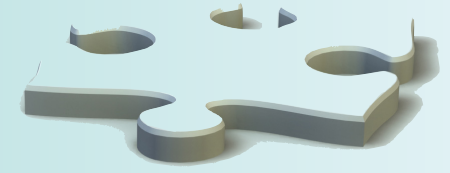
The background of the slide is a light blue-grey surface with several white, three-dimensional puzzle pieces scattered across it. Some pieces are in sharp focus, while others are blurred in the foreground and background, creating a sense of depth.

# **Amputees In Motion**

A snapshot of people living with limb loss in Australia



# Amputees In Motion Public Education Project



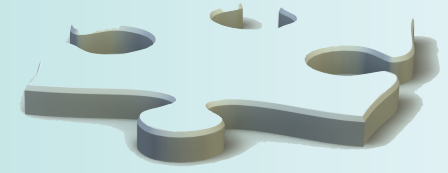
This project was funded by a grant from the WFC Thomas Charitable Trust, which is managed by ANZ Trustees.

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Limbs 4 Life would like to acknowledge everyone who took part in this project. Your contribution and participation has been invaluable not only to the outcomes, but also, to those who will benefit from the information in the future.





Amputation affects each person differently. There is the emotional impact of living with limb loss in addition to the physical implications. Everyone is an individual, and reactions to these changes can be different for each person.

For a number of years Limbs 4 Life has fielded calls, listened to concerns and received feedback from people living with limb loss. While some information is forthcoming, it is necessary to gain personal insight regarding quality of life following amputation, what a person needs in order to achieve the best possible outcomes, and how they fare after returning home.

As part of Limbs 4 Life's mission to provide amputees with information, support and access to resources, the organisation set out to develop a public education program to highlight the needs of amputees, identify any gaps in the system, and obtain feedback from community members regarding their personal experience of living with limb loss.

The purpose of this project was to develop a public education program to better inform the amputee community, their families and primary care givers. With our mission in mind and as part of our strategic plan Limbs 4 Life set about to collect information about the Australian amputee population.

The aims behind this project were twofold:

- *To research and collect data about the issues that concern amputees and their carer's*
- *To create an awareness/education plan focusing on promoting healthy lifestyle and health management.*

## About the project

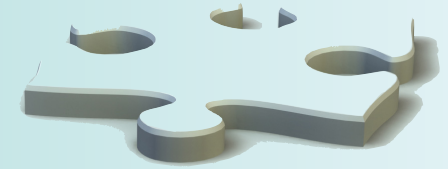
The project was titled 'Amputees in Motion' and adopted the image of a jigsaw puzzle to show how all of the pieces of the puzzle fit together. We wanted to know about your engagement with the health system, about your prosthesis, assistive devices and how you have fared since returning home, and any barriers you face in participating in the community.

The Amputees in Motion Public Education Project was developed to research and analyse the needs of the amputee community and by using survey data transpire that information to create a public awareness education campaign. The campaign aimed to raise awareness in the community and highlight the needs facing the amputee community, further to this, the study aimed to identify the factors that would make a difference; such as healthy lifestyle and positive health management.

## Research and data collection

The initial research looked at individual experience pre or post amputation. This included analysing stories and the information that Limbs 4 Life receives on a regular basis through its connections with amputees. The organisation facilitates up to seventy inquiries each month and receives regular feedback from peer support volunteers about experiences faced by amputees, together with comments via the website and our social media networks. In order to create a comparison, investigations were carried out with amputee groups/organisations in other countries, such as the ACA (Amputee Coalition of America) and Limbless Association in the UK.

After analysing all of this material a survey was developed. The information collected from the survey would provide the hard data needed to direct the creation of the public education campaign 'Amputees in Motion'. It was the first national survey of its kind ever conducted in Australia. It is essential that a health and service system has access to the views of its consumers, and that the amputee public have a benchmark to measure their care.



### Survey Rollout

In July 2010, amputees from across the country were invited to participate in a survey. The survey was made available online and in hard copy format. Participants who chose the hard copy option were provided with free return postage and Limbs 4 Life then entered their responses into the online collection tool. Participants were able to remain anonymous and were not asked to give their names or any identifying information, and none were collected. Participants were able to skip questions at any point if they wished to do so.

