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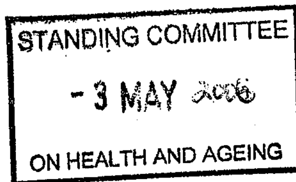
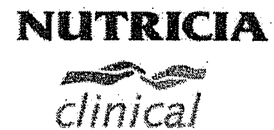


Home Enteral Nutrition in Australia: The Need for a More Equitable System

Submission from the Enteral Industry Group to the Inquiry into Health Funding

April 2006



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Home Enteral Nutrition in Australia: The Need for a More Equitable System

Executive Summary

Home Enteral Nutrition (HEN) is a medical technique capable of prolonging life and providing greater freedom for between seven and ten thousand disabled and unwell Australians. However, there is no national system for the delivery of HEN services at a consistent and affordable cost to consumers. This submission outlines the case for an improved, more consistent and more equitable system for the provision of and access to HEN supplies and equipment across Australia.

Specifically, this submission responds to the following Terms of Reference for the Inquiry into Health Funding:

a. examining the roles and responsibilities of the different levels of government (including local government) for health and related services;

b. simplifying funding arrangements, and better defining roles and responsibilities, between the different levels of government, with a particular emphasis on hospitals;

c. considering whether and how accountability to the Australian community for the quality and delivery of public hospitals and medical services can be improved;

Current frameworks for HEN are inconsistent and inequitable...

The cost of HEN varies greatly between different States, regions and even hospitals within Area Health Services. Patients can access variable rates for HEN supplies and equipment and experience different delivery methods, solely on the basis of where they live. It is difficult for consumers to access clear information on the amount of public funding allocated to the provision of HEN services and funding arrangements appear to be developed in an ad hoc fashion by a range of stakeholders.

By not providing an efficient and effective system for the delivery of HEN services, the Australian healthcare system is missing a significant opportunity. HEN enables patients to return home from hospital earlier, and allows hospitals and policy-makers to make more hospital beds available sooner. However, the system is underutilised - in large part due to its complexity and the difficulty of accessing information about it.

This paper argues that a national subsidy for the provision of HEN services is required and identifies three specific policy options to provide a more consistent, national approach. These are:

This paper proposes three models for a more consistent, national system for HEN...

1. Creating a model similar to the existing Department of Veterans' Affairs scheme to provide HEN supplies and equipment through retail pharmacies at an equitably subsidised price.

   OR

2. An NGO outsourcing arrangement (similar to diabetes) where a relevant non-government organisation manages the subsidisation of HEN products in each State and Territory.

OR

3. Creating a specialised body to administer the subsidy and HEN from this point onwards.

These options are raised for the consideration of decision-makers, and the medical nutrition industry would welcome the opportunity to discuss them in greater detail at a public hearing of the Inquiry into Health Funding.

Note: This submission has been prepared by the Enteral Industry Group which consists of Abbott, Nutricia and Novartis Consumer Health. It should be acknowledged that these three companies are the leading suppliers of HEN supplies in Australia. This submission is also a working document the Group is currently developing and refining through a series of meetings across Australia with hospital, government and dietetic stakeholders. As such, its findings and recommendations should be considered well-informed but preliminary.

Introduction to Home Enteral Nutrition (HEN)

According to the NSW Greater Metropolitan Clinical Taskforce, 'Home Enteral Nutrition (HEN) is the delivery of nutrition either by the mouth or by tube into the gastrointestinal tract of a patient in their home setting'. In this submission, references to Home Enteral Nutrition relate to the nutritional supplement, feeding tubes and all ancillary equipment.

HEN fulfills the nutritional requirements of thousands of disabled and unwell Australians...

Patients include those with swallowing difficulties as a result of neurological disease (e.g. Stroke, Multiple Sclerosis, Facial Trauma, Cerebral Palsy, Parkinson's Disease), head and neck cancer, or those who struggle to satisfy their nutritional and energy requirements via their usual diet (e.g. Cystic Fibrosis, failure to thrive in children, short bowel syndrome).[1]

Home Enteral Nutrition (HEN) is an essential alternative to solid foods for many ill or incapacitated people. Dietitians and to a lesser extent Doctors are the main prescribers of HEN. It provides for the nutritional needs of those unable to feed themselves through other means. Importantly, due to a patients' ability to self administer HEN, patients in metropolitan, rural and regional areas will benefit equally under this proposal.

