is the role of the ward nurse to actually perform the administration of the client's formula and care of their tube/stoma (unless the client is able to manage independently). This provides another learning opportunity for the client. As such aspects of the education conducted by the dietitian will be shared with nursing staff (denoted by *). The ward nurse or stomal therapist will also undertake some formal education of the client and carer. The details of this are discussed under the roles and responsibilities of the **'ward nurse / stomal therapist'**, below.

The 'unit' dietitian will formally educate the client and/or carer in the following aspects of HEN:

- Administration of formula*
- Feeding regimen*
- Oral intake and/or mouth care*
- Care of enteral tube*
- Administration of medication*
- Management of complications
- Hygiene principles*

In this phase the 'unit' dietitian will also:

- Provide the client with written information covering all aspects of the education received.
- Document all education conducted in the client's medical history.
- Complete the assessment form for hand-over to the dietetic HEN coordinator.

Ward Nurse / Stomal Therapist

With regard to establishing the client's feeding regimen, the ward nurse will:

- Administer the enteral formula, as per the regimen established by the 'unit' dietitian.
- Provide the appropriate care of the enteral tube and stoma (as applicable).
- Administer medication via the enteral tube as specified by the client's medical team.

- In performing these functions, the ward nurse will provide a secondary level of education to that given by the unit dietitian, as denoted by the * in the previous section under **'unit dietitian'**.

As indicated above, the ward nurse is also responsible for formally educating the client or carer in specific aspects of HEN care. In our model the ward nurse is the primary nursing professional involved in educating the client in this phase of the model. However if a stomal therapist was available to the organisation they might take on the dominant role in education. The ward nurse would then provide a secondary level of education, through practical application, as described above in reference to supporting the education undertaken by the dietitian.

The ward nurse (or stomal therapist) will:
- Formally educate the client regarding appropriate care of the tube and stoma (as applicable).
- Formally educate the client with respect to emergency procedures such as in the situation of the tube falling out.
- Will provide the client with written information covering all aspects of the education received.
- Document all education received in the client's medical history.

'Unit' Dietitian / Dietetic HEN Coordinator

As indicated in Table 6, the dietetic HEN coordinator will ideally be responsible for arranging a client's HEN discharge in person. However if this is not appropriate, the 'unit' dietitian will liaise with the nominated dietetic HEN coordinator and the client's HEN discharge plan will be arranged collaboratively.

In this role the 'unit' dietitian and/or the dietetic HEN coordinator will:
- Liaise with the all health professionals involved in the clients HEN during the hospital admission (key professionals and support professionals) regarding the education received and assessment of the client's competency in their ability to self manage their HEN.
- Meet with the client and their carer and discuss discharge plans.
- Arrange for a RDNS visit on the day of discharge as required.
- Communicate with the client's GP with regard to discharge plans.
- Make arrangements for supply of HEN product.
- Complete appropriate documentation, including medical history documentation, client consent forms, HEN database and discharge plan summaries for community based practitioners.
- Make arrangements for the dietetic HEN coordinator to visit the client within 24 hours of discharge.

5.2.2 Support Professionals – Roles and Responsibilities

Speech Pathologist

The speech pathologist will be involved with clients who are enterally fed as result of dysphagia. In this situation, the speech pathologist will:
- Assess the client's swallow.
- Recommend an appropriate texture modification, if applicable.
- Provide written literature of any education undertaken.
- Consult the unit dietitian with regard to their assessment and recommendations.
- Document their assessment and education undertaken in the client's medical history.

Gastroenterologist
The gastroenterologist will provide support to ward nurses (and stomal therapist) with regard to:
- Management of enteral tubes.
- Management of stoma sites.

Social Worker
The social worker will:
- Manage psychosocial issues identified during the client's initial assessment.

5.3 Phase III (Post Discharge)

Phase III commences once the HEN client has been discharged home from hospital. The professionals commonly involved in this phase of the model are depicted below in Table 7.

Key Professionals	Support Professionals
• Dietetic HEN coordinator • RDNS	• GP • HEN stomal therapist • Gastroenterologist • Social Worker

Table 7 Professionals Involved in Phase III

The local dietetic HEN coordinator will conduct a home visit within 24 hours of the HEN client's discharge. If an RDNS visit has been arranged, the dietetic HEN coordinator will ideally arranged their visit to coincide with RDNS. Lines of communication are then established between all parties involved and care plans are discussed. The processes that have not been completed in the initiation phase in hospital (phase II) will be continued in this phase of the model.

5.3.1 Key Professionals – Roles and Responsibilities

Dietetic HEN Coordinator
The HEN dietitian will:
- Bring an initial supply of all products required for administering the client's HEN.
- Assist the client with setting up for home feeding.
- Review the initial assessment of the client and their HEN in the context of their home environment and lifestyle.
- Perform a practical assessment of the client's and/or their carer's ability to manage their HEN.
- Continue education (or re-education) of the client and/or carer if required. If further education is required subsequent home visits will be arranged until the client and/or carer is able to manage independently.
- Make adjustments to the clients feeding regimen or mode of delivery, if deemed appropriate once the assessment in the client's home is complete.

- Ensure the client and/or carer has the appropriate contact numbers.
- Ensure the client and/or carer is familiar with the system for provision of HEN supplies.
- Arrange an appropriate follow up appointment based on their assessment.
- Follow up with the client's GP to establish lines of communication and management of the client's care.

RDNS

The role of the RDNS will vary slightly depending on the type of enteral tube the HEN client has in situ.

If the client has a naso-gastric tube the RDNS will:

- Assess the position of the naso-gastric tube.
- Assess the client and/or carer's ability to independently check the position of the naso-gastric tube.
- Ensure the client, or carer, are familiar with procedures for reinsertion of the naso-gastric. A professional contact should be pre-arranged for insertion of dislodged tubes. Alternatively the carer might be educated in inserting the naso-gastric tube. The appropriate option would be assessed an individual basis depending on the carer's level of confidence and competence.
- Re-educate the client and/or carer as necessary regarding care of tubing.
- Make follow-up appointments as deemed appropriate.

If the client has a gastrostomy or jejunostomy feeding tube, the RDNS will:

- Assess the stoma site.
- Assess the client and/or carer's ability to independently care for the stoma.
- Educate or re-educate the client and/or carer as necessary.
- Make follow-up appointments as deemed appropriate.

Ongoing care of the stoma is generally managed by one of the options described in Phase IV.

5.3.2 Support Professionals – Roles and Responsibilities

HEN Stomal Therapist

The HEN stomal therapist will provide support in this phase in the following situations:

- Where the primary RDNS nurse has minimal experience or expertise with HEN.
- If a difficult or unusual case occurs.

GP

The GP will provide general medical support as required. In the initial discharge phase, GP input might be required in the following situations:

- Infected stoma sites
- Gastrointestinal complications that cannot be resolved through modification of the enteral formula and feeding regimen.

Gastroenterologist

The Gastroenterologist will:

- Provide specialist medical support to all team members involved in HEN in difficult or unusual cases.
- Change enteral tubes, particularly gastrostomy tubes as appropriate (See Section 5.4.2, **Recommendation 5**).

Social Worker

The social worker will:

- Be referred HEN clients with psychosocial issues that are unable to be dealt with by other members of the team.