The project (survey) was marketed using a variety of different methods including the distribution of project flyers, announcements and links to the survey were placed on the Limbs 4 Life website and social media networks, notifications were also sent to community groups, amputee organisations, prosthetic providers and advertised in Amplified magazine.

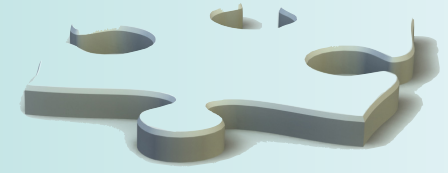
The first part of this survey sought information 'About you' including the site of amputation, the cause, and the types of supports used whether it be a wheelchair or prosthesis for example. It then went on to explore respondents experiences during their journey; from the time of amputation, to their experience of the health system, through to going home and resuming participation in recreation, work or the community. This approach roughly corresponds with the timeline of experiencing the amputation, moving through the hospital and rehabilitation system, being fitted with prosthetics (where appropriate), and provided with aids and equipment (assistive devices) and then going home. The survey was set up along a journey timeline path to identify any particular difficulties experienced by individuals at these crucial points. Key timelines are vital in the process from prior to amputation - through to going home. The right information and support at these times can have a significant impact on each person's outcome.



There were specific questions regarding information and support and at what point it was received. If the prosthesis supplied was suitable, the length of waiting time prior to receiving it, and if individuals were required to contribute their own money. Other questions included employment details and the experience of long term and ongoing pain.

By identifying if a person received access to information and support, have a prosthesis that suits their lifestyle, are able to live pain free or at least manage pain, are identifying factors regarding good quality of life, this also includes a person being able to participate in the activities they choose and nurture the relationships that are important. The survey covered emotional and physical areas and the impact of those upon the individual's life.

# Survey Findings



## About the methodology

This survey was answered by a diverse group of people within the amputee community. Those who completed this survey included individuals born with limb difference, as well as people whose amputation occurred over sixty years ago and even as recent as 2009 (year the survey was undertaken). It was acknowledged that the health system and prosthetics have changed over time. This however, does not make the responses any less valid as the reporting focus's on people's experiences.

This is the first time in Australia that amputees have been asked to participate in such a survey.

\*For the purpose of this report people who took the survey are referred to as participants

## Survey Findings

### About you

The first part of this survey sought information 'About you'. This included site of the amputation, the cause of the amputation/s and the types of supports used.

Table One: Who participated in the survey?

Gender	68% men 32% women
Ages	Ages ranged from 18 to over 81 years old 42% were aged 41-60; 20% aged 21-40
Which states did participants live in ?	37% Victoria; 23% NSW; 22% Qld; 9% SA; 5% WA; 2% Tas; 1% ACT 0.1% NT
Type of household	62% live with their partner or their partner and children; 20% live alone 15% live with other family members 2.4% live in a share house
Employment status	38% work full or part time; 4.8% study and 4.8% are unemployed; 21% are retired while a further 20% retired due to disability

### Comments:

More than half of the survey participants were male and the average age was 52 years. The majority lived with either their partner or their partner and children. While the highest number of respondents came from Victoria, this can be attributed to the fact that Limbs 4 Life was established in Victoria and has more members in this state.