In general, providing enteral nutrition in the home at a price patients can afford enables hospitals to discharge patients that would otherwise require longer hospital stays. Some hospitals currently provide partial HEN subsidies to patients leaving hospital, however this is applied inconsistently across individual States and Territories and regions within each jurisdiction.

Clinical studies have demonstrated that HEN has assisted:

- Cancer patients in experiencing improved comfort and quality of life;
- Cystic Fibrosis sufferers through the ease of self-intubation and resultant positive weight gain;
- Short bowel syndrome sufferers in a stimulation of intestinal adaptation; and a
- Liver disease sufferers through the provision of a cost-effective nutrition support regime.

As a technique, Home Enteral Nutrition offers a number of advantages to patients, hospitals and health policy-makers.

HEN offers advantages to patients, hospitals and decision-makers alike...

- When administered safety and effectively, HEN enables hospitals to discharge patients earlier and frees up much-needed beds.
- With appropriate support in the home, HEN can prevent unnecessary and costly hospital readmissions due to feeding problems (eg. blocked feeding tubes).
- Patients are able to return to the comfort of their homes sooner, and experience an improved quality of life by getting out of hospital earlier with a convenient option for nutrition delivered to their door.

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[1] Hunter Health, 'Home Enteral Nutrition', http://www.hunter.health.nsw.gov.au/hen/, accessed January 2006.

- Policy-makers have an opportunity to enable faster hospital discharges, free more hospital beds and improve the quality of life for patients unable to fulfill their nutritional requirements by mouth.

How many patients are involved?

Between 7,000 and 9,800 Australians rely on HEN for their nutrition each year, in private and nursing homes...

The Enteral Industry Group estimates the number of enterally fed patients discharged from hospital to home across Australia to be between 5,000 and 7,000 at any one time. In addition, it is estimated that a further 2,000 to 2,800 nursing home residents require enteral feeding at any one time.

However, these are only estimates and the Department of Health and Ageing was not able to provide the industry with exact numbers on the number of HEN patients in residential care.

Estimating the Cost of HEN Supplies and Equipment

The actual cost of HEN supplies and equipment to hospitals and providers is not publicly available. Members of the Enteral Industry Group have not discussed pricing at any stage, in accordance with competition law requirements.

The most recent publicly available indications are a Hospital Circular from the Victorian Department of Human Services in October 2004, the NSW Hunter Health Question and Answer Document from August 2004 and a Queensland Health policy updated in 2003. Even these are inconclusive and somewhat dated, but the co-payment schedules provide an indication of the cost of HEN supplies, equipment and delivery.

In the Victorian circular, the maximum co-payment for adults is listed at $45 per week which means HEN supplies must cost at least that amount - or $6.42 per day. As this is a co-payment, it is likely they actually cost more but the figure is a useful indication. However, the figure is likely based on the cost of regular food and not medical nutrition products specifically.

According to the Hunter Health document, the maximum co-payment (or 'client contribution') until 2007 is listed at $62 per week - or $8.86 per day. This is for supplies and equipment, and according to Hunter Health is less than the retail price charged in pharmacies.

The Queensland Health policy for the Supply of Enteral Nutrition Products to Outpatients sets the maximum weekly co-payment at $45.50, but this was set in accordance with the Australian Bureau of Statistics estimate of 'weekly costs of normal food' - and not the cost of medical nutrition products specifically.[2]

The cost of HEN supplies and equipment varies, but has been estimated at around $9.64 per person per day...

However, the most useful estimate was offered by an ACT-based dietitian we spoke to in January 2006. While the ACT subsidy is fixed - and not based on the actual cost of the products in question - as a rough average it was estimated that the subsidy is approximately 1/3 of the total cost. With an adult co-payment of $45 per week, the Canberra estimate suggests HEN supplies actually cost $67.50 per week (or $9.64 per day).

[2] Queensland Health, 'Policy/Guidelines: Supply of Enteral Nutrition Products to Outpatients Through Queensland Health Services', Version 5, Amended 20/12/2003, http://www.health.qld.gov.au/phs/Documents/pas/22041.pdf, p.1-2.