5.4 Phase IV (Ongoing Management)

Phase IV (ongoing management) commences once the HEN client has been assessed as able to independently manage their HEN. In this phase the client continues to require ongoing review and management of their HEN, however the level of service provision is generally less intensive.

Location of Review

A major objective of this phase of the model is to facilitate flexible and convenient access to follow up support for HEN clients. As such, in contrast to previous phases where location of interventions has been clearly defined, this phase of the model incorporates a number of possible options for review, to ensure ease of access for all clients. The convenience of locations for follow-up can vary from client to client, depending upon their physical, medical, geographical and social circumstances.

Potentially the possible locations a client could be followed up include:

- **Hospital outpatient clinic**
  A client might be followed up by a member of the HEN team as part of their primary medical review. A few hospitals have a specific HEN clinic established.
- **Hospital in-patient admission**
  If clients are admitted to hospital for any reason, their HEN should be able to be reviewed at this time.
- **Home visit**
  Clients who are house bound through physical or medical disability, or those who have no means of transport, should be reviewed in their home environment.
- **Local community**
  A HEN clinic could be established at a local community or medical centre. Access is often easier at these locations than at hospitals.

The locations of services for review of HEN will be best determined at the local or regional level. This enables consideration to be given to details specific to particular service catchment areas such as the types of services already established and the number and location of HEN clients in the area. The key criteria that should be ensured when determining review locations are:

- That access is local.
- That home visits are made possible.

Team Review

In accordance with the recommendations made by AuSPEN, our model incorporates review of the client by a team of professionals, however a variation on the recommendation is used. The AuSPEN guidelines infer the whole HEN team should be available to review the client at a given time. If a number of review options are to be made available to the client, in order to accommodate their particular circumstances, it will not always be economically feasible to have a whole team available in each location. The reality will be that often only one member of the HEN team is available at a particular location at any given time.

In this situation all team members would need to be cross trained, or provided with tools, to enable them to take a global approach to review of the client's HEN. Each member of the team should be able to screen for issues requiring the specialist input of other health professionals and refer to the appropriate professional as necessary. This means the client ought to be able to make contact with the most convenient team member and have their total HEN needs reviewed.

The team of key professionals, nominated in this part of the model, effectively operates as a virtual organisation. Despite operating out of different organisations (hospital, community organisation and GP divisions), these professionals work together collaboratively as a team.

The professionals that are involved with the ongoing review and management of HEN in our model are listed below in Table 8.

Key professionals	Support professionals
• Dietetic HEN coordinator	• Gastroenterologist
• General Practitioner	• Speech pathologist
• HEN stomal therapist	• Social worker

Table 8 Professionals Involved in Phase IV

In our model the dietetic HEN coordinator is responsible for overseeing the coordination of the client's care and the associated administration. In the majority of cases the dietetic HEN coordinator will be the primary professional reviewing the client, involving other members of the team as necessary. The creation of a domiciliary coordinator position, that works across both health care sectors, enables the flexibility for clients to be reviewed in both hospital and community settings.

While the HEN coordinator is nominated as the primary person to review the client's HEN there will be instances where the client will have contact with other members of the team in isolation of the HEN coordinator. For example a client might see their GP for a reason unrelated to HEN. The GP should be equipped, as described above, to review the client's HEN at the same time. In situations, such as might occur in some rural areas, where the clients could live distant to the location of the HEN coordinator, another professional such as the GP might be the most convenient contact for the client. In this scenario the HEN coordinator would liaise with the client's primary contact. In phases II and III the HEN coordinator will have assessed the client's circumstances and negotiated an appropriate plan for follow-up with the other members of the team.

5.4.1 Key Professionals – Roles and Responsibilities

Dietetic HEN Coordinator

As described above, the dietetic HEN coordinator in our model is the primary person responsible for the ongoing management of the HEN client. It follows that the professional undertaking the HEN coordinator position should have an extensive and rounded knowledge of HEN. The dietetic HEN coordinator will:

- Undertake review of aspects of HEN that are not discipline specific but rather HEN specific. These include:
  - Adjustment to therapy.
  - Psychosocial problems (consult social worker as required).
  - Changes in home environment.
- Be the key contact for the client (unless otherwise negotiated in phase II and III).
- Review the client on a regular basis by telephone and in person. At minimum the dietetic HEN coordinator will review the client in person, initially at 3 months and then 6 monthly. More frequent reviews will be undertaken as clinically indicated.
- Monitor:
  - Continued need for HEN.
  - Nutrient intake – enteral and oral (consult speech pathologist as required).
  - Signs of intolerance to feeds (consult gastroenterologist as required).
  - Weight changes.
  - Biochemical, haematological data (obtained from GP as required).
  - Review of current medications with respect to drug nutrient interactions (consult GP as required).
- Screen for:
  - Problems with tube and stoma site (consult HEN stomal therapist, GP or gastroenterologist as required).
- Coordinate review of the client by other health professionals as required.

General Practitioner (GP)

The dietetic HEN coordinator or HEN stomal therapist will refer to the GP to:

- Take routine bloods for monitoring.
- Treat infected stoma sites.
- Review current medications.

When reviewing the HEN client, the GP will screen for:

- Changes in weight and refer to dietetic HEN coordinator, as indicated.
- Changes in intake (oral or enteral) and refer the dietetic HEN coordinator, as indicated.
- Signs of intolerance to enteral feeds and refer to the dietetic HEN coordinator, as indicated.
- Problems with tube or stoma site and refer to the HEN stomal therapist or gastroenterologist, as indicated.
- Psychosocial issues and refer to the dietetic HEN coordinator for coordination of appropriate management.

HEN Stomal Therapist

The dietetic HEN coordinator or GP will refer to the HEN stomal therapist to:

- Review problematic stoma sites.
- Replace broken tubing parts.
- Replace gastrostomies as appropriate (See Section 5.4.2, Recommendation 5).

When reviewing the HEN client, the HEN stomal therapist will screen for:
- Changes in weight and refer to dietetic HEN coordinator, as indicated.
- Changes in intake (oral or enteral) and refer the dietetic HEN coordinator, as indicated.
- Signs of intolerance to enteral feeds and refer to the dietetic HEN coordinator, as indicated.
- Psychosocial issues and refer to the dietetic HEN coordinator for coordination of appropriate management.

5.4.2 Support Professionals– Roles and Responsibilities

Gastroenterologist

The Gastroenterologist will
- Provide specialist medical support to all team members involved in HEN in difficult or unusual cases.
- Change enteral tubes, particularly gastrostomy tubes*.

***Note:**
Anecdotal evidence suggests there is an apparent lack of consensus between professionals regarding changing of replacement gastrostomy tubes. The issues appear to be around the appropriate professional (gastroenterologist versus GP versus nurse or stomal therapist), the appropriate location (hospital versus community) and the medico/legalities surrounding this aspect of care. As such the following recommendation is made:

Recommendation 5
An expert panel be formed to review and develop policies for replacement of gastrostomy tubes in the community.

Speech Pathologist

The speech pathologist will be involved with clients who are enterally fed as result of dysphagia. In this situation, the speech pathologist will:
- Continue to assess the client's swallow at appropriate intervals.
- Recommend an appropriate texture modification, if appropriate.
- Consult the dietetic HEN coordinator with regard to their assessment and recommendations.