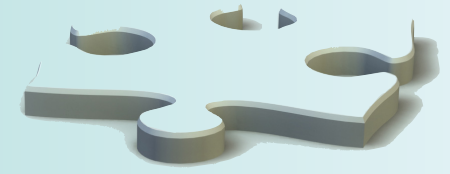
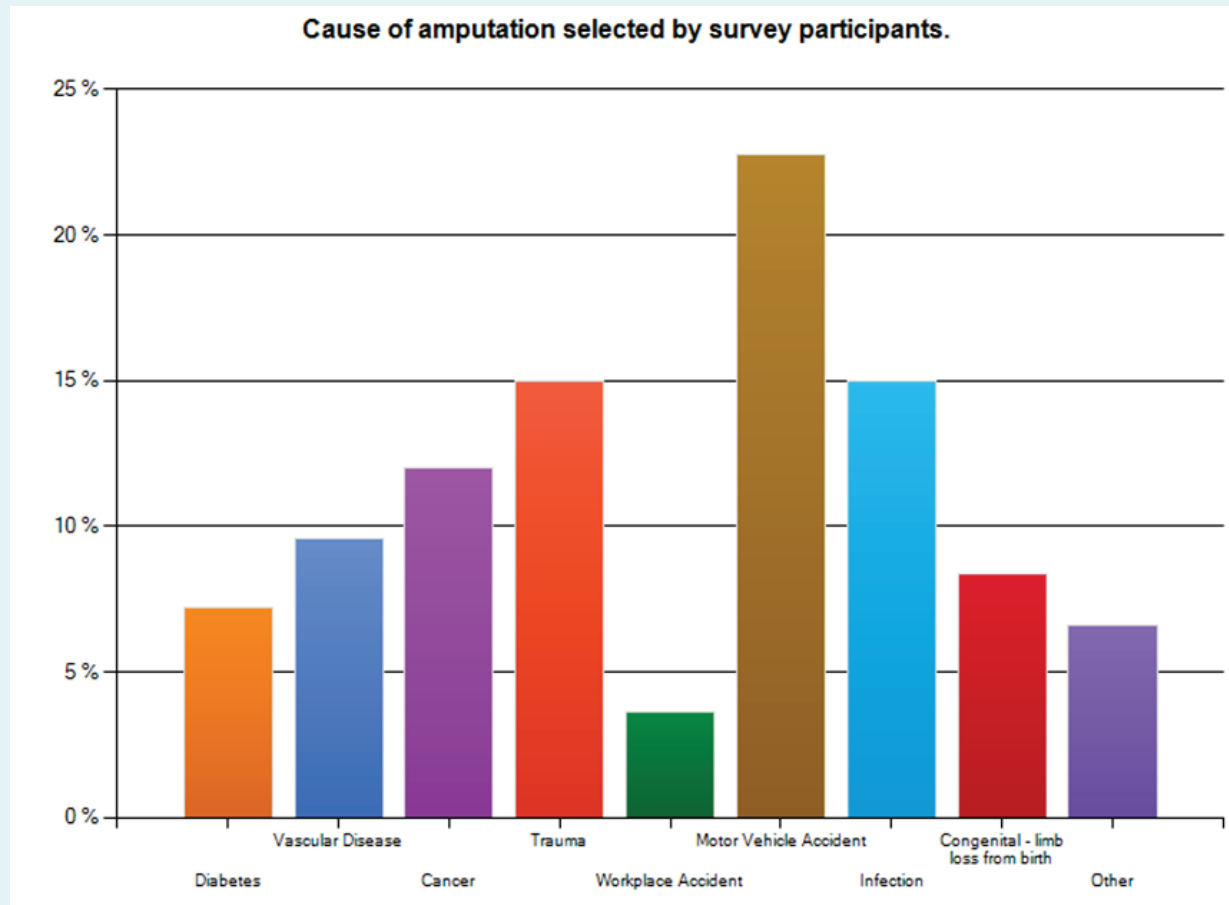


Table Two: Cause of amputation



**Comments:**

Evidence shows that the largest number of amputations in Australia is attributed to diabetes and vascular disease. However this was not highlighted by respondents with the majority of participant's amputations being a result of trauma. This may be due to those affected by diabetes or vascular disease having a higher morbidity rate and or other groups being more active.

