



Proudly supporting amputees in Victoria.

Health Services Preliminary Inquiry - Victorian Artificial Limb Program

Limbs 4 Life Inc. October 2010



Background

Limbs 4 Life is a non profit non government organisation which was developed in 2004 to provide information, access to support and resources to amputees. Limbs 4 Life believes that no amputee should go through the process of limb loss alone and facilitates services for the individual, their families and primary care givers. Our goals are to promote social inclusion and to assist amputees to re-engage with their community.

We work to voice the concerns of amputees within the disability sector, at forums, seminars and through alliance with disability governance boards and health professionals.

Limbs 4 Life would like to thank you for the opportunity to provide comment for this inquiry on behalf of our stakeholders, members and interested parties. Every individual who is missing a limb has experienced a personal trauma and tragedy; this is why we believe that the process following the loss of a limb should be as holistic and effective as possible.

In July 2010, Limbs 4 Life surveyed over 1,000 amputees to seek their views on their hospital experience, rehabilitation, prosthetics and equipment, returning home and regaining independence following an amputation. Victorian information from this survey together with comments and opinions from the letters and emails we receive on a regular basis has been used to complete this submission to Health Services.

We would welcome the opportunity to further comment and provide assistance if required to benefit the outcomes of the inquiry.

Melissa Noonan
Executive Officer
Limbs 4 Life Inc.

Victorian Artificial Limb Program

Limbs 4 Life has identified four key areas which we believe require further consideration during the preliminary inquiry of the artificial limb program.

They are;

- Data collection
- Equality
- Support services; and
- Provision of information for patient centred care.

Data Collection

We are unaware of a current data collection system in Victoria which relates to the number of individuals being treated each year. There is no central information base of all Australian amputees. There is no current system of identifying the number or distribution of amputees or their prosthetic devices on a national basis or for Victoria. There is no reliable and complete data for planning or research exercises.

Limbs 4 Life believes this information could provide valuable insight about how Victoria compares to the other states in Australia and would help to identify any areas which require attention. Having access to data would enable further analysis of the current system, enable checks and balances to be put in place and highlight any inconsistencies which may occur. The New Zealand Artificial Limbs Board makes all of their information publicly available via their website, promoting transparency and accountability.

Access to financial data about the artificial limb programme in Victorian is currently not available to the general public. As a result, it is difficult to compare services between States other than via feedback from our members and stakeholders.

In a number of Australian States the following types of information are publicly available;

- the total amount of funding allocated
- the number of patients treated (per 12 month period)
- the amount of new limbs fitted (eg: below knee, above knee, syme, above elbow and below elbow)
- the number of limbs repaired (funding allocated to repairs)
- average spend per level of amputation (eg: below knee, above knee etc)
- gender of each patient
- age of each patient

Recommendation

That each facility provides;

Statistics in line with the above guidelines to ensure that the Victoria system can be evaluated.

References:

<http://www.enable.health.nsw.gov.au/services/als>

<http://www.health.qld.gov.au/qals/>

<http://www.nzalb.govt.nz/index.html>

Equality

It would appear that there is no consistent parity with respect to the different funding models operating in Victoria. On one hand, there is the difference between compensable and publicly funded patients (eg: Workcover/TAC) and the public system and on the other there are some facilities that can provide better (and more costly) than others. When the funding allocation is derived from one funding source, it is difficult to comprehend why this is the case.

It is common knowledge within the sector that St Vincent's Prosthetic and Orthotic Department have more flexibility in the provision of equipment than, for example, Royal Melbourne Parkville campus. Amputees report that those who live in rural and regional communities and attend Latrobe Valley Prosthetic and Orthotic Centre and Anne Caudle Bendigo (OAPL) have more flexibility in choice of prosthetic componentry and support aids such as silicone liners.

It would be interesting to know if other facilities experience this same problem. A number of regional centres, for example, Latrobe Valley and OAPL Bendigo, can also offer higher end equipment than a number of their counterparts in the Melbourne metropolitan region.

There is also considerable disparity between funds which are available for external prosthetics and funds which are available for internal prosthetic components, such as those commonly used in hip, knee and shoulder replacements. In addition, the current funding does not reflect increasing costs of prosthetic components nor advancing technology – a prosthetic limb for an above knee amputee can cost up to \$80,000 with a median cost being about \$15 to \$20,000.

For example, in Queensland the average funding allocated for a below knee amputee is between \$4,000 to \$5,000 while funding allocated for an above knee amputee ranges between \$6,500 to \$8,000. This is in sharp contrast to the average funded cost of an internal prosthetic, which is generally about \$23,000.