The speech pathologist will also assess existing HEN clients, as referred by the dietetic HEN coordinator.

Social Worker

The social worker will be referred HEN clients with psychosocial issues that are unable to be dealt with by other members of the team.

6. Support Services

In addition to the services provided by the professionals described in the previous section, a number of other support services are also essential to the management of HEN. These are depicted below in Figure 8.

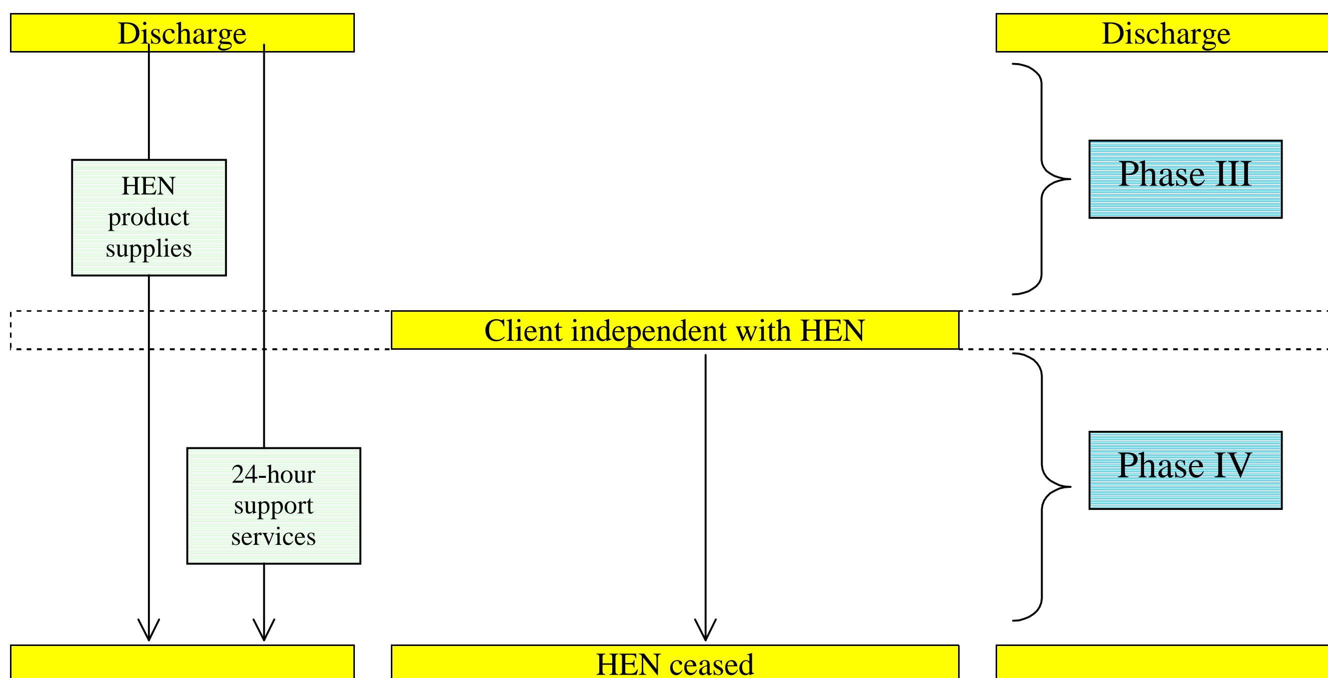


Figure 8 Support Services for HEN

Access to 24-hour support is a service that we see as essential to best practice for HEN. As indicated in Figure 8, this service is a necessary support for HEN clients from the time they are discharged home from the hospital (phase III) right through until the time the client's HEN is ceased (end of phase IV).

The ability to supply HEN products to clients is also a central component to the provision of a HEN service. As with 24-hour support services, supply of HEN products is a service that is required from the time a client is discharged home from hospital.

6.1 24-hour Support Services

The AuSPEN Clinical Practice Guidelines for HEN (Appendix 1) recommend that once discharged there will be an on-call system for providing expert medical advice and support to the patient/carer by telephone 24 hours a day. At the time of our research we found little evidence of such services that were specific to HEN. The lack of specific 24-hour HEN support services was perceived to be an issue by HEN clients and dietetic practitioners interviewed during our research. The main need for a 24-hour HEN service was seen to be in the scenario of an enteral tube falling out. Other problems raised that might need support were in cases of equipment difficulties, such as enteral feeding pumps breaking down, or gastrointestinal disturbances, such as vomiting or diarrhoea.

The case of a gastrostomy tube falling out is an issue that requires attention within a few hours in order to prevent the stoma closing over. In a case of a few paediatric clients, the carer had been taught to reinsert a replacement tube. However in the majority of cases professional support is sought.

At the time of our research hospital emergency departments appeared to be the main source of medical advice outside of business hours. However there was a feeling of dissatisfaction or lack of confidence amongst HEN clients interviewed in the ability of these services to adequately manage such issues. Emergency department medical and nursing staff were perceived to have a general lack of knowledge with regard to HEN and enteral feeding tubes. Subsequently there often seemed to be no formal procedure in place for managing HEN related issues.

Other issues such as equipment failure or gastrointestinal disturbances are often less urgent than a tube falling out. In many cases these issues do not require immediate attention through out of hours services, such as emergency departments. Initial support could be provided by telephone until general HEN services could be accessed the next day.

Without timely access to professional support, HEN complications can be very distressing for a HEN client and their carer. This is compounded when emergency services are inadequately equipped to deal with these situations. The feedback during our research suggests that new options or modifications of existing systems might be needed for managing HEN related problems, out of hours.

Recommendations for Change

In making recommendations for provision of a 24-hour support for our model, a number of key components should be considered. Firstly, in line with the AuSPEN recommendations, HEN clients should be able to receive expert HEN-specific advice and support over the telephone 24 hours per day. Ideally this telephone service would effectively act as triage function to prioritise issues in terms of needs and their urgency. This service would then either provide initial support and counselling until referral is able to be made to general HEN services, or will refer immediately to emergency, out of hour's services.

This type of service is also in line with policy directions for the primary health and community support system reforms presently being initiated. Access to information and advice 24 hours a day is a key recommendation for improving access, quality and responsiveness of health care services to consumers. The ultimate aim of these reforms is to have a state-wide 'Out of Hours Information and Referral Response Service with one state-wide telephone number. This service would then link to other local after hour's information and crisis support services (DHS December 1998, p.14).

The issue then is who should provide this localised telephone support. Possible options might be:

- Dietetic HEN coordinator
- Emergency departments
- RDNS

Each of these options is considered below.

Dietetic HEN coordinator

The dietetic HEN coordinator might be on call via pager. Given that only one dietetic HEN coordinator is generally nominated per health care facility, a rotating roster involving all dietetic HEN coordinator in a particular Health Care Network or Region might be an option. A down side to this option is that the dietetic HEN coordinator is not usually able to deal displacement of an enteral tube, the situation that most requires attention after hours. As such other support services, like hospital emergency department or RDNS, would need to be called upon.

