

Submission
No 48

INQUIRY INTO DENTAL SERVICES IN NSW

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Theme:

Summary

Home Enteral Nutrition

A proposal for the Inquiry into Dental Services in NSW

 NOVARTIS

1. **Executive Summary: A proposal for HEN users subsidy or co-payment**

Patients suffering Stroke, Multiple Sclerosis, Facial Trauma, Cerebral Palsy, Parkinson's Disease, and other neurological or cancer related illnesses are often unable to digest food in a manner most Australians take for granted.

Home Enteral Nutrition (HEN) is an essential alternative to solid foods for many ill or incapacitated people. 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, in addition to its low unit cost, patients in metropolitan, rural and regional areas will benefit equally under this proposal.

Some hospitals currently provide partial HEN subsidies to patients leaving hospital. The few schemes that do operate in NSW are inconsistent and not readily accessible.

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 cost-effective nutrition support regime to liver disease sufferers.

This submission therefore seeks the establishment of a **State-wide full subsidy or co-payment scheme for the provision of Home Enteral Nutrition**. In doing so, the NSW Government would be able to extend support to the many within NSW suffering from both health and financial burdens.

The projected annual costs of the proposal are modest. With an estimated 925 current patient users, the provision of a subsidy or co-payment system will not amount to a significant new expense.

This submission has been prepared by Novartis Consumer Health, in support of consumers of HEN in NSW.

2. 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.

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)'.

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. It is estimated that there are 925 HEN users in New South Wales.

Novartis Consumer Health is one of three suppliers of the medical nutrition products (feeds) that Home Enteral Nutrition (HEN) patients rely on for their nutritional requirements. The other suppliers are Nutricia and Abbott Laboratories. Tyco provide the equipment required to administer enteral nutrition in the home.

3. Current Arrangements

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.

Dieticians tend to agree that HEN supplies are 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. In fact, it has been revealed to Novartis that in one Sydney hospital (at least), **dieticians will often recommend medical nutrition products that are not optimal for their patients, solely on the basis of the inability of the patient to meet out of pocket costs.**

Importantly, the Greater Metropolitan Clinical Taskforce (GMCT, formerly the Greater Metropolitan Transition Taskforce or GMT²) has recently established **a HEN Working Group**. The group's Executive currently meets every 4-6 weeks, while the entire group convenes every two months. The HEN working group is to conduct a review that will seek to identify inequities and needs faced by HEN consumers in NSW. **The review will make recommendations to the Minister for Health, probably towards the end of 2005.**

4. Victorian Arrangements

In response to a 1997 report from the Victorian Ministerial Working Party on Home Nutrition, the Victorian Department of Human Services allocated capped funding for area health networks to subsidise Home Enteral Nutrition through their hospitals.

This program has since been modified. Following the Ministerial Review of Healthcare Networks, funding for HEN was allocated to the Victorian Ambulatory Classification and Funding System (VACS). Under this arrangement, HEN is considered part of a hospital's broader outpatient services and is funded through their non-acquitted VACS base grant. However, the co-payment schedule from the original HEN program still applies.

Age	Weekly co-payment (per week)	Weekly concessional co-payment (per week)
Adult	\$45.00	\$22.50
12 to 18	\$30.00	\$15.00
8 to 11	\$27.00	\$13.50
5 to 7	\$24.00	\$12.00
2 to 4	\$19.00	\$9.50
<2	\$15.00	\$7.50

HEN Co-Payment Schedule – Victorian Public Hospitals (Metropolitan Health and Aged Care Services, Department of Human Services), 14 October 2005
<http://www.health.vic.gov.au/hospitalcirculars/circ3204.htm>

Patient co-payments range from \$7.50 to \$45.00 per week, on the basis of age and concession status. However, the Department of Human Services has instructed hospitals to take into account the particular circumstances of the patient, and 'establish a mechanism whereby any patient/carer can seek special consideration of their circumstances and a waiver of the fee'¹.

The Department of Human Services allocation contributes to the cost of enteral feeds, equipment and tube replacement. Some hospitals are able to use their allocation to also cover the cost of home delivery services.

The Australasian Society for Parenteral and Enteral Nutrition (AuSPEN) published the Clinical Practice Guidelines for HEN in Australia'. According to AuSPEN, the Multidisciplinary Team approach these guidelines recommend can:

- Improve the standard of care
- Increase the cost-effectiveness of Home Enteral Nutrition
- Ensure appropriate training and counseling of patients and/or carers
- Reduce the rates of complication².

