



A national program to address equity of access for Australians requiring Home Enteral Nutrition

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Dietitians Association of Australia**

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Recommendation

The right to food is a basic human right. The Dietitians Association of Australia (DAA) calls on the Australian Government to implement an equitable and consistent program for access to Home Enteral Nutrition (HEN) to enable all community based patients to maintain their health and quality of life at home, and reduce hospital admissions.

A national program to address equity of access for Australians requiring Home Enteral Nutrition

Area of concern

Australians requiring Home Enteral Nutrition (HEN) products and professional services experience inequity across the States and Territories which impacts on their quality of care and their quality of life.

Background

Who needs HEN and why

Enteral nutrition (EN), or tube feeding, is the delivery of specialised nutritional products in liquid form through a feeding tube into the stomach or small intestine when children or adults cannot eat safely or adequately to meet their nutritional needs.

- Advances in technology over the last two decades have made it possible for patients requiring EN to live at home rather than in hospital¹.
- Patients may need EN temporarily or permanently. 40% of patients require feeding for 2 or more years, 11% for 5 or more years².
- Patients living at home require formula and equipment which generally cost more than a normal diet and are only available at pharmacies or through specialist suppliers. Recent estimates are in the order of \$18/day, and can be up to \$50/day (member communication).
- Patients living at home need professional advice from Accredited Practising Dietitians and other health care professionals, such as nurses. Some patients require assistance from carers to deliver their formula.
- There is no single medical condition which characterises the need for enteral nutrition. HEN may be needed by patients across the lifecycle for a variety of reasons, including premature infants, failure to thrive, motor neurone disease, multiple sclerosis, acquired brain injury or other trauma, cancer, stroke, cystic fibrosis, Crohn's disease, short bowel syndrome, etc.
- Health insurance funds do not cover HEN products.
- In May 2009 it was estimated that around 5,000 to 5,500 Australians needed HEN to meet their nutritional needs although it is difficult to be exact in the absence of a national data collection.

Adverse consequences

This is a silent group who are very often disabled, debilitated or dying. HEN is relatively safe and easy to administer at home but is expensive, and requires time and effort to administer. Problems in accessing products and advice contribute to an increased financial burden and stress for families and caregivers¹ which is exacerbated by issues in accessing HEN products and services.

Patients are exposed to food hygiene risks³ when they are unable to afford to use 'single use only' equipment as intended, and when their jurisdictional service provides insufficient equipment for 'single use only'.

Work done under AHMAC

DAA presented a comprehensive report about issues in HEN to the Australian Health Ministers Advisory Council in 2009⁴. During 2009 and 2010 DAA members contributed to a jurisdictional working group under the Health Policy Priorities Principal Committee to prepare a common set of principles for HEN funding and service delivery, for presentation to the Australian Health Ministers Advisory Council. Progress halted at the last meeting in May 2010 when barriers were identified with the development of a national scheme i.e.

- The disparity in state and territory HEN services and funding models
- The lack of information and data on current HEN services
- The lack of capacity to resource a project from within jurisdictional health services.

Work done by jurisdictions

Both Western Australia and New South Wales have produced comprehensive reports on barriers and inequities in HEN systems within those jurisdictions. These include

- Lack of polity for state-wide HEN provision
- Inequities in access to clinical care
- Inequities in access to products and equipment
- Variable costs to patients
- Reliance on acute care settings
- Barriers to transition between services
- Absence of data management
- Lack of standardised clinical practice guidelines and procedures.

While there have been improvements within some jurisdictions, inequities remain across the country. Members report new problems arising from the introduction of aged care reforms and the establishment of the National Disability Insurance Scheme whereby planners do not include HEN in care packages, or costs are only partially covered. Clinical governance is also of concern.

Inequity in supply continues

An online discussion in November 2012 by dietetic managers who are members of DAA (see Appendix 1) confirmed that the process of obtaining and paying for enteral nutrition products varies from state to state

- In Tasmania and Queensland there is a copayment required of the patient (but not the same copayment)
- NSW requires clients to pay through distributors at NSW Government tender pricing
- In Victoria there is no copayment
- In WA it is reported to be illegal to charge public hospital patients.

In most cases individuals who are treated in private hospitals are excluded from outpatient HEN services despite the fact that private health funds do not provide rebates for products and

provide only limited rebates for professional services. Patients and their families are disadvantaged not only by cost, but also by the time needed to negotiate the system operating in their jurisdiction. This is valuable time in the context of dealing with complex health needs with many other pressures on patients and families.