Emergency Departments

Emergency departments presently appear to be the main source of 24-hour medical care utilised by HEN clients. The issues raised above would indicate the need to develop clear policy and procedures with regard to dealing with HEN complications, particularly replacement of dislodged tubing. Some professional development of staff would also be required.

In the case of tube dislodgment, appropriate replacement tubing is also needed. There is now an extensive range of enteral tubes available on the market place. The emergency department might keep a selection in stock. This would work well if the client's tube was quite common or had been inserted at the same hospital as the emergency department attended. However, this is not always the case, as is quite common in rural areas. Possibly a better alternative is for the client to be given a spare tube, particularly if discharged to a location distant from the initiating hospital.

RDNS

The local RDNS 24 hour on-call service is an existing service that could also potentially provide a localised HEN specific service. RDNS could be trained by the HEN stomal therapist as to how to deal with a dislodged tube. The benefit of utilising this option is that the RDNS are able to deal with situations in the client's home, eliminating the waiting times associated with emergency departments. If further medical assistance were required the client would then be referred on to the closest hospital emergency department.

As with emergency departments, standardised policy and procedures would need to be developed for dealing with other HEN complications. Similarly the options for provision of replacement enteral tubes would be similar to that for hospital emergency departments. The present disadvantage with this option is that night RDNS services are presently stretched. Centres amalgamate for provision of after hours services. As such the staff are extremely busy, and the territory covered is quite large.

Regardless of the option chosen for provision of 24-hour emergency services the client should be empowered with certain knowledge and information to enable them to deal with complications. This should have occurred in phases II and III. The client should:

- Be aware of possible complications.
- Know how to deal with basic complications.
- Know whom to contact for support in dealing with complications, both during and outside of office hours.
- Have written details of their enteral tube including the type, size, date of insertion and external length of tubing.
- Should have a replacement gastrostomy tube if living distant from the hospital where the original tube was inserted.

Recommendation 6
Each Health Care Network / Region establish policies and procedures for 24-hour support of HEN emergencies.

6.2 HEN Product Supplies

Since the implementation of the HEN Pilot Program in 1997, HEN clients managed in the public health care system have been eligible for subsidy of their HEN supplies. Under the current funding model for the HEN program, health care facilities or Networks receive an annual block grant. From here it is up to the individual organisation to determine the most appropriate vehicle of supply for their HEN client population. Networks and health care facilities presently utilise a variety of options including provision through internal hospital supplies or they might use alternative suppliers such as community agencies or other hospitals.

Given the variety of systems that are presently established, this model is not going to attempt to describe a system for supply and delivery of HEN products. However, given a number of issues pertaining to equity of access were raised during our data collection, some features of present supply systems that overcome these issues will be recommended as part of the best practice model.

Best Practice in Supply of HEN Product

Subsidised Supplies

This subsidy is to cover supply all formula and equipment required. This might include a combination of any, or all, of those listed below:

- Enteral Formula
- Consumables (syringes, pump delivery sets, gravity delivery sets, formula containers).
- Non-consumable hardware (pumps, drip stands)
- Enteral tubing replacements (replacement parts, spare tubes)

In our data collection there was some apparent confusion as to the range of supplies the subsidy covered. In particular there was some uncertainty regarding enteral tubing. As part of best practice we would recommend that replacement enteral tubing and parts be subsidised as these products can be of considerable cost. It would be recommended that clients who live distant from the hospital where the initial tube was inserted would be given a spare replacement tube. This arrangement would be made on an individual basis, at the discretion of the dietetic HEN coordinator.

Replacement tube supplies held in emergency departments for replacement of dislodged tubes would also be funded through the HEN subsidy scheme. The dietetic HEN coordinator would be responsible for overseeing this supply.

Collection and Delivery of Supplies

In our data collection an issue raised, by clients and professionals alike, was equity of access to HEN supplies for clients. Access difficulties can occur for non-ambulatory clients, for clients with no means of transport and for clients who live in geographically isolated areas. Access restricted to business hours was also a limitation for many supply systems.

A solution to these access issues is home delivery of HEN supplies. While some supply systems offered this service, it was not a service generically integrated into all supply structures at the time of our research. In those systems that did offer home delivery, there was some variation in the cost and subsidy policies for provision of this service.

As such, to ensure equitable access to all clients, our model of best practice recommends that a home delivery service be made available to all clients, at a minimal fee. To ensure that geographically distant clients are not financially disadvantaged, either a standard co-payment or a maximum cap should be made on delivery fees. The HEN funding should cover the differential costs.

Recommendation 7

HEN clients be ensured of easy and equitable access to subsidised HEN supplies. The option of home delivery of supplies should be incorporated into all HEN supply systems. There should be an agreed standard for provision of supplies and services across the state.

7. Supporting Resources

The provision of HEN requires input from a team of professionals with specialised knowledge and experience in HEN (AuSPEN 1997). This is of particular importance for the key professionals that comprise the core of the HEN team (dietetic HEN coordinator, specialist HEN stomal therapist, primary care physician). The development of teaching and training resources is required to support and facilitate this expertise.

Short Courses

While these key team members should have discipline specific expertise and knowledge in HEN, our model of best practice recommends that these professionals should also have some knowledge of HEN in relation to the roles and responsibilities of other team members. The rationale for this is to facilitate flexible and responsive care for the client. The client should be able to make contact with any one of these professionals and have their needs responded to. With cross training, all team members should be able screen for issues requiring specialist input from other team members. This cross training of team members has been shown by other HEN teams to streamline and enhance patient care (Klein et al. 1998).

In particular it was clear from our research that access to professionals with specialist knowledge in the management of enteral tubing and stomal issues was perceived to be a gap in present service structures. The creation of regional, specialist HEN stomal therapists has been proposed to fill this gap. However the aim of this position is to address issues in regard to these aspects of care, not screen for them. In our model it is the aim that the dietitian takes on the key role in reviewing and coordinating HEN clients care. As such the HEN dietitian should be able to assess a stoma site and enteral tube for any problems and refer on to the HEN stomal therapist as necessary. In our survey dietitians supported the view that dietitians involved in HEN should be able to assess these aspects of care and refer on. However these same respondents rated their level of expertise or knowledge in these areas as quite low. Correspondingly these areas ranked highly as topics requested for professional development.

At the time of our research no formalised training or qualification was available to support the development of knowledge and expertise for professionals involved in the management of HEN. Some eduction and training in HEN was reported in discipline specific training courses, however anecdotal evidence suggests this is minimal. Expertise was generally reported to be gained through experience and self-directed learning. Responses from dietitians throughout our research suggest that development of some ongoing professional development activities in the area of HEN would be well supported.

Multiple options exist for the development of professional short courses. Multi-disciplinary associations such as AuSPEN, or discipline specific associations such as Dietitians Association of Australia (DAA) or the RDNS education and training service, Healthlinks, could conduct them. Affiliations with universities have been made in the past with other health related courses. Investigation into undergraduate training might also be an option.

Supporting Resources

In our research the need for additional professional development resources, to support the management of HEN, received considerable response from dietitians. The general feeling was that there was a paucity of good resources available. Suggestions for development included:

- Practical handbooks
- Videos
- Web sites
- Practitioner contact directory
- Standardised client education material

Recommendation 8

Further investigation be undertaken into the options for development of multi-disciplinary short courses and supporting resources for HEN.