¹ Metropolitan Health and Aged Care Services, 'Public Hospital Charges – Changes', Hospital Circular, 13 October 2004, www.health.vic.gov.au/hospitalcirculars/circ3204.htm

² Australasian Society for Parenteral and Enteral Nutrition (AuSPEN), 'Home Enteral Nutrition: Clinical Practice Guidelines', www.auspen.org.au/guidelines/index.asp, accessed 22.2.2005.

According to the Department of Human Services, applying the AuSPEN recommendations was a pre-requisite for accessing the original HEN funding scheme.

Despite an established subsidy scheme, the management of HEN in Victoria is still characterised by a degree of inconsistency. In October 2004, the Department of Human Services issues a 'Hospital Circular' stating that 'Hospitals have been implementing the schedule of HEN co-payments inconsistently.

This is causing confusion both amongst patients and hospital staff. In seeking to avoid program inconsistency, it is proposed to establish a well defined co-payment or subsidy in NSW, enabling easy and transparent access to consumers.

5. Commonwealth Arrangements

The Commonwealth provides a \$13.66 per day payment to nursing homes for the purposes of enteral feeding³, this equates to an annual payment of \$4,986 per patient per annum.

This payment is based on the inclusion of the complete dietary formulas (as outlined in footnote 3), and does not account for any additional inclusions that may be requested by a doctor or a dietician.

6. Detailed Proposal: A Better Model for NSW

It is proposed that the New South Wales Government introduce a consistent State-wide program for the provision of Home Enteral Nutrition (HEN). The cost of HEN supplies and equipment is potentially prohibitive for patients whose ability to work is inevitably diminished. Secondly, improving the ability of NSW residents to access HEN services will enable more outpatient services to be provided, freeing up much needed beds in the State's public hospitals. The individual benefits in terms of patient comfort and independence should also not be underestimated.

Our modeling is based on the premise that the cost of HEN supplies, equipment and delivery works out to approximately \$3,500 per patient

³ <http://www.seniors.gov.au/internet/wcms/publishing.nsf/Content/ageing-manuals-rcm-contents-6subsi6.htm#rate6>

on an annual basis. Secondly, it is estimated that there are currently 925 HEN patients in NSW but that number would likely increase if a subsidy was made available for feed, equipment and delivery.

The following table projects the likely annual cost to the NSW Health budget of providing a 100% subsidy for HEN in NSW, and secondly a 70% subsidy with a 30% patient co-payment. Both options would greatly enhance the ability of NSW residents to access HEN services should they require them.

	70% Subsidy (with a 30% co-payment)	100% Subsidy (with no co-payment) ⁴
925 Patients (current numbers in 2005)	\$2,266,250	\$3,237,500
2,500 Patients (partial uptake of patient group)	\$6,125,000	\$8,750,000

7. Comparisons of the Schemes

In comparing the Victorian and Commonwealth schemes to the proposed NSW scheme, the following inclusions have been made as they are the most relevant comparable schemes when compared to the NSW HEN's proposed scheme.

With respect to the Commonwealth payment, the Commonwealth denotes this payment as used in nursing homes for enteral feeding, equating to an annual payment of \$4,986 per patient.

With respect to the Victorian VACS arrangements, the Victorian government has introduced a tiered funding approach, (see the HEN Co-Payment Schedule above). In arriving at an appropriate comparison, the weekly co-payment (\$45.00) and weekly concessional co-payments (\$22.50) for adults were chosen, equating to annual payments of \$2,340 and \$1,170 per patient respectively.

These schemes were then compared to the proposed NSW HEN scheme with a 100% and 70% subsidy, the results are as follows. Figures are given as a per annum payment per patient, a positive

⁴ A 100% subsidy (without a co-payment) also minimises hospital administration and enables dietetic staff to focus on patient care, advice and support.

figure denotes a less costly scheme as compared to NSW, a negative figure denotes a more costly scheme as compared to NSW.

Difference b/w Vic \$45.00 Payment and 70% NSW Subsidy	Difference b/w Vic \$45.00 Payment and 100% NSW Subsidy	Difference b/w Vic \$22.50 Payment and 70% NSW Subsidy	Difference b/w Vic \$22.50 Payment and 100% NSW Subsidy	Difference b/w Commonwealth and 70% NSW Subsidy	Difference b/w Commonwealth and 100% NSW Subsidy
\$1,180	-\$2,340	\$110	\$1,160	-\$2,536	-\$1,486

In comparing the various schemes, it is apparent that the proposed NSW HEN scheme of 100% subsidy or 70% subsidy is at the very least similar to the schemes offered in Victoria. Furthermore, the proposed schemes are substantially cost effective when compared to the Commonwealth equivalent.