Recommendation

That funding levels be investigated to enable all facilities to be able to equitably access suitable equipment of an acceptable standard, whilst providing amputees with the best possible opportunity to be successfully able to contribute to the economy and lead a healthy, happy and fulfilling life.

"At the age of seventeen I lost my leg to cancer – why is it that I am fitted with the same kind of leg that someone also on the public system is when they are in their 70's?"

"Some days I find it very difficult."

Peter, 27, Greensborough.

Support services

In a number of States in Australia, consumer support panels have been developed to offer additional services to amputee patients. Enable Health NSW and Queensland Health both have consumer support panels, which usually consist of two or three amputees, prosthetist's and in some cases a medical practitioner. The purpose of these panels is to provide individuals who believe that they have been unfairly treated with recourse to overturn a decision, advocate on their behalf or answer additional questions regarding their care.

Prosthetics is a specialised field and whilst we understand that individuals are able to seek assistance from the Disability Ombudsman or Health Services Commissioner, there is a pressing need for this service to be supported by a specialised panel that can understand, advocate and facilitate their needs. Whilst AOPA (the body for Orthotics and Prosthetics) in Australia attempt to ensure that all clinicians are members, services and standards are not monitored or regulated.

Limbs 4 Life continues to contribute and invest heavily in social capital through our volunteer peer support program, which aids amputees in their recovery after limb loss and aims to prevent long term mental health issues such as depression. The implementation of a Victorian consumer support panel could further support and benefit the long term outcomes for amputees in Victoria.

Recommendation

That a consumer panel be developed (as exists in a number of other states – eg: Queensland, NSW) made up of consumers, both public and private practising prosthetists (AOPA Members for example a member for a public hospital facility and a member from a private (VALP funded) facility who can offer guidance, support and recommendations when and if required. We recommend that the panel meet on a regular basis (once a month) to discuss new products and best course of practice.

Patient centred care – provision of information

The lack of information is cited as the biggest concern for all amputees. 90% of amputees surveyed (July, 2010) stated that they would like more information in relation to;

- Prosthetics
- New technology and what is available
- Prosthetics relating to safety such as shower/water legs
- Information about funding and issues related to choice (eg: if they were to contribute financially, could they access prosthetic equipment of a higher standard?)
- Information about amputee services and support

In order to empower an individual and to promote good mental health an outstanding 74.2% also stated that they would have greatly benefited from the opportunity to meet and discuss issues with another amputee. Only someone else who has gone through such a process can truly empathise with an individual's situation. The Limbs 4 Life peer support program has proven to promote good mental health, facilitate support and peer networking opportunities and equip a new amputee with knowledge to make person centred informed decisions.

We maintain that the provision of information is paramount in the recovery and rehabilitation of amputees. Other States have implemented initiatives to assist with provision of information; for example, many States include details of amputee support organisations and services on the Health Services websites with contact numbers and links to support services websites.

(Please see link to Queensland and NSW Health as above as an example)

Our survey provided information about the number of amputees who were affected through lack of provision of information.

- 59.8% of respondents were not given information about choosing their own prosthesis to best suit their needs and lifestyle
- 64.1% of respondents were not given information to be able to choose where they did their rehabilitation and in some cases were tied to a hospital unit which was away from where they reside. It was not until after they had returned home that they could access information only to find out that there was a facility closer to their home.

In a number of cases amputees reported that even though they had lost limbs many years prior that they were still not aware that services are available closer to their place of residence. For example, amputees reported that they had travelled from country Victorian areas to metropolitan facilities for years without being made aware that services were operating only thirty kilometres from their place of residence.

It is interesting to note that in “The Queensland Amputee Needs Assessment Report” – Queensland Health June 2006; that the same/similar areas of information as above were highlighted as the key areas of information that amputees had requested.

“I was provided with the most basic prosthesis. I was 45 years old and very active and wanted to return to work.”

Barbara, 45, Heidelberg

“Being able to talk to active amputees in my age group would have been very helpful.”

Rebecca, 55, Malvern

Recommendation

That all facilities which provide publicly funded services are listed on the Victorian Health Services website (as carried out in other states) to ensure that individuals can make informed choices about their care.

Summary

Limbs 4 Life would welcome the opportunity to further contribute to the inquiry into the Victorian Artificial Limb Program inquiry and would be happy to provide additional information or comment to represent our stakeholders, their families and to support the work of allied health care professionals.

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