It is not acceptable that patients in one side of a state border should be able to access HEN products without charge, while in another they must pay full price. Moreover some patients are unable to access professional services to meet their health needs close to home, or at all.

It is unreasonable that consumers with some chronic conditions, such as diabetes, are supported in self management through government funded schemes, but not people requiring HEN.

Precedents for a national program

There are precedents for a national funding scheme to assist self management of chronic conditions by consumers living in the community. These schemes were established to assist with the high costs of treatment and to ensure a nationally consistent level of timely, reliable and affordable care. These schemes include

- National Epidermolysis Bullosa Dressing Scheme assisting 136 people
- Stoma Appliance Scheme assisting 39,000 people.
- National Diabetes Subsidy Scheme assisting 1.1 million people.

Proposal

The aim of the program is a nationally consistent approach to the provision of HEN that minimises the differences between States and Territories and ensures all Australians requiring HEN

- Have equity in cost and delivery of formula and equipment (including but not restricted to syringes, giving sets, containers, pumps, stands)
- Have ready access to timely, skilled and ongoing management by appropriately trained health professionals
- Experience safe, high quality care.

The program will benefit

- 5000 or more Australians having safe, timely, reliable, affordable and equitable access to products and services to meet their nutritional needs
- Patients, families and caregivers with improved ease of access to products and services for greater well being and capacity to self-manage their enteral nutrition
- Smooth transition between health services, including between jurisdictions
- Reduced hospital readmissions due to malnutrition and feeding tube complications
- Health professionals by being able to support patients, families and caregivers more efficiently and effectively.

Process of implementation

- Phase 1 - Convene a committee including Accredited Practising Dietitians, officers from Department of Health, officers from state and territory Departments of Health, and a consumer representative. Undertake full costing of system.
- Phase 2 - Prepare implementation plan, including clinical practice guidelines, and procedure for ordering products. Prepare monitoring and evaluation plan, including data collection for program delivery and monitoring purposes
- Phase 3 – Implement program
- Phase 4 – Ongoing monitoring. Evaluate program at one year and after five years.

Costs

Data compiled in May 2009 put the annual cost at around \$27.9 million dollars for formula and equipment for an estimated 5274 patients. This is an underestimate of the true cost as it does not include infrastructure costs such as home delivery of products, administrative support or multidisciplinary care costs.

HEN reduces healthcare costs by allowing patients to receive nutrition care at home. Advanced delivery systems allow more flexibility for patients who are able to be more independent, thus reducing health care costs. In a small number of cases patients may even be able to participate in the workforce.

Better supported HEN programs would reduce costs by reducing avoidable hospital admissions².

Relationship to government policy

The Australian Government provides

- Residential Aged Care Supplements (Care Related) for older Australians in Residential Aged Care Facilities of \$17.17/day (bolus) or \$19.29/day (non-bolus).
- Enteral nutrition products and services for veteran clients of the Department of Veterans Affairs.

At a State or Territory level the policy regarding provision of HEN products and services varies between jurisdictions. Some jurisdictions discriminate on the basis of patients who were treated in public or private hospitals, even though private health insurance does not cover EN formula or equipment.

The Coalition government committed to delivering better services and a better society prior to taking office in 2013⁷.

References

1. Forchielli M, Bines J. Enteral Nutrition in Duggan C, et al. Nutrition in Pediatrics. 4th Ed. Hamilton. Ontario. Canada: BC Decker Inc; 2008.
2. Watt WH, Needham KA, Talbot PL, Bell JP, Pang GJ. Poor outcomes among gastrostomy-fed patients in the community. MJA 2009; 191:294
3. Osland E. Promoting the reuse of enteral feeding equipment in ambulatory patients: Where do we stand? Nutr Diet 2008; 65: 23-28
4. Dietitians association of Australia. Towards a National Home Enteral nutrition Service for patients requiring nutrition support at home. DAA 2009.
5. Department of Health. Western Australia Home Enteral Nutrition Model of Care; Perth. Health Networks Branch, Department of Health, Western Australia, 2010.
6. Greater metropolitan Clinical Taskforce. Home Enteral Nutrition Report. NSW Health 2007.
7. Liberal Party of Australia. Real Solutions for all Australians. Melbourne. Bamba Press. 2013.