The Enteral Industry Group has been unable to ascertain the value of individual State and Federal Government contributions to HEN patients in each jurisdiction. However, it is clear that the system is applied inconsistently between States and Territories (eg. Victoria has a broad subsidy scheme, while NSW does not) and even varies between different Area Health Services or regions within each State (eg. patients in the Hunter region of NSW will pay a different amount for the same HEN service than those in the West of Sydney).

This is unnecessarily complicated and inequitable.

HEN in the States and Territories

Frameworks for HEN are inconsistent, and some patients get a better deal than others...

In early 2005 and again in early 2006, the Enteral Industry Group contacted health departments and hospitals in each State and Territory seeking to develop a map of HEN systems across Australia. We also conducted a scan of relevant government websites seeking details on HEN-related policies and assistance programs.

Unfortunately, very little information is publicly available and nearly all knowledge appears to reside in the Dietetics Departments of individual hospitals. The systems appear to be highly inconsistent, but it is difficult to find out for sure.

This paper includes the information we were able to obtain, but highlights the gaps and inconsistency that characterise the HEN systems across different States and Territories. For this reason, the first recommendation in this paper is for a comprehensive, national scan to be conducted of HEN programs and delivery methods. The following is a starting point:

NSW

There is no NSW Health policy available online.

However, a HEN Working Group has been established and is seeking funding from the Greater Metropolitan Clinical Taskforce to conduct a study into current practice and identifying a preferred model for HEN services in NSW.

The Working Group was established in 2003 by a group of clinicians who found the current management and funding of HEN service delivery 'inadequate and inequitable across the State'.[3]

The Enteral Industry Group spoke with the co-ordinator of the HEN Working Group who provided the following insights:

HEN in NSW is currently delivered in an ad hoc fashion - and each Area Health Service determines its own model. Some hospitals run various subsidy programs, and special medical units do also (eg. HIV, liver).

The Working Group is currently conducting its surveying process. It will present its report in July 2006 and make recommendations to NSW Health then. This data is sensitive (confidential), which means much of it can not be revealed. As such, these comments do not necessarily reflect the position of the HEN Working Group.

The study will seek to establish the Best Practice, and recommend a suitable and sustainable model for HEN in NSW. This could mean a partial or a full subsidy, or funding from another source - but none of this is confirmed. They are still investigating international models.

Since Victoria, QLD and the ACT have all developed their own subsidy programs for HEN - it sounds logical that we will eventually have a National system.

The most recent publicly available survey from 1998 showed there were around 800+ people tube-fed people in NSW.

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[3] Greater Metropolitan Clinical Taskforce, 'Home Enteral Nutrition', http://www.health.nsw.gov.au/gmct/programs.html#home, accessed January 2006.

From a scan conducted in early 2005, current arrangements are as follows:

There is very little, if any, centralised management of HEN at the state-level in NSW. HEN policies are determined by each Area Health Service and even at the level of individual hospitals. In fact, attempts made in 2004 to reach someone at NSW Health with responsibility for HEN services were completely unsuccessful.

There is certainly no broadly available subsidy scheme for HEN in NSW. Consumers are directed by their clinicians to existing government assistance programs, such as Department of Veterans' Affairs support and the Program of Appliances for Disabled People (PADP) administered by NSW Health. These initiatives are only available for those that can satisfy their relatively prescriptive eligibility criteria, meaning many people are unable to access the financial assistance that they require.

A number of hospitals offer discharged patients HEN supplies (feed) at cost price plus a small handling fee (15% at the Children's Hospital at Westmead). This is not applied consistently across the state, or even across each Area Health Service. Access to HEN services in NSW is characterised by a significant degree of inequity, with availability and price greatly affected by where you live in the State.

The dietitians we spoke to generally agreed that HEN supplies can be costly to the patient. The requirement for the patient to meet these feed costs from their own pockets can lead to less nutritional alternatives being used.

VIC

There is no Department of Human Services policy for HEN available online.

The most comprehensive resource available is the Report of the Ministerial Working Party on Home Enteral Nutrition from 1997. This report led to the establishment of a broad program for HEN in Victoria which subsidised the products for hospital outpatients.

However, The HEN funding program no longer exists. In 2001, it was rolled into the VACS Base Grant following the Ministerial Review of Healthcare Networks - which sought to remove the 'network' level of bureaucracy and return discretionary power to individual hospitals.