## Survey Findings continued

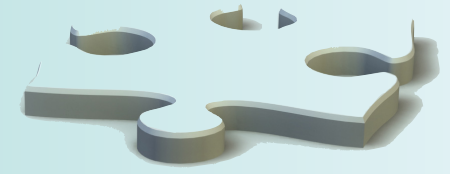
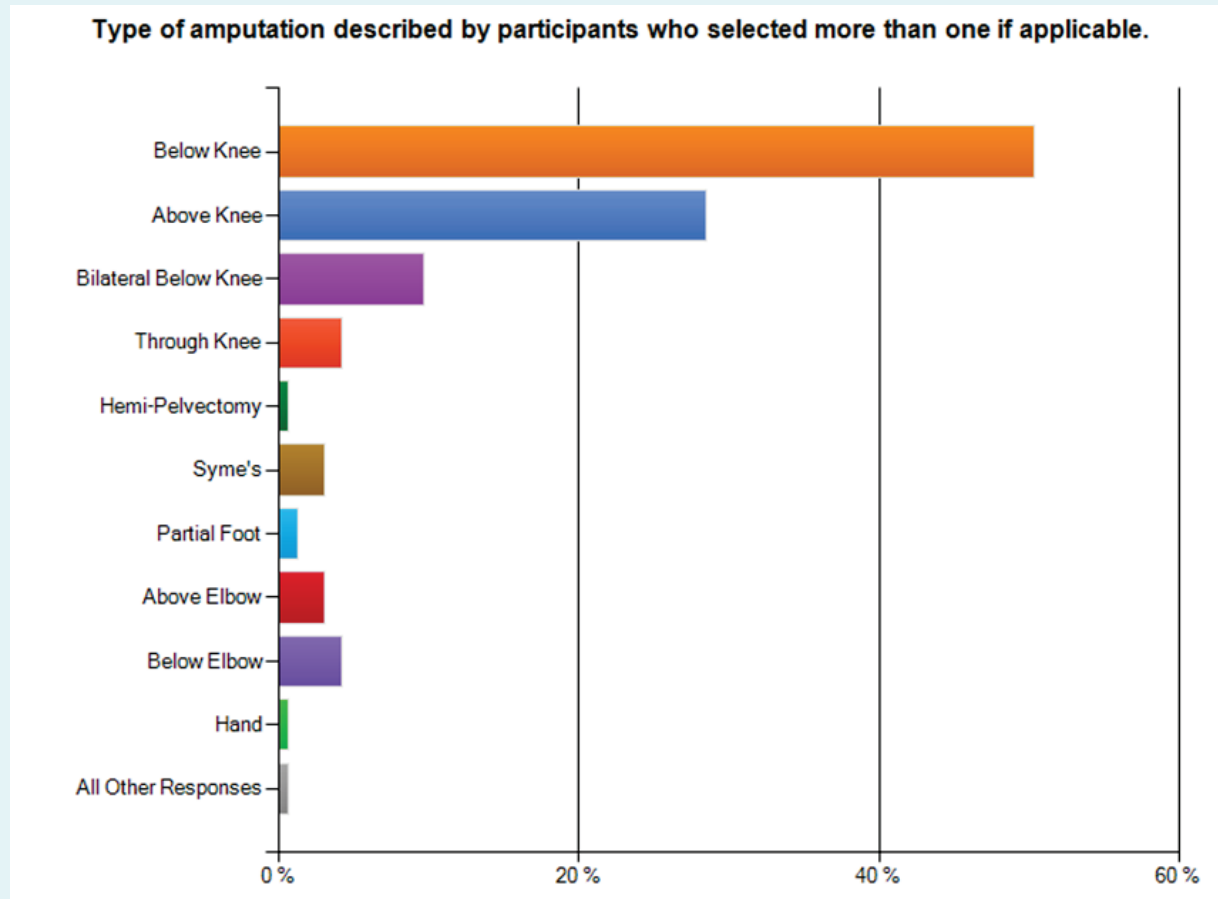
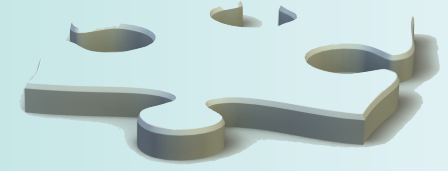


Table Three: Site of amputation

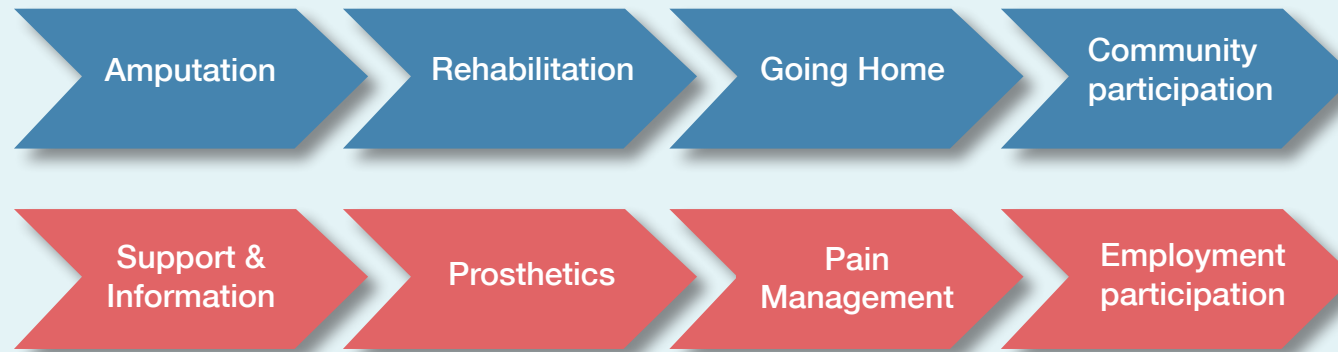


**Comments:**

Table three indicates the site of amputation of survey respondents. More than 75 percent of participants had lower limb amputations.