**Summary of responses by Dietetic Managers on HEN payments
November 2012**

State	Comment
Victoria	<p>I have checked with xxxx xxxx to whom I have been directed in the past for HEN matters within the DoH. Co-payments are not permitted within Victoria at this time. It will be interesting to see how the shift to activity based outpatient funding for non-VACS health services will affect how we manage HEN. Interesting to hear from other states.</p> <p><u>here is a brief history of HEN in Victoria:</u></p> <p>The HEN Program commenced in Victoria as a Pilot in about 1989, and after a period of several years, became established in acute care hospitals as an on-going service with recurrent block funding. At various times from its inception, until 1997, the Program was either fully-funded, or required patient co-payments (usually \$25/week). When the final report was published, <i>Report of the Ministerial Working Party on Home Enteral Nutrition in Victoria. 1997. Department of Human Services, Melbourne, VIC</i>, the Victorian government scrapped the existing patient co-payment scheme. http://hnb.dhs.vic.gov.au/web/pubaff/medrel.nsf/0/22a83936847125474a25657000038707?OpenDocument&Click. In 2004, the DHS advised hospitals that from 4 November 2005, the co-payments for HEN were no longer to be charged, pending a review of funding for the program. The cessation of co-payments applied both to adults and children, and that hospitals would be reimbursed for the revenue forgone effective from the date of this change. http://health.vic.gov.au/hospitalcirculars/circ05/circ2305.htm . As of July 2001, the Victorian Home Enteral Nutrition (HEN) program ceased being funded as a separate program with Specified Grants. Funding for this service was incorporated into the VACS outpatient base grant for Metropolitan Health Services/major Rural Regional hospitals, or the general outpatient grant for non-VACS funded hospitals, and the amount a particular agency allocated for these services became a matter for each agency to determine . Routine reporting of these services to the department was no longer required. http://www.health.vic.gov.au/archive/archive2011/pfg1011/downloads/hospitals/conditions_funding.pdf</p> <p>Recently a number of Victorian hospitals (including my own), investigated the possibility of re-introducing co-payments. It is only something we would do reluctantly, as it creates considerable additional work. We have decided not proceed with this course, for the meantime.</p>

Queensland	<p>It is statewide practice in Qld governed by Queensland Health</p> <p>Attached are all our policies/procedures.</p> <p>(A special charging arrangement is applied based on cost sharing between the health service and the patient, the policy outlines this)</p>																			
Tasmania	<p>In Tasmania we have a co-payment system. We based it a few years ago on ABS weekly food costs and we've been applying CPI each year since then, so our current max weekly charges are below. If products themselves cost less than this then the patient is charged the lower amount, but this very rarely occurs.</p> <table border="1" data-bbox="395 712 1385 1003"> <thead> <tr> <th rowspan="2"></th> <th colspan="2">Complete (>75% energy req's)</th> <th colspan="2">Supplements (75% energy req's or less)</th> </tr> <tr> <th>With HCC</th> <th>Without HCC</th> <th>With HCC</th> <th>Without HCC</th> </tr> </thead> <tbody> <tr> <td>Adults</td> <td>36.05</td> <td>71.90</td> <td>11.20</td> <td>21.65</td> </tr> <tr> <td>Children (<17 yo)</td> <td>21.65</td> <td>43.40</td> <td>6.60</td> <td>12.95</td> </tr> </tbody> </table> <p>In retrospect I think we're under-charging on the supplements because they contribute a lot more than normal snacks to patients' nutrition. They're also the largest part of our program.</p> <p>We have different ways of paying around the state. In southern Tas, the patient is sent an invoice when they order their products and they can pay their account in any of the usual ways for Govt services, including online.</p> <p>I think the small fee here might play the role of reminding clients that products are part of their medical management, and are to be valued, taken as prescribed, and treated with care. Our patients can request 'hardship' and be given access at no charge to them, but often those people seem to want more from the system than those who pay and are less willing to work to our accountability requirements.</p> <p>No, we haven't built in admin costs. The general approach is that these people shouldn't have to pay more than the rest of us because their condition means they need special products. So we charge them what we think other people would normally spend on food, and the rest is subsidised by DHHS.</p> <p>We have had to set boundaries, such as the list of exclusions below that we plan to add in the current revision of the policy and guideline.</p>		Complete (>75% energy req's)		Supplements (75% energy req's or less)		With HCC	Without HCC	With HCC	Without HCC	Adults	36.05	71.90	11.20	21.65	Children (<17 yo)	21.65	43.40	6.60	12.95
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New South Wales	It is very different in NSW our clients pay for all of their HEN feeds and supplements through distributors at NSW Government tender pricing.
Western Australia	We did this for many years, but recently there was a legislation passed re <i>it is illegal to charge public hospital patients</i> (Aust citizens and perm residents) with goods and services. Check if this legislation applies to your state as I am not sure now whether this is part of Medicare Act or a state legislation.