8. Information Management

Documentation and Communication

Documentation of interventions undertaken with patients or clients is a requirement of any health care organisation. Management of this information is an area of concern to all organisations. A difficulty highlighted in a recent discussion paper on primary health and community support services (PHACS) was the ability of service providers to effectively exchange information. This was an issue that impacted on the continuity of care both within and between health care sectors.

In our research, with regard to HEN services, difficulties in relation to documentation and communication were also raised. Inconsistency in the standard of communication between health care providers was noted, particularly with the transfer of a HEN client's care from one health care facility to another. Communication between professionals involved in the care of a HEN client was often seen as inefficient or inadequate. Within the hospital setting communication was not generally emphasised as an issue, as the client's unit record served as a central point of documentation and communication. Difficulties were largely seen to arise when professionals from a variety of settings and different organisations become involved in the management of a HEN client. In this situation there was generally no central point of documentation that all service providers could access. This was seen to result in poor or untimely, communication between professionals.

As noted in our research, and in the review of PHACS, each organisation has its own approach to documentation and exchange of information. As such there is a lack of standardisation in the information collected, often resulting in duplication of assessments. The lack of structure and standardisation in documentation and communication was seen to contribute to inefficient and uncoordinated care of clients.

It is clear that effective and efficient operation of health services, particularly when multiple sectors and operators are involved requires an integrated system of information management. This is required at a number of levels. Service providers need access to care management information if they are to provide the best possible care. Statistical information is also required by government and service purchasers to guide service planning. In discussion surrounding PHACS reforms it has been noted that a number of conditions need to be satisfied if these aims are to be achieved. These conditions are quoted below:

- "Information must be structured in standardised ways so that it is intelligible to a variety of readers.
- Protocols for the timely exchange of information, including adequate protection of client privacy and confidentiality, need to be in place.
- Mechanisms for the efficient exchange of information need to be available to all the providers involved in a client's care.
- Summary information needs to be passed to service purchasers on a regular, periodic basis.
- This summary information needs to be capable of being linked across sectors" (DHS December 1998b).

Information technology can provide the solution to these information management issues. The Department of Human Services is presently encouraging development of strategic directions for the creation of information management systems as part of PHACS demonstration projects.

Addressing the management of information within the acute sector and communication between the acute sector and external service providers is also a key mandate of the Effective Discharge Strategy projects (DHS December 1998a).
With regard to HEN service systems, achievement of best practice will be greatly assisted with the development of integrated information management systems that enable seamless exchange of client information between providers. However until this infrastructure is in place alternative information management strategies should be examined to support the delivery of HEN services. This is considered below.

Assessment and Communication Tools

As noted previously, most organisations have their own approach to the management and dissemination of client related information. Similarly the Ministerial Working Party for HEN (ref) found that there was a paucity of standardised information available with regard to the management of HEN in Victoria. As such a sub-committee was formed to identify a minimum dataset for HEN. The outcome of this was the development of a HEN database to capture clinical and financial information. Data on client details, use of HEN product and costing is required to be fed into this database by all health care facilities funded through the HEN Pilot Program. At the time of writing, all funded health care facilities and Networks have local access to a database. The data is centrally managed by the Department of Human Services who require that expenditure reports and aggregate client information be forwarded on a regular basis.

The development of this database has introduced some state-wide standardisation of the type of information collected on publicly managed HEN clients however it is not electronically linked, centrally or between HEN funded organisations. As such it was found during our research that there were still variances between hospitals in their assessment documentation and communication procedures. While there were commonalities between the tools used for these processes there were generally organisation specific variances. In accordance with the PHACS information management recommendations quoted above, we propose that state-wide standardisation of communication procedures and communication tools would facilitate smooth exchange of client related information.

In the absence of established system wide electronic information systems, we have suggested a range of standard assessment and communication tools to support the delivery of HEN services. These have been made on the basis of existing practices, identified in our research, and suggestions made to address identified gaps. The suggestions made are in accordance with the recommendations made in the DHS report on effective discharge (DHS December 1998a) and PHACS reform discussions (DHS December 1998b). The tools have been described in the sequence they would be commonly used throughout a HEN client's episode of care.

HEN Care Plan

In the initial phases of HEN the client must undergo assessment for their HEN, have their care plan established and receive education on the management of HEN. All of this information should be documented and communicated between the service providers involved in the client's care. As such, a tool is proposed that would incorporate input from relevant multi-disciplinary team members. This proposed tool would serve a number of purposes. It should:

- Form a HEN summary of the initial assessment and care plan for the client's unit file.

- Provide a summary for hand-over to the dietetic HEN coordinator for their reference and maintenance of the database
- Provide a discharge summary for hand-over to other service providers that will be central to the HEN client's ongoing management.

Given the functions this tool must perform, multiple copies of the form will need to be made or a triplicate form developed. The form should have at minimum the following information:
- All data required for entry into the HEN database, including client details, HEN requirements and details regarding administration.
- A checklist of education provided and an assessment of client capability.
- Discharge care plan, including follow-up arrangements.
- A checklist of service providers to whom a copy was forwarded

Development of a standardised state-wide form would require broad consultation. Flexibility for organisation specific details would need to be incorporated in this process.

It is envisaged that the dietetic HEN coordinator from each HEN funded health care facility would coordinate this documentation and communication.
With regard to communication with service providers external to the health care facility initiating the client's HEN, some organisations had preformatted letters that were routinely sent out to other service providers, such as to GPs.

Another idea put forward regarding communication with other service providers was an information or promotional brochure describing state and local HEN services, particularly for those professionals who might not have had previous involvement with HEN. This type of communication would need to be developed at a local level.

Ongoing Communication and Documentation

A major difficulty raised in our research, as noted previously, was documentation and communication of interventions by service providers from different organisations. Our model is also faced with this issue. In Phase IV of the model, dealing with the ongoing management and review of the HEN client, service providers from a number of settings have been utilised in order to provide local and flexible follow-up arrangements. At present each of these service providers have their own files for documentation associated with their respective organisations. Communication regarding interventions is often managed in an ad-hoc manner through written or verbal means.

Until electronic exchange of data is established, protocols need to be established within local HEN service systems to manage this issue. Below are some examples of strategies being used or investigated by various health care programs:

- Clients receiving home based services funded through the HACC program record information in a common file kept by the client. This is primarily as a means of communication between professionals.

- RDNS also document interventions in a communication book kept with the client.

- Current Coordinated Care Trials have also investigated solutions to improve provider communication and access to consumer-focused information (DHS December 1998, p.38).

- The Australian Institute of Health and Welfare has recently completed a report on the notion of common unit records between hospitals and community care providers (DHS May 1998, p.58).

As discussed in Section 5.4, the model recommends that key service providers should all have the capacity to screen for issues requiring input from other health professionals. The need to develop a tool to facilitate this cross screening was also highlighted. A review form that acted as a checklist might assist this process.

Recommendation 9

Standardised tools be developed to assist information management (assessment, data collection, documentation and communication).

9. Quality & Outcome Indicators

The success of health care interventions is determined by their ability to achieve or deliver desired outcomes. Quality of care performance indicators are essential components to the measurement of this success. With these tools the structure and process of health care delivery can be evaluated and continuously improved.

