

THE PROGRAM OF APPLIANCES FOR DISABLED PEOPLE (PADP)

Organisation: Gastrostomy Information and Support Society NSW
Name: Mr Glen Pang and Ms Alison Kennedy
Position: GISS NSW Coordinators
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Ms Beverly Duffy
Director GPSC2
Legislative Council
Parliament House
Macquarie St
Sydney NSW 2000



3 September 2008

Dear Ms Duffy,

**Submission to Legislative Council General Purpose Standing Committee No 2.
Inquiry into the Program of Appliances for Disabled People (PADP)**

The Gastrostomy Information Support Society (GISS) NSW Branch is a non-profit community based support group for people who need tube feeding and their carers. GISS provides information and support to people with gastrostomies and advocates for the rights of people with gastrostomies.

A gastrostomy is a feeding tube placed surgically or by endoscopy into the stomach when a person cannot eat (eg swallowing disorders resulting from stroke, head and neck cancer, gastro-oesophageal reflux disease, cerebral palsy) or cannot eat enough (eg cystic fibrosis, failure to thrive). People may need gastrostomy feeding for a short time while they recover from illness or this may be needed permanently. People who require tube feeding require specialised formula and additional equipment to receive their nutrition safely at home. This formula and equipment is necessary for people with gastrostomies to survive. Most people with gastrostomies rely on tube feeding as their sole source of nutrition.

GISS NSW would like to make a submission to the NSW Parliament Legislative Council inquiry into PADP in particular addressing (i) adequacy of funding of present and projected program demand and (ii) appropriateness and equity of eligibility requirements.

(i) Adequacy of funding of present and projected program demand

GISS NSW believes that PADP funding for gastrostomy equipment is inadequate. Gastrostomy equipment (called consumables and includes oral syringes, plastic tubing and containers) are needed to administer specialised formula through the gastrostomy tube. Our members have told us of long waiting lists to get equipment that people need to feed themselves daily. There is also confusion regarding whether these products should be reused (people are given 2 sets per week). These consumables cost \$5-\$15 per item and manufacturers' instructions recommend they should be changed daily. Some people with gastrostomies also require a feeding pump. These can be hired at \$50 per month or purchased for ~\$800-\$1000.

(ii) Appropriateness and equity of eligibility requirements.

GISS NSW believes that all people who require gastrostomy feeding should have access to affordable formula and equipment to feed themselves. Costs for gastrostomy feeding can be very expensive with costs ranging from \$250-\$800/month. Not all people with gastrostomies are eligible for PADP, particularly if they require gastrostomy feeding for less than a year (eg. people undergoing treatment for cancer). Our members have reported differences between PADP

lodgement centres with some providing gastrostomy equipment with minimal delay, some with long waiting lists and some that do not provide gastrostomy equipment at all. For people who are not eligible for PADP, there are no other alternatives as formula and equipment are not covered by private health insurers, other federal or NSW government schemes. There is a risk of people diluting their formula or unsafely reusing equipment because they cannot afford to feed themselves.

GISS NSW position:

GISS NSW advocates for all persons with gastrostomies to have affordable and timely access to the formula and equipment they need to feed themselves daily. Affordable access to food and nutrition is an essential human right. In other states, formula and equipment are either partially subsidised (ACT, Queensland) or fully subsidised (Victoria, Tasmania). Without affordable and timely access to formula and equipment, people with gastrostomies cannot feed themselves safely at home.

Should you require further information, please contact Glen Pang, GISS NSW coordinator on Ph 0432 339 752.

Yours sincerely

A handwritten signature in black ink that reads "Glen Pang". The signature is written in a cursive style with a large, sweeping flourish under the name.

Glen Pang and Alison Kennedy
GISS NSW Coordinators
On behalf of GISS NSW Executive Committee and Members