The survey then went on to explore participants experiences from the time of amputation and their in-patient experience of the health system, through to going home and resuming participation in recreation, work and community. This mirrors a very typical timeline and assisted to identify if there were any gaps at the particular points through this timeframe.



### Survey findings

The results of the survey highlighted four main areas faced by amputees;

- The provision of information and support
- Cost and ongoing satisfaction with prostheses
- Impact of ongoing pain
- Challenge to regain independence

### The value of information and support

The survey asked if amputees received information and support at these points;

- Preparing for amputation
- Choosing a prosthesis
- Resettling at home
- Keeping up to date with advances in prosthetics

It was noted that information and support included printed material and visits from allied health professionals and other amputees. These points are crucial in the process from prior to amputation through to going home. The right support and information at these times can have an impact on an individual's outcome.

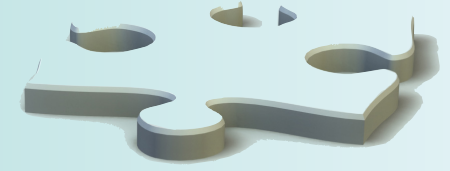
Preparing for amputation is a critical time. It has been identified that information and support can assist some people to mentally prepare and alleviate fears of the unknown. It must be stated that for some respondents support prior to surgery was not an option as they lost limbs due to traumatic injuries.

The experience of the overwhelming number of participants was that they did not receive information and support at key points.

Only 30 percent of respondents received support and information prior to amputation. When asked what helped, 46 percent nominated a visit from an amputee.



## Survey Findings continued



This response is typical of the comments:

*'Conversations with fellow amputees and discussions on what I could expect and things I could still do post amputation.'*

For some of the 70 percent that did not receive information and support, the circumstances of the amputation through birth or trauma precluded its provision, for example, *'I was only given 7 hour's notice'*, and *'Limbs got torn off at time of accident, no time for consultation'*.

Some participants directly linked talking to another amputee with better recovery:

*'If I could talk to previous amputees about the change in one's life, I would know what to expect'.*

*'Would have liked to be able to speak to other amputees it would have made life a lot easier during the first 6 months or so'.*

*'Thought I would have been in a wheelchair forever, would have liked to have seen a successful amputee like myself now, to show how you can get on with your life'.*

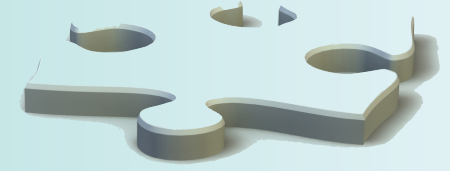
One participant noted that it is important for carers and family to also receive information and support. In this instance, the participant required urgent surgery and his wife had to make critical health decisions on his behalf:

*'I was in a coma, and required urgent surgery. My wife was responsible and would have appreciated advice from a similar amputee as to future potential, pain etc so that the decision would be made easier'.* It could have been written as a handout'.

*'Some written material describing the support services available to amputees from before amputation to death. 'It's like groping through a maze in the dark'.*



Participants at the South Australia Forum



### Choosing a Prosthesis

Participants were asked if they received support and information to assist them to choose a prosthesis and if they were given the opportunity to trial a number of different forms of componentry.

While 41.5 percent of participants were given support and information about how to choose a prosthesis or other aid, 58.5 percent were not. The most common form of information and support provided was printed information (43 percent) followed by a visit by an amputee (39 percent).

Participants were asked to nominate what information and support they would have liked at the time, some participants wanted to understand more about how prosthetics worked, for example: *'a thorough explanation of how the limb system worked and what was available'* and *'given samples of prosthetics to study'*.

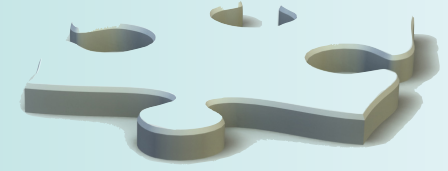
Some participants directly linked the lack of information and support provided to their lack of satisfaction with the prosthetic. *'More information, the first