Parenteral Nutrition - Down Under

"a consumer support group for people with intestinal failure (IF),
dependent on Home Parenteral Nutrition (HPN)"

Consumer costs of managing Home Parenteral Nutrition

In February 2013, Parenteral Nutrition – Down Under (PN-DU) conducted a survey of its membership to determine the costs of managing Home Parenteral Nutrition (HPN). The survey asked about HPN-related costs such as HPN solution, clinical consumables and equipment and other costs such as medications, doctor's fees and therapies.

A total of 22 members completed the survey. Of these, 15 (68%) were adult consumers while the remaining seven (32%) were parents or carers of children dependent on HPN.

Participation in the survey was entirely voluntary, anonymous and confidential.

The survey, although not statistically valid in terms of the total Australian and New Zealand HPN patient group, nonetheless serves as a useful snapshot and highlights some concerning issues and challenges affecting our members.

Findings related to costs directly associated with HPN use

- **Location**: 18 respondents (82%) live in Australia, with four (18%) in New Zealand.
    - **NB**: HPN supplies are provided free of charge in New Zealand.

- **Cost of HPN solution**: 20 respondents (91%) reported that they do not pay anything for their HPN solution. One respondent (5%) is a private patient in Australia who pays the full cost personally and reported that this is becoming increasingly difficult due to the high cost of HPN. This person did not know what to do when they reach the stage where they are unable to pay. Whilst the public system is an option for this patient, it highlights the very limited options available to HPN dependent patients with private health insurance, as compared with other patient groups that receive a higher level of cover when choosing private treatment. The remaining respondent (5%) a public patient also located in Australia, reported that they have been informed they will have to pay for the HPN solution but the final cost has not yet been settled.

- **Cost of HPN infusion pump**: 19 respondents (86%) did not pay anything for the pump nor for ongoing use of the pump. One Australian respondent (5%) had not paid for the pump but was unsure of future cost implications. Another Australian (5%) was provided with a pump free of charge and a second pump at a reduced price. Another Australian (5%) had initially purchased two ambulatory pumps, paid for by their private health fund, and some years later was provided with a free ambulatory pump by their HPN provider.

- **HPN infusion pump maintenance and support**: 21 respondents (95%) do not pay for pump servicing, maintenance or support services. The remaining Australian respondent (5%) would have been required to meet service and maintenance costs for their original pump, hence they chose to use the pump provided more recently by their service provider which includes free maintenance and servicing.

- **HPN giving sets (pump tubing)**: 21 respondents (95%) do not pay for sterile single use HPN giving sets (also called pump tubing), while the remaining Australian respondent (5%) met the cost of giving sets for their original pump and this was the main reason for changing to the pump provided by their provider, which includes giving sets provided at no cost. Therefore, none of the respondents currently pay for their giving sets.

- **Consumables needed to care for a central venous access device (CVAD) - eg syringes, dressings, drawing up needles, dressing packs:** 19 respondents (86%) did not pay for their single use consumables. In the case of the remaining three respondents, all Australian: one met the full cost; the second sourced and paid for some of their own consumables from a pharmacy; while the third is negotiating with their hospital since the hospital announced patients would have to buy their own consumables.

Additional costs associated with HPN use and health care

The survey concluded with a series of optional questions. Eighteen people responded to the question about additional costs associated with HPN use and health care. In contrast to the earlier questions, both New Zealand and Australian consumers reported facing additional costs. The chart on the next page gives a snapshot of the diverse costs facing some HPN users. Analysis below relates to expenses where at least half of the respondents faced some financial cost.

- **Medications**: Fifteen respondents (83%) reported having regular medication expenses. Of these, three people (17%) had weekly medication costs and a further ten (56%) had monthly medication costs.