The Enteral Industry Group has been advised that as part of the VACS Base Grant, expenditure is 'non-acquitted' which means hospitals do not need to indicate exactly how much will be spent on each program for the year. The system is designed so that hospitals can prioritise their different services, and allocate their VACS funding as they see most appropriate.

The VACS Base Grant makes an allowance for HEN feeds (probably equipment too). We understand that some smaller hospitals receive their funding through their 'non-admitted grant'.

The VACS Base Grant is adjusted by the CPI, but we have been advised that hospitals can apply for a bigger grant if an increase is required (an 'outpatient non-acquittable rise').

This is independent of VACS Variable Grants, which are specifically allocated to individual services.

According to the Department of Human Services representative we spoke to in February 2005, there is no written policy on HEN readily available. The policy would have consisted of the co-payment schedule, now only available in an October 2004 Hospital Circular and a reporting component, advising hospitals how to report back to the Department on their HEN numbers.

The Enteral Industry Group has been advised confidentially that under the current arrangements, 'internal departments argue with the hospital just like government departments argue with Treasury'. It has been argued that the small, stand-alone programs under the dedicated HEN funding program were of more value as they were 'protected/ringfenced'. However, funding was 'capped' which meant no extra money could be provided if hospitals had more patients than expected.

QLD

The Queensland Government has published its policy for the 'Supply of Enteral Nutrition Products to Outpatients Through Queensland Health Services' on the Department's website.

This policy is based on a principle of 'cost sharing between the health service and the patient',[4] meaning a partial subsidy is provided for HEN consumers. The maximum weekly co-payment for adults is set at $45.50, but this was set in accordance with the Australian Bureau of Statistics estimate of 'weekly costs of normal food' - and not the cost of medical nutrition products specifically.[5]

http://www.health.qld.gov.au/phs/Documents/pas/22041.pdf

ACT

No ACT policy for HEN is available online, but a local dietitian provided the following summary of the ACT system for HEN:

The ACT Government provides a subsidy for HEN, administered by hospitals.

The range of products provided under this scheme is limited, and dietitians determine what products patients will use.

Patients pay a co-payment according to their age - from $25 per week for under-4s, up to $45 per week for an adult. The co-payments are fixed by age, and not by the particular formula used by each patient. It is likely that this is again based on the ABS estimate on the weekly cost of normal food.

If patients rely on HEN for less than 50% of their weekly nutrition, then they are offered a discounted co-payment.

Where possible, powdered formula is recommended under the scheme, as the funding is not sufficient to cover 'ready-made' formula. (Note from the Authors: This

[4] Queensland Health, 'Policy/Guidelines: Supply of Enteral Nutrition Products to Outpatients Through Queensland Health Services', Version 5, Amended 20/12/2003, http://www.health.qld.gov.au/phs/Documents/pas/22041.pdf, p.1.
[5] *Ibid.*, p.2.

raises concerns about inappropriate use of enteral feeding products in the home setting such as preparation errors and unhygienic reconstitution of powdered formula. Ultimately this can cause harm to the patient and potentially require a hospital readmission.)

The program also provides limited pieces of equipment - including 1 feeding reservoir per month, 2 giving sets per week, up to 2 syringes per week. Extras must be paid for by the patients our of their own pocket, but the equipment provided is sufficient to meet their needs. (Note from the Authors: This level of equipment supply is not unlike other centres across Australia. However, it does not conform with a number of guidelines including those of the manufacturers which state 'single use only'. In addition, the TGA is expected to issue regulatory guidelines in 2006 stating that single use (SU) devices are to be changed daily.)

The hospital will replace the end of PEG tubes when necessary, but does not provide spares for patients to keep at home.

Patients purchase their HEN supplies from Capital Chemists - and some others. They pay only their co-payment and the chemists claim the remainder back from the hospital.

The cost of different HEN supplies varies greatly. The dietitian we spoke with identified the Ketogenic diet as particularly expensive, and explained that the cost of the subsidy (or gap between co-payment and actual cost) is not uniform for all patients. However, as a rough average it was estimated that the subsidy is approximately 1/3 of the total cost. With an adult co-payment of $45 per week, the Canberra estimate suggests HEN supplies actually cost $67.50 per week (or $9.64 per day).

WA

No clear policy for HEN in WA exists online.

After liaising with the Department and an individual area health service, it was clear that HEN decisions are largely the responsibility of individual hospitals.