On a broader scale development of quality indicators are essential for benchmarking. Benchmarking is the search for best industry practice that will lead to superior performance. In effect benchmarking is a core principle of a best practice environment. Through the development of standardised quality indicators, comparative information about performance operations can be shared between health care organisations.

There is a paucity of research and development into performance indicators for the measurement and evaluation of HEN services. Development of quality of care performance measures is a current major strategic direction for all levels of health care. The following are key dimensions of quality care for which indicators are ultimately sought:

- Access to care
- Acceptability of care
- Appropriateness
- Effectiveness and safety
- Variations in care
- Continuity of care (DHS June 1999, p.8; Boyce et al. 1997).

With the development of the HEN database, an opportunity exists to develop and integrate state-wide performance indicators for the management of HEN. This would provide the means for benchmarking of HEN service delivery systems across Victoria and enable evaluation of the model of best practice, described in this document.

Recommendation 10

Performance measures for HEN be developed, with corresponding tools for measurement.

10. State-wide Management

State-wide HEN Coordinator

At present, the state-wide administrative coordination of the HEN Pilot Program is managed centrally through the Department of Human Services (DHS). To date this has entailed management and delegation of funding grants. Data collected through the HEN database has also been managed centrally by DHS. Ongoing state-wide coordination of HEN is important to the implementation of best practice service delivery for HEN in Victoria.

In addition to the functions currently undertaken by DHS, a number of other potential state-wide functions were suggested, during our research, to improve the standardisation and efficiency of service delivery throughout Victoria. Many of these would require an intimate understanding and knowledge of HEN. As such it could be proposed that implementation of HEN services might be optimised by appointment of a professional with HEN experience to undertake state coordination responsibilities. Some issues and suggestions raised during our research that support the need for state-wide coordination are outlined below:

- A state-wide HEN coordinator was perceived as important for development of standardised policies and procedures for HEN across the state. Some ambiguity in HEN policies was noted during our research, pertaining particularly to supply of product. In addition a number of issues were raised that were seen to require review and subsequent development of policy statements to standardise practices.

- Dietitians perceived an issue with effectiveness of communication and transfer of information from a state level to the local level. A state-wide contact was seen as important for ongoing dissemination of information pertaining to policy updates. Communication of information obtained from the database was also seen as important.

- Information from the database needs to be collated and analysed in an ongoing manner. This includes analysis of financial information and clinical data. This will be important for monitoring cost effectiveness and clinical outcomes associated with the management of HEN. The information obtained from the database will be a vital tool in informing and guiding future program developments, service delivery structures and clinical management of HEN in Victoria.

- A state-wide coordinator was also seen as a vital resource for directing to specialists around Victoria.

Recommendation 11
A state-wide coordinator, with intimate knowledge of HEN services, be appointed to oversee the delivery of HEN in Victoria. This position should be funded through the HEN Pilot Program.

HEN Special Interest Group

In Sections 7.0 and 8.0, recommendations have been made regarding the development of standardised state-wide communication tools and resources to support the implementation of HEN services. A state-wide coordinator was one possible option for facilitating development of these resources.

Another option put forward to facilitate the development of resources was the establishment of a multi-disciplinary Special Interest Group (SIG). This type of group could potentially be an extremely important to the management of HEN. Aside from developing resources this group could form the basis for a state-wide expert advisory committee to support the state-wide coordination of HEN.

An ideal combination of these two options would be to have a HEN SIG to act as an advisory committee to a state-wide coordinator.

Recommendation 12

A multi-disciplinary HEN Special Interest Group be formed, under the auspice of an appropriate professional body (eg AuSPEN, DAA), to support the state-wide HEN coordinator and facilitate development of supporting resources for HEN.

11. Resource Requirements

The provision of HEN services requires considerable resources. These resources include:

- HEN product.
- Human resources.
- Supporting resources.

With the increasing use of HEN as a community-based treatment modality, the implementation of best practice HEN services is dependent on equitable allocation of resources for service provision. The HEN Pilot Program to date has funded provision of enteral formula and equipment only. It does not make provision for service provider requirements or the development of supporting resources.

In the development of the best practice model, outlined in this document, careful consideration has been given to cost containment and the economic viability of options for service provision. The service structures that have been recommended for implementation of quality HEN services have attempted to incorporate existing service providers and programs.

However the research undertaken in the first phase of this project identified some significant gaps in HEN service systems. Most notably a lack of available professionals to manage HEN in the community was an issue in many areas of the state. In order to address these gaps the model has incorporated some recommendations that will require a shift in the allocation of resources.

Through realignment of resources for HEN it is proposed that implementation of this model will ultimately result in overall cost savings to the health care system. The proposed cost savings would come about as a result of:

- Decreased length of hospital stay through facilitation of more timely discharge.
- Decreased readmission rates through more effective discharge.
- Decreased reliance on hospital resources, such as emergency services, through appropriate and timely management of potential complications.
- Increased cost efficiency through more streamlined coordination of services, minimising duplication of interventions and resources.

The key resources required for implementation of the proposed best practice model for service delivery of HEN are highlighted below with possible funding options for consideration.

Purchaser / Provider Arrangements

HEN Supplies

HEN clients require access to:

- Formula
- Consumable hardware
- Non-consumable hardware
- Supply costs (eg courier)

Since October 1997 the provision of enteral feeding products and equipment has been funded through the HEN Pilot Program. This entitles HEN clients, managed in the community through a health care provider participating in the HEN Services Pilot Program, to subsidised provision of formula and equipment.

To date this $2 million recurrent funding commitment has been allocated in specified block grants to Public Health Care Networks and Major Regional Hospitals. In the future, the Department of Human Services will aim to mainstream the HEN Pilot Program. The Victorian Ambulatory Classification System (VACS) has been proposed as an option through which purchase of HEN funding might be mainstreamed (DHS June 1999, Appendix 8).

Service Providers

In determining a model for best practice in service delivery of HEN, three key professional disciplines were seen as integral to the implementation of HEN. These core team members are:

- Dietetic HEN coordinator.
- Regional HEN stomal therapist.
- Medical Professionals (General Practitioner).

Dietetic HEN Coordinators

Implementation of the best practice model centres on this position. The key components of this position that facilitate best practice are:

- The domiciliary role.
- The case management or coordination of HEN care.

At the time of our research these roles and responsibilities were being undertaken, to various degrees, in only a sampling of organisations managing HEN. Often these two responsibilities were not integrated into the one position.

At the time of our research, the majority of dietitians involved in the management of HEN clients were funded through public hospitals or in the community, in Home And Community Care (HACC) funded roles. In the majority of hospitals the capacity to undertake domiciliary visits was not funded. In some instances other funding programs such as Post Acute Care (PAC) or Hospital In The Home (HITH) might be used if an organisation had access to these programs and the HEN client met the programs' eligibility criteria.

Consideration needs also to be given to allocation of resources for the overall administrative and coordination roles required for HEN in either hospital or community funded positions.

Other funded programs such as HACC, PAC and HITH, while they all have some limitations, present potential opportunities for the funding of service provision of HEN that should be further explored. Appendix 3 outlines these programs in more detail and highlights some of their limitations for the management of HEN.