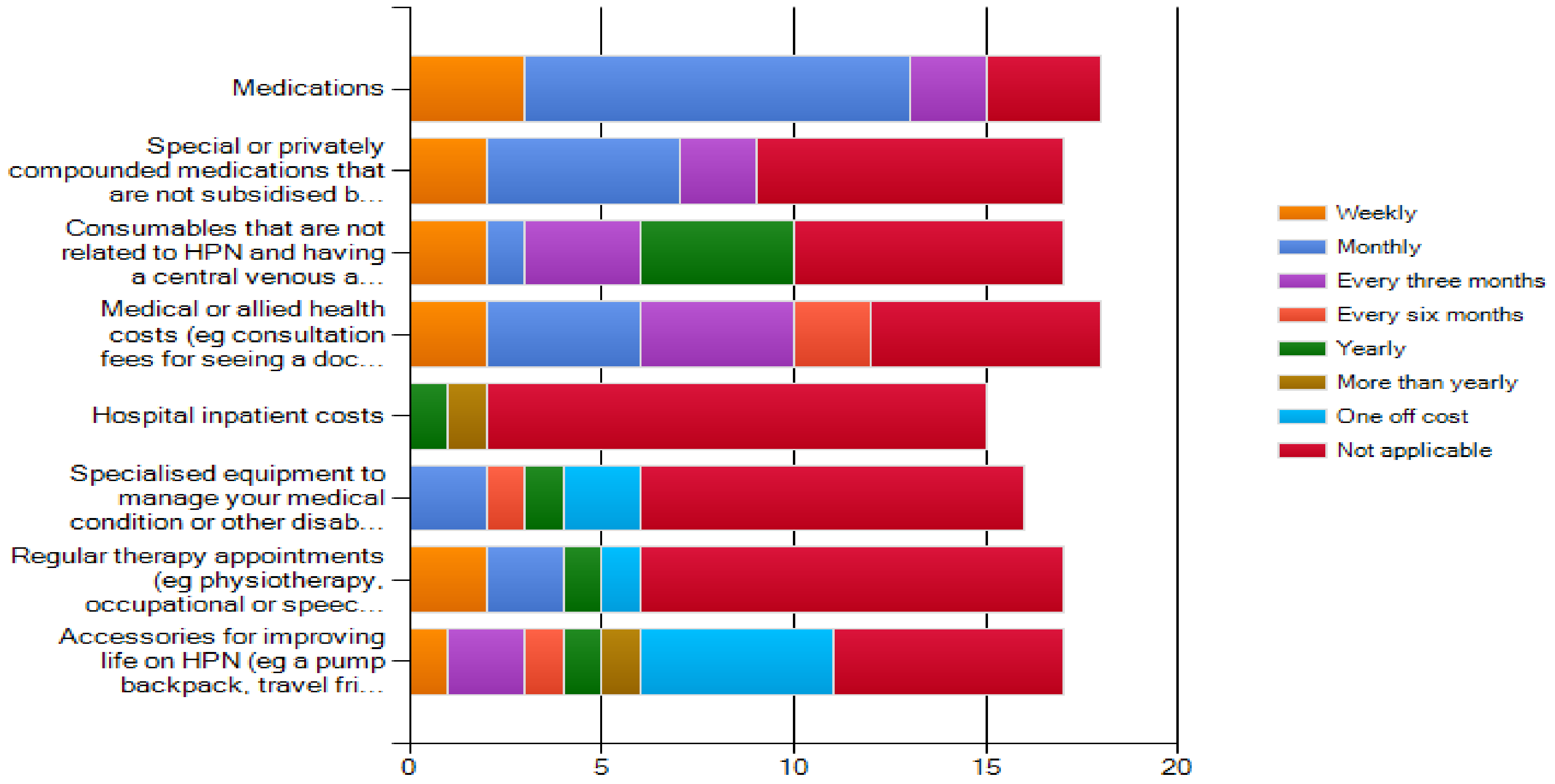
- **Non-subsidised medications**: Nine (50%) of the respondents reported regular expenses for special or privately compounded medications that are not covered by any government pharmaceutical benefits scheme. For two people (11%) these costs occurred weekly, while for a further five people (28%) the costs occurred monthly.

- **Medical and allied health consultation fees (eg doctor, dietitian appointments)**: The frequency of this expense for HPN users varied from weekly (2 or 11%); to monthly (4 or 22%), three-monthly (4 or 22%) and six-monthly (2 or 11%).

- **Consumables not related to HPN**: Over half the respondents faced costs for consumables that do not relate to HPN use – eg gastrostomy tubing, stoma bags. Frequency of this expense varied from weekly (2 or 11%); monthly (1 or 6%); three-monthly (3 or 17%) and yearly (4 or 22%).

- **HPN accessories:** Over half the respondents had spent money on accessories to improve life on HPN eg a pump backpack, travel fridge. For six (33%) respondents the accessories presented a regular cost ranging from weekly to yearly, while for five (28%) the cost was a one-off purchase.

Regular expenses affecting less than half the respondents included: specialized equipment to manage a medical condition or other disability; regular therapy appointments; and hospital inpatient costs. Other expenses reported included private health insurance premiums and travel and parking for regular hospital appointments.



Please indicate if you face any of the costs listed below in managing your/your child's medical condition/s or disabilities, and how often you pay these costs.