TAS

No policy exists online for HEN in Tasmania and we were unable to make contact with a hospital-based nutrition department to answer our queries. There was no clear contact for HEN services apparent in Government or in the health sector.

SA

There is no South Australian HEN policy online.

The Enteral Industry Group spoke informally with the Department and was advised that the actual delivery of HEN services would probably be different in each region. As such, we were advised to speak with some of the regional offices.

An Adelaide-based regional health service provided the following response to our queries:

Currently the SA Government subsidises Home Enteral Feeding through the major public hospitals. The systems of delivery and patient co-payments vary to some

extent and the heads of Nutrition and Dietetic Departments across Adelaide have set up a group to review a number of aspects of the present arrangements including feeding systems, management of equipment, rising numbers and costs and the possibility of introducing consistency in guidelines and the system of co-payments.

NT

There is no HEN policy for the Northern Territory available online.

Our discussions with the Department and a local dietitian provided the following summary of the NT system for HEN:

The NT Government funds a Home Enteral and Parenteral Nutrition program - for formula only.

There is a separate program called the Time scheme for equipment. This is actually a broader program for other kinds of disability equipment too.

Access to both programs (formula and equipment) is effectively means-tested, and available to those on Aged Pension, Carer pension or disability support pension assistance. In addition, clients can be assessed for eligibility based on financial hardship. Applicants are not eligible if they are able to assess formula and equipment through, DVA, CRS or CAAS.

If you are eligible, the formula and equipment is completely subsidised. If you are not eligible, there is no co-payment schedule and you must purchase your equipment and supplies direct from the manufacturers. Hospitals can not sell supplies and equipment to those that are ineligible.

The hospitals are required to review each patient every three months, and order their supplies and equipment for them.

Equipment through the Time scheme is delivered, but formula supplies must be collected.

The NT Government allocates a specific budget for HEN/HEPN funding. It was set up in 1992 and the budget is periodically reviewed as numbers increase.

A General Note from the Authors

Almost universally, hospital departments including pharmacy, supply and dietetics complain about the current system in place for the collection of HEN products. In most instances patients are required to visit the hospital at least monthly to collect their supplies. This raises a number of issues for all stakeholders:

- a lack of storage space for HEN supplies in hospitals
- the cost of administering the service
- physical and financial difficulties in traveling to the hospital on a monthly basis
- practical difficulties in transporting HEN supplies which often weigh in excess of 50kg from hospital to home

- a lack of storage space for HEN supplies at home

Existing Support

Commonwealth support programs exist, but information isn't easily accessible...

From previous research, the Enteral Industry Group understands that the Commonwealth Government provides a payment of $13.66 per patient per day to residential aged care facilities for the purposes of enteral nutrition. This equates to an annual payment of $4,986 per patient per year. However, the Department of Health and Ageing was unable to confirm figures on the actual rebate paid and the numbers of patients involved. In contrast, such support is not afforded to patients discharged from hospital into their own homes, raising the question of equity.

The Department of Health and Ageing also administers the Low Protein Food Grant which some HEN users may be eligible for. Through this program, grant payments are scheduled on the first day of each month. As of October 2005, 718 patients had registered to receive the monthly payment of $200. The grant is indexed to ensure that the current monthly payment keeps up with the cost of living.

The Enteral Industry Group understands that the program costs $1.72 million per year at present. It is estimated by the Department that 900 people are actually eligible for the grant (which would cost $2.16 million per year at current settings).

Following a review in 2004-05, it was decided that patient eligibility would require a bi-annual review by their nutrition consultant. However, the Enteral Industry Group understands there is little scrutiny of this process and specialist guidance for patients is lacking.

The Department of Veterans' Affairs provides a HEN program for eligible patients where, for the cost of a script patients can access any enteral nutrition product(s) prescribed by their General Practitioner. Through the DVA scheme, patients access their products through local pharmacies.

Finally, support also exists through the Pharmaceutical Benefits Scheme (PBS) to the value of almost $15 million per annum. These funds are dedicated to the reimbursement of specialised nutrition products for use in a home setting. These particular subsidies only apply in a limited number of disease areas including paediatric allergy and metabolic disorders.

Why should food be subsidised at all?