HEN Stomal Therapist

This position does not presently exist. The model has suggested affiliation of this position with RDNS. However other viable funding options also exist for purchase or provision of the services of regional HEN stomal therapists. The HEN stomal therapist position could be potentially associated or funded through:

- A nominated funded hospital in each Health Care Network.
- RDNS.
- DHS funded position through the HEN Program.
- HACC.
- Joint Commonwealth and State funded position if Nursing Homes were incorporated into the roles and responsibilities.

> **Recommendation 13**
> Investigation be undertaken into purchaser / provider arrangements for provision of:
> - Dietetic HEN coordinators.
> - Regional HEN stomal therapists.

Medical Practitioners

General Practitioners (GPs) have been nominated as the primary medical contact for HEN clients. Secondary support from the acute sector is required from gastroenterology or surgical units associated with insertion of long term enteral feeding tubes.

GP networks are already well established. GPs derive a large proportion of their income through the Commonwealth funded Medical Benefits Scheme. Additional funding would need to be allocated for development of professional support structures or resources for supporting GPs in the management of HEN. A collaborative project with GP Divisions would be an appropriate option for implementation of such a project. See Recommendation 4, Section 4.4.

Post discharge provision of gastroenterology or surgical support for HEN clients would be calculated into their respective VACS category cost weights.

Supporting Resources

State Coordinator

The broad proposed functions of a state-wide HEN coordinator have been outlined in Section 10.0. The primary responsibilities are associated with the HEN funding program. As such it would be recommended that allocation for such a position be allocated in the recurrent funding of the HEN Pilot rogram. See Recommendation 11, Section 10.0.

Professional Development

Management of HEN requires professionals with specialist knowledge in this area. In order to support this expertise and knowledge professional development resources are required. See Recommendation 8, Section 7.0.

12. Future Directions

This document proposes a best practice model for the service delivery of HEN. Accompanying the model is a series of recommendations outlining procedural suggestions and structural resources required for implementation of the model.

Preceding the implementation and evaluation of the proposed model, a number of priority recommendations must firstly be addressed. The recommendations seen as priority areas for action are:

- The development of state-wide performance indicators for monitoring and evaluating HEN services.

- The investigation into purchaser / provider arrangements for provision of dietetic HEN coordinators and regional HEN stomal therapists.

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Appendices

Appendix 1 – Clinical Practice Guidelines for HEN in Australia (AuSPEN 1997)

Introduction

The aim of these guidelines is to achieve better health outcomes by improving the practice of health professionals involved in the care of patients requiring home enteral nutrition (HEN).

Multi-disciplinary Nutrition Teams

Nutrition support teams operating within hospitals have demonstrated that their involvement improves standards of care and increases cost-effectiveness of artificial nutrition support.

The best care of the patient receiving HEN will occur when the primary care physician working with a nutrition support team (comprising medical practitioner, nurse, dietitian, stomal therapist) takes responsibility for the initial and ongoing care of the patient receiving HEN.

All members of the team have specialised knowledge and experience in HEN. The team familiar with HEN liaises with all other health professionals involved with all other health professionals involved with other aspects of clinical care. The team makes a joint decision regarding patient selection and ongoing management.

The team approach can:

- Improve standard of care
- Increase cost-effectiveness
- Ensure appropriate training and counselling of patient / or carer
- Reduce complication rates

Indications

Home Enteral Nutrition can be considered in the management of the following conditions, including:

1. Impaired ability to ingest nutrients

- Oropharyngeal, oesophageal tumours
- Neurological disorders, eg cerebrovascular accident, multiple sclerosis, motor neurone disease, trauma

2. Impaired absorption of nutrients

- Surgical resection / bypass, eg gastrectomy, small bowel resection
- Malignancy of GIT, eg Ca pancreas
- Inflammatory disorders, eg Crohn's disease
- Short bowel syndrome
- Gastrointestinal fistulae
- Radiation enteritis

3. Miscellaneous

- Chronic pulmonary disease, eg Cystic Fibrosis
- Chronic renal failure
- Anorexia nervosa
- Congestive cardiac failure

HIV / AIDS

4. Paediatric indications

- Neurological disorders, eg Cerebral Palsy
- Failure to thrive
- Short bowel syndrome
- Chronic pulmonary disease, eg Cystic Fibrosis
- Inflammatory bowel disease
- Gastro-oesophageal reflux
- Metabolic disorders
- Chronic renal failure
- Malignancy

Contraindications

Patient / carer not motivated or able to maintain the discipline involved in delivering HEN.

Selection of patients for HEN

- Inability to meet nutritional requirements by oral intake as documented by dietitian's nutrition history.
- Clinical status is stable and allows discharge to the home.
- Quality of life will be maintained / improved by nutrition support.
- Patient has the ability to comply with and tolerate the nutrition therapy.
- The patient and the carer are able to cope with changes in lifestyle and demonstrate ability to perform procedures to acceptable standards.
- The home environment is appropriate for the safe and effective use of nutrition support.
- The patient and carer understand the cost of nutrition support and are aware of financial responsibilities.

Assessment

1. Clinical History
The following clinical data will be assessed:
- Underlying disease
- Age
- Metabolic demands including growth requirements
- Fluid requirements

2. Medications and Supplements
Consideration will be given to the method of delivery of medications and supplements.

3. Nutrition History
The dietitian, through appropriate dietary methodology, will assess the nutrient intake of the client.

4. Anthropometry
The following anthropometric measures will be assessed:
- Weight, height, BMI
- Weight history
- In children, include percentile growth data and head circumference in young children and infants
- If body weight cannot be measured, an estimation of body weight should be obtained from family or carer.

5. Biochemical Data
The following biochemical data will be assessed:
- Liver function, renal function
- Serum electrolytes, glucose, phosphate and calcium

6. Social Considerations
The home environment and the patient / carer's ability to cope with the necessary procedures shall be assessed.

7. Activity Pattern and Lifestyle
The recreational and relaxation activities of the client will be considered including how these will impact on home feeding regimen.

Planning

A care plan will be based on the results of the assessment and should include the following:

Selection of Most Appropriate Route of Administration for HEN
The selection of the most appropriate route of administration for HEN will take into account the expected duration of support, the conscious state and clinical condition of the patient. Possible routes include:

- Nasogastric
- Nasoduodenal
- Nasojejunal
- Gastrostomy
- Jejunostomy

Methods of Delivery of HEN

The safest and most efficient method of delivery of HEN must be determined clinically for each patient. Enteral feeds may be delivered by intermittent bolus, gravity infusion or pump-controlled techniques.

Selection of Formula and Timing of Feeds for HEN

- The selection of formula will be based on a balance between the clinical requirements, mode of delivery tolerance, long-term cost and availability.
- The formulae will be appropriate for the disease process and be adjusted according to metabolic requirements.
- Formula will meet estimated nutritional and fluid requirements, with consideration for other sources of fluid / restrictions.
- The cost implications of type and quantity of feeds and the availability of government subsidies for HEN should be considered in the selection process.
- Rate and timing of administration of solutions shall be based on patient tolerance and home routine.

Implementation

There shall be written guidelines (an instruction manual) for the education of patient / carer.