Capacity to undertake paid work

The degree of impost presented by regular expenses is linked to income and a person's ability to work. 21 people answered the optional question related to capacity to work. To summarise, two (10%) respondents were or had been able to maintain full-time employment while on HPN. In all other cases, capacity to work was limited or eliminated by HPN dependence.

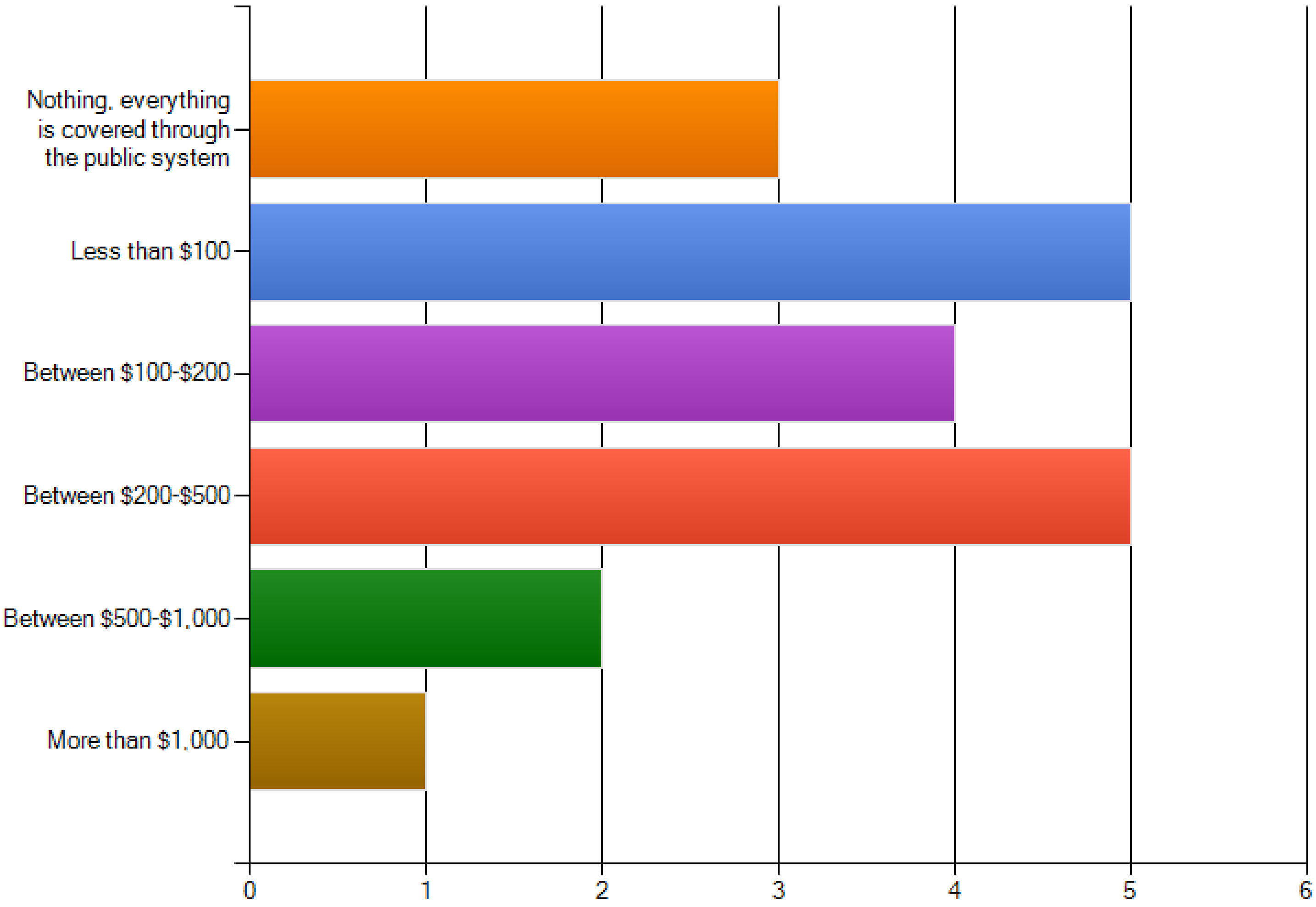
- Five (24%) respondents reported they are unable to work and are supported by a family member.
- Six (29%) reported they are unable to work and rely on government income support.
- Of those who worked: one (5%) worked full-time, another person was retired but had worked full-time for ten years whilst on HPN; six (29%) reported they can only work part-time and another person (5%) reported they can only undertake contract or intermittent work during periods of stability.
- Another person (5%) reported their income is derived from income protection payments.