Medical nutrition is not the same as food by mouth. Financial support for HEN is reasonable for two main reasons:

- Without the technique, HEN patients would otherwise occupy hospital beds for longer periods.
- Commonly, HEN patients experience separate health challenges compounding social and economic disadvantage. An equitable system for HEN providing financial assistance is entirely reasonable for this group of patients.

Specialist Support and The Alfred Hospital Case Study

Specialist support is critical to minimise complications and emergency room presentations...

Specialist advice and support is critical for a safe and effective HEN system. However, the current arrangements do not ensure that all HEN patients have genuine access to the advice and support they require. The Alfred Hospital's PEG (tube feeding) study showed an intensive PEG support program providing intense, mobile, medical and nutritional management of tube fed patients in nursing homes led to a reduced number of hospital Emergency Department presentations. The program also provided education and training for nursing home staff.

Bayside Health Service incorporates The Alfred Hospital, and administers up to 170 tube fed patients each year. Over half of these patients are the discharged into the community, either home (35 per cent) or to residential care facilities (17 per cent).

The Health Service was experiencing 'hundreds of PEG patients' reporting to the Emergency Department (ED) of The Alfred Hospital, mostly due to tubes falling out or getting blocked. Between January 2000 and April 2001, 87 ED presentations were related to tube feeding complications.

In response, the Bayside Health Service established a mobile PEG clinic which visited residential facilities (primarily nursing homes) to improve the management of patients in the home and prevent readmission to hospital due to tube feeding complications. In the period April 2004 to January 2005, only 20 ED presentations related to PEG complications occurred.

This example illustrates that proper management and education of tube fed patients will lessen complications and further hospital costs. The provision of adequate specialist support is a critical element in a better system for the provision of HEN services in Australia.

Shortcomings of the Current Arrangements

The existing arrangements for HEN across Australia have a number of shortcomings:

Current arrangements are characterised by inequity, cost-driven outcomes and a lack of awareness...

1. Geographic inequity on price and accessibility between different States, different regions or Area Health Services, and even different hospitals within a single region.
2. Inequity on the basis of living arrangements for patients accessing enteral nutrition in hospital, private homes or in residential care facilities.
3. Inequity on the basis of disease state. Patients requiring nutritional products with conditions such as paediatric allergy or metabolic disorders are subsidised through the PBS while other conditions such as cystic fibrosis, cancer and neurological disorders do not receive the same support.
4. The Enteral Industry Group understands that at least one Australian hospital will prescribe HEN supplies on the basis of cost, leading to sub-optimal nutrition outcomes.
5. Currently, most patients access HEN supplies through their hospital pharmacy, supply or dietetics department. This is impractical and inefficient for patients, carers and hospitals.
6. The service is underutilised, and with greater support, awareness and more effective management could make more hospital beds available across Australia

According to the Australian Nursing Federation, 'Public hospitals have major problems because of ever-increasing demand, lack of funding, and shortages of appropriately skilled health professionals'.[6] The submission notes the impact State and Federal jurisdictions can have on the efficient delivery of health services.[7] The development of an effective, equitable and National system for the delivery of HEN in Australia will alleviate one driver of hospital demand and demonstrate constructive State and Federal collaboration on health.

Key Insight: **Intergovernmental coordination** is required to create a more nationally consistent, equitable and transparent system for HEN in Australia. Doing so will make the practice more affordable, understood and accessible - leading to earlier discharges, more hospital beds in each state and territory, and better outcomes for patients able to leave hospital earlier, or requiring HEN on an ongoing basis.

[6] Australian Nursing Federation, 'Submission - Inquiry into Health Funding', 24 May 2005, http://www.aph.gov.au/house/committee/haa/healthfunding/subs/sub039.pdf, p.4.

[7] *Ibid.*

Policy Options for the Consideration of Decision-Makers

The Enteral Industry Group is keen to engage policy-makers and stakeholders in a discussion on how the accessibility, cost and quality of HEN services can be made more equitable across the country. The current arrangements are characterised by inconsistency, and a fairer, more equitable system is needed across all States and Territories.

The Enteral Industry Group raises the following policy proposals for the consideration of the Committee, and would be happy to discuss the following in greater detail at a public hearing:

1. Applying the DVA model to a broader patient group, providing universal access to subsidised HEN supplies. In this model, patients would access their supplies through local pharmacies at a subsidised price alleviating the administrative responsibilities on hospitals. If appropriate support is also made available, this model is as safe as, and more convenient than, the current arrangements.

New approaches should be considered and discussed by government, industry and healthcare stakeholders...

2. An NGO outsourcing arrangement where a relevant non-government organisation manages the subsidisation of HEN products in each State and Territory.

   This kind of arrangement is demonstrated by the National Diabetes Services Scheme (NDSS), an Australian Government initiative administered by Diabetes Australia. The NDSS aims to 'enhance the capacity of people with diabetes to understand and manage their life with diabetes' and to promote self management.[8] The scheme provides diabetes related products at subsidised prices, and delivers information and support services.[9] As at 30 June 2005, over 715,000 people had registered for the NDSS - a national Government program administered by a non-government organisation.[10]

   A similar model could be considered for the delivery of HEN support and information. Based on The Alfred Hospital experience - where a mobile clinic yielded significant results - the creation of a centralised hub for the provision of advice would lessen the strain on hospital emergency departments across Australia.

3. Creating a specialised body to administer the subsidy and HEN from this point onwards.

   This model would be identical to the NGO outsourcing arrangement outlined above except Federal, State and Territory Governments would create a specialised body to administer the program. Government and non-government leaders in the area of nutrition, dietetics, hospital policy, parenteral and enteral nutrition would be appointed to manage the body's activities.

   The newly created body would administer the subsidy program and facilitate the provision of information and specialist advice to patients and their carers.

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[8] Diabetes Australia, 'National Diabetes Services Scheme (NDSS)', Fact Sheet, 30 June 2005, http://www.diabetesaustralia.com.au/ndss/doc_pdf/NDSS-Fact-Sheet.pdf

[9] *Ibid.*

[10] *Ibid.*

How much would a National subsidy scheme cost?

This section seeks to model the cost of a national subsidy scheme for HEN supplies and equipment. These calculations are not precise, due to the difficulty in accessing the necessary figures. We are basing the following analysis on:

- The ACT estimate that HEN supplies cost $9.64 per patient per day ($67.48 per week or $3,518.60 per annum);
- Industry estimates that there are between 7,000 and 11,800 HEN users in Australia at any one time - including those in residential aged care facilities. In this analysis, we assume many new HEN patients replace those who no longer require the service creating an effectively fixed population over the course of the year;
- An assumption that the number of HEN users is likely to grow if a more efficient and effective system is introduced for its delivery.

Governments have a range of subsidy options - and program costs - available...

		Estimated Annual Cost of Program to the Government/s		
Degree of Subsidy	Patient Co-Payment	7,000 Patients	9,800 Patients	12,000 Patients
1/3 Subsidy	$45 p/week	$8,205,190	$11,487,266	$14,066,040
1/2 Subsidy	$33.74 p/week	$12,315,100	$17,241,140	$21,111,600
Full Subsidy	N/A	$24,630,200	$34,482,280	$42,223,200

Note: The annual cost has been calculated by dividing the weekly cost of $67.48 by seven, and multiplying the result of $9.64 by 365 days. On this basis, HEN costs $3,518.60 per patient per annum.

International Examples

The Enteral Industry Group understands that national subsidy programs exist for Home Enteral Nutrition in Europe, the UK and in New Zealand (commonly a full subsidy through the Pharmac Schedule).[11]

It is highly recommended that Australian decision-makers conduct a scan of international HEN subsidy models to identify the elements that are most effective in different jurisdictions. Ideally, Australia can introduce a model based on the best elements of HEN support from around the world.

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[11] Pharmaceutical Management Agency (Pharmac), Pharmaceutical Schedule, December 2005, http://www.pharmac.govt.nz/pdf/Sched.pdf, p.161.

Conclusion

HEN provides an opportunity for policy-makers and healthcare professionals to shorten hospital stays and give patients greater freedom to return to their own home settings. With the correct level of home support, unnecessary and costly hospital readmissions can also be prevented. When managed effectively with adequate guidance and advice, HEN offers a significant public benefit for patients and health systems across Australia.

However, the existing frameworks for the delivery of HEN services are developing in an ad hoc and inconsistent fashion. Different policies exist in each State and Territory, and even among different Area Health Services within some States and Territories. In addition, different policies exist for different product categories and disease segments. The current arrangements are characterised by uncertainty and inequity - based solely on where patients live or what particular condition they are experiencing.

The Enteral Industry Group has conducted a cursory scan of the environment and identified a number of policy options for consideration. Each one seeks to make the delivery of HEN more equitable and consistent across Australia.

As a first step, the Enteral Industry Group recommends that a national study be conducted of the different models in place for the delivery of HEN services. There will be many, often based on a particular co-payment schedule but with different funding arrangements and management frameworks.

A national study will enable policy-makers to identify the elements of best practice in the delivery of HEN and the provision of follow-up guidance and support. The Enteral Industry Group is keen to discuss this and other options further with health decision-makers at State and Federal levels.

On this matter, we would urge State and Federal Governments, the medical nutrition industry and the healthcare sector to combine their knowledge and resources to develop a more efficient and effective system for the delivery of HEN across Australia.

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The Enteral Industry Group made contact with the following organisations in the preparation of this discussion paper:

NSW Health

Victorian Department of Human Services

Tasmanian Department of Human Services

WA Department of Health

SA Health

Central Northern Adelaide Health Service

Hospital Services Division, NT Department of Health and Community Services

Darwin Hospital, NT

Sir Charles Gardiner Hospital, Western Australia

Canberra Hospital, ACT

The Royal Hobart Hospital, Tasmania

NSW Greater Metropolitan Clinical Taskforce

Note: These organisations do not necessarily endorse the views presented in this paper and were contacted by phone in an informal manner between February 2005 and January 2006.

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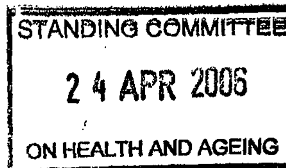
Hon Alex Somlyay
Chair
House of Representatives
Health & Ageing Committee
Parliament House
Canberra ACT 2600


STANDING COMMITTEE
24 APR 2006
ON HEALTH AND AGEING

Dear Alex,

I write to you following our conversation last week and your invitation to provide further information relevant to what we spoke about.

I believe I need to alert you to a significant problem associated with the initial training and continuing education of urologists which thus far is not widely recognised. I would be surprised if the issues I will raise are not also issues for other medical specialties.

Urologists want to be involved in the training of new urologists and the continuing education of urologists. The reality is that there is nobody else qualified to do this as the few academic urologists in the country could not cope with the volume of work required to be done. In any event most of the academic urologists are researchers rather than educationalists.

The VMO appointments to public hospitals have long recognized the need for these specialists to have the education of new urologists as part of their responsibilities. For the most part this is well done as it concentrates on the supervision and assessment of practical surgical skills.

However, the understandable demands for more accountable training and continuing education put enormous strain on the voluntary contributions of urologists. Part of he problem is that while the urologists obviously know urology, they do not have expertise in curriculum construction, the development of instructional materials, the modern ways of delivering these and the assessment of competency in urology theory. Assessment of competence in theory obviously needs to be comprehensive as well as valid and reliable and inevitably this puts even more demands on the voluntary time of those who supervise. Contemporary medico-legal standards also demand that if a trainee or consultant is found to be below the required standards that proper due processes are in place which can withstand legal challenge if necessary.

The Society needs access to medical educators who have a grasp of the educational issues who can work with urologists to develop the materials I have referred to above. The Society needs the capacity to pay a group of urologists (who are obviously foregoing income from their practice while still absorbing ongoing costs) to set aside a period of time to work with the medical educators to write and update these materials. For example 10 urologists might need to be freed for 2 separate weeks each year to be in a residential school to write these materials. With payments to the participating urologists and educators and their residential accommodation, this might cost in the order of $350,000 per year.

The consultant supervisors of registrars are very visible to those in the medical environment but those who have to provide the materials I have spoken of are unseen and therefore not well recognized for the essential contribution they make. The demands on this group have escalated in the last three years and there is no sign of this going away. One only has to look at the demands of the ACCC and the impact of the assessment of international medical graduates to realise what has been happening. It will very surprising if this is not a continuing need.

I am grateful to you for the opportunity of putting this matter before you. The Society would be pleased to pilot such a program for the Government if this was thought to be worthwhile. Frankly, I am concerned that the current scheme might become unworkable if the pressures on these volunteers are not recognized and addressed sooner rather than later.

Yours sincerely,

Ross A. Cartmill
President