Upon discharge from hospital, the patient / carer will know:

- How the function of GIT has changed and the reason for enteral nutrition.
- How to manage the delivery system; pump or gravity drip or syringe.
- The principles of hygiene.
- How to prevent and recognise complications such as infection, aspiration, and mechanical complications such as occlusion or misplacement of the tube.
- How to irrigate a blocked tube.
- How to change malfunctioning parts of the tube.
- Storage, hang-time, and means of provision of feeds.
- Names of personnel to contact 24-hours/day.

The patient / carer will be able to:

- Check tube position.
- Prepare feed ready for administration.
- Connect feed to feed tube.
- Program feeding pump.
- Administer a bolus feed down the tube.
- Administer medication down the tube.
- Disconnect feed and flush water down the tube.

Documentation

1. There will be a written staff protocol for initiating, monitoring and terminating HEN.
2. The nutrition support team will document in medical history all relevant aspects of assessment and management of HEN, and send information to all involved in health professionals upon discharge.
   In the medical history, the following will be documented:
   - Nutrition care plan including;
   - Initial assessment
     - anthropometry, biochemistry, nutrient requirements
     - route and method of administration of HEN
     - delivery times or duration of feeding period
     - formula
     - nutrient and fluid composition

3. There will be a patient / carer instruction manual for HEN, which is regularly updated in order to reflect developments and innovations in tube feeding, access, nutrients and delivery systems.
4. There will be a written prescription for the enteral feed, and other prescribable items.
5. There will be a list of the required equipment eg syringes, pump, drip stand.
6. There will be a written patient / carer learning goals for HEN.

Monitoring

- Protocols shall be developed for the periodic review of the patient's clinical and biochemical status, and quality of life.
- There is an agreed time-frame for follow-up and reassessment by the nutrition support team.
- Patients receiving HEN feeding shall be reviewed by the nutrition support team after the first 3 months of initial treatment. After this review at no longer than 6 monthly intervals.

The patient will be monitored for:
- Effectiveness of therapy.
- Adverse effects
- Clinical changes.

Routine monitoring should include:
- Continued need for HEN.
- Nutrient intake.
- Review of current medications.
- Signs of intolerance to feeds.
- Weight changes.
- Biochemical, haematological data.
- Adjustment to therapy.
- Psychosocial problems.
- Changes in home environment.
- There will be an on-call system for providing expert medical advice and support to the patient / carer by telephone 24 hours a day.

Termination

- Protocols will exist which indicate when feeding should be stopped, and what alternative action should be taken.
- Enteral nutrition should be stopped when the nutrition support team and patient / carer judge that the patient no longer benefits from the therapy.

Transitional feeding

- If the patient is changing over to oral intake, they must be seen to be achieving adequate nutrition by this method before HEN is stopped.
- Close dietetic involvement is important to ensure adequate nutrient intake.
- An intermediate period of increasing oral intake and decreasing enteral feeding will be often necessary to assess this.
- If swallowing difficulties are present, a speech pathologist will be required to assist in transition from enteral feeding to oral intake, and to minimise aspiration risk.

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Appendix 2 – Recommendations of the Ministerial Working Party on HEN (July 1997)

The Working Party recommended that:

Recommendation 1

A small sub-committed comprising of HEN service providers be convened to identify a HEN minimum dataset and to consider how this dataset should be best funded, monitored and maintained.

Recommendation 2

The Department of Human Services considers funding Victorian-based research trials into the outcomes and cost-effectiveness of HEN therapy.

Recommendation 3

The provision of HEN in Victoria should be based on the best practice framework detailed in the 'Clinical Practice Guidelines for HEN in Australia' developed by the Australian Society of Parenteral and Enteral Nutrition (AuSPEN). This incorporates:

- Written criteria for the selection, initiation, monitoring and termination of HEN therapy.
- Standards for HEN care including discharge planning guidelines and education protocols
- Adoption of a multi-disciplinary team approach or a case management approach for HEN clients.
- Regular clinical review of HEN clients, at least within the first three months of discharge and every six months thereafter (at a minimum) with clinical reviews to be undertaken by a dietitian and a medical specialist.

Recommendation 4

The Minister writes to the Commonwealth Minister for Health and Family Services seeking Commonwealth assistance for HEN costs for clients in community settings.

Recommendation 5

The Department of Human Services invites Health Care Networks and hospitals to apply for funding for HEN services, contingent on agreement to meet the following conditions:

- Assumption of demand risk.
- Compliance with AuSPEN 'Clinical Practice Guidelines for HEN in Australia'.
- Collection of patient co-payment for enteral formula.
- Distribution of enteral formula.
- Collection of an agreed minimum dataset.
- Provision of all necessary aids and equipment for all HEN clients.
- Participation in ongoing monitoring and review by the Department of Human Services.
- Maximise access for rural clients.

Recommendation 6

The Working Party reconvenes to review the impact of changed funding arrangements, outcomes or research and changes in clinical practice on the provision of HEN services in Victoria, with particular emphasis on the equity of co-payment arrangements and on accessibility for rural clients.

Appendix 3 – HEN and Other DHS Programs

In our research a number of existing service delivery and funding programs and were noted to interface with HEN services. These were:

- Post Acute Care Program
- Hospital in the Home
- Home and Community Care

Post Acute Care

PAC is a joint initiative of the Acute Health and Aged, Community and Mental Health Divisions of the Department of Human Services. PAC projects are gradually expanding to extend coverage in metropolitan areas and rural regions across Victoria. The resources allocated to PAC projects are dedicated to coordination and service provision following discharge.

Post Acute Care is a time limited short term intervention designed to assist patients to recuperate following an acute hospital admission and to facilitate their independence or transition to continuing care where required. Funding enables the purchase of individually tailored packages of health and community care services such as home nursing, personal care, childcare, allied health services and home help following discharge from hospital. The PAC program provides funding for the provision of additional post acute care services as required, and in doing so acts to augment the current service system, not substitute existing services (DHS June 1999, Appendix 6).

PAC has been used by a few organisations to manage HEN clients in the initial post discharge phase. This has enabled generally been used to purchase community nursing services and has enabled domiciliary dietetic services.

The limitations with using PAC as a funding source of service provision for HEN is the fact that it is a short-term service. The provision of continuing care must still be addressed.

Hospital in the Home (HITH)

Hospital in the Home provides consumers with more health care options by incorporating a home based component in, or providing a complete home based alternative to, an episode of acute care (DHS June 1999, p.51). For some short-term HEN clients undergoing specific treatment, eg radiotherapy and chemotherapy clients, HITH is a useful alternative. HITH is not however available for HEN clients with particular conditions who require long term HEN.

Home and Community Care (HACC)

The HACC Program is a national, cost-shared program between Commonwealth and State governments. The aim of the HACC Program is to provide a comprehensive and integrated range of support services for frail aged and other people with a disability, and their carers. Multi-disciplinary services are provided to assist people to be more to be more independent at home and in the community and to assist carers in their caring role. The aim is to prevent inappropriate admission to long-term residential care and to enhance the consumer's quality of life.

Home and Community Care (HACC) teams, namely HACC dietitians have become involved with the care of non-ambulatory HEN clients. The present limitations with this program are that not all areas are serviced by HACC teams, or HACC dietitians, and not all HEN clients fall under the Program's eligibility criteria (DHS May 1998).