Estimated monthly costs relating to HPN and management of medical conditions and/or disabilities

The final optional question asked people to estimate their regular costs. The bar chart, below, provides a snapshot of the following responses from twenty people. Two people reported they were negotiating with their hospital about pending additional costs for HPN and/or related consumables. In one case, a favourable outcome has since been reached, with all HPN and CVAD consumables continuing to be provided at no cost by the treating hospital. The other case is not yet resolved, so it is possible the snapshot below would reflect higher costs for one respondent if the survey occurred in the future. Possibly reflecting the different national health care arrangements in Australia and New Zealand, **all** of the respondents facing costs above $200 per month (eight, or 47%) were Australian.

- Three (15%) reported all costs were fully met by the public system and they had no additional out of pocket expenses.
- Five (25%) reported their monthly costs to be less than $100.
- Four (20%) reported their monthly costs to be between $100-$200.
- Five (25%) reported their monthly costs to be between $200-$500.
- Two (10%) reported their monthly costs to be between $500-$1,000.
- One (5%) reported their monthly costs to be greater than $1,000.

Could you estimate the monthly costs of managing your/your child's medical condition/s and/or disabilities?



Summary

HPN is a high risk home therapy. However, when consumers are suitably equipped to manage HPN safely at home, evidence across the world shows there are significant cost savings as compared with high cost inpatient care and treatment of hospital acquired infections.

While this survey was being undertaken, PN-DU researched arrangements in Commonwealth countries with socialized medicine, namely Canada and the United Kingdom. In both countries, as in New Zealand, the provision of HPN solution, lines and associated consumables for nursing a CVAD are provided free of charge through each country's respective public health system.

It is reassuring that most respondents in the Australian and New Zealand consumer survey similarly receive their HPN and associated supplies free of charge. However, this survey highlights three issues are of concern:

1. **Cost shifting for HPN solution**: Of most concern is the case of an Australian patient whose public hospital is considering charging for HPN solution. If this occurs, it would begin to put Australia out of step with other Commonwealth countries and set a concerning precedent. If this move became more widespread - given the prohibitive cost of HPN solution - it would make HPN therapy unattainable for all but the very wealthiest of our citizens.

2. **Cost shifting for CVAD consumables**: Currently, one public hospital patient has to meet the cost of some their CVAD consumables. Of concern is the Australian public children's hospital which proposed that families of HPN patients source and pay for their own CVAD consumables. Since this survey was completed, PN-DU has been made aware that the hospital did not proceed with this policy change. This is welcome news.

   However, it is worth noting that two of PN-DU's members were advised by the hospital in question that their monthly CVAD consumable order would cost $500 and $1000 respectively, at hospital bulk purchasing prices. Costs would be in the order of $1000 and $2000 respectively if consumers were to purchase consumables privately. An annual cost of $12,000-$24,000 would be unattainable for most Australian households, let alone those where capacity to work is diminished or non-existent due to the toll of chronic illness and managing the demands of daily, intensive, high risk home therapy.

   Expecting HPN users to source their own CVAD supplies also poses safety and quality control risks, as lay people may not necessarily source the safest or most appropriate consumables for their CVAD and may be at higher risk of using contaminated supplies if they are financially constrained and unable to purchase sufficient supplies to ensure a "contingency" supply for unplanned CVAD cares or replacing items that are contaminated during preparation.

3. **Income earning capacity and additional health care costs for HPN consumers**: As HPN is used in people with widely ranging health conditions, often with additional co-morbidities, the HPN patient group could be expected to have quite varied costs in

managing their health condition and/or additional disabilities. This is reflected in our survey findings, with monthly costs ranging from nothing through to more than $500 and even $1,000 per month. Additionally, compromised health and the demands of an intensive home therapy had limited most respondents' ability to undertake paid work. These additional financial constraints need to be considered by policy makers when proposing user pays or co-payment policy changes.

Conclusions

The Australian and New Zealand HPN service models differ in that New Zealand has a national, centralized HPN and intestinal failure service, whereas the federated health system in Australia allows for variation between States and Territories.

This variation has already led to some inequity in terms of meeting the costs of CVAD consumables for one public HPN patient and would have created hardship for a significant number of paediatric patients at a large tertiary children's hospital had a proposed cost shifting proposal been implemented as originally proposed.

PN-DU would welcome a discussion about the potential cost and health benefits of a nationalized HPN and intestinal failure service in Australia to standardize care and provide equitable service and supplies to everyone in Australia and New Zealand, regardless of where they live.