8. Case Study

Patient A was discharged from hospital to home with a Gastrostomy tube requiring enteral feeds to provide sufficient energy to meet Patient A's daily needs.

A representative from Novartis met with Patient A within 24-48 hours of discharge to discuss training as well as the needs required to self administered feeding. Training was undertaken of the Novartis Compat pump and feeding set as well as care and maintenance of the gastrostomy tube.

Normally patients are advised to purchase the feed and equipment through a local distributor called Axxcess. There are two different types of feed available one is called Novartis Ready to hang. This is the preferred option as it is a closed system which reduces the risk of contamination of the feed. The total cost of this system is on average \$18.00.

The second option is the use of tinned formula which needs to be opened and poured into a feeding bag this is termed as "decanting". Quite often if patients are unable to afford the feed they will purchase it from the dietetic department of the local hospital at a discounted price.

This means the patients are required to collect the feed which is often quite heavy and transport it to their car or by means of public transport.

Patient A decided to purchase the feed from the hospital and the equipment through Axxess. The Novartis manufacturing recommendations are to change the equipment after 24- 48 hours depending on how long the patient is feeding for.

Two weeks following discharge a Novartis representative was contacted by patient A regarding a blocked tube. On arrival it was found that in an attempt to save money, Patient A had been re-using the equipment by rinsing out with warm water. The re-use of tubes is not recommended due to the increased risk of bacterial contamination.

The re-use resulted in a blocked tube which meant the patient was unable to receive any nutrition. After over an hour of trying to unblock the tube the patient was asked to return to hospital to have the tube removed. Patient A was an Insulin dependant diabetic so on arrival to Hospital had an elevated BSL which was the result of no nutrition for over several hours.

Patient A was admitted to hospital for 7-10 days for stabilisation and management of his/her diabetes.

Typically, patients who are requiring requiring home enteral feeding are unable to resume normal working duties. As a result, these patients face financial predicaments such that:

- 1. The patient finds it financially difficult to afford new tubes;**
- 2. Due to the patients financial constraints they attempts to save money by re-using the tubes the best way they knows how.**

(The following case study is a factually correct and current case study in the State of New South Wales. The identity and the locality of the patient has been withheld to preserve the patients identity and integrity.)

9. Results from Recent Clinical Studies

A review of recent clinical studies have indicated overwhelming positive effects of the use of HEN's⁵. These reviews and findings are summarized as follows:

⁵ <http://www.dhs.vic.gov.au/ahs/archive/hen/appen.htm>

1. Cancer

Campos, Butters, and Meguid (1990) concluded that patients experienced improved comfort and quality during their limited life at home, in familiar surroundings, this being particularly important with respect to individuals coping with the final effects of cancer.

2. Cystic Fibrosis

Smith, Clarke, and Stableforth (1994) assessed that all (control) patients were able to successfully achieve self-intubation; all patients achieved positive weight gain, reinforcing the positive association of weight gain and improved lung function in CF patients.

3. Short Bowel Syndrome

Bernard and Shaw (1993) maintain that some of the advantages that patients experienced as a result of early interventional enteral feeding included;

- a reversal of mucosal atrophy induced by total parenteral nutrition (TPN);
- a stimulation of intestinal adaptation; and
- a decreased risk of bacterial translocation

4. Inflammatory Bowel Disease

Aiges et al (1989) hypothesised that HEN would accelerated positive growth in growth-retarded adolescents with Crohn's disease.

Matsueda et al (1995) concluded that in Crohn's disease, HEN was superior to that of drug treatment.

5. Liver Disease

Wicks et al (1994) assessed the efficacy and tolerability of early enteral feeding with total parenteral nutrition after liver transplantation, in doing so, they concluded that the use of enteral nutrition is a cost-effective nutrition support regime.

10. Conclusions & Recommendations

Given the comparative cost structures to the relevant Commonwealth and Victorian schemes when compared to a proposed 100% or 70% NSW subsidy in conjunction with the positive and beneficial findings from the recent clinical studies, it is the recommendation of the Burson-Marsteller and Novartis that the NSW government consider, with a view of adopting, the proposed Novartis HEN scheme with a 100% NSW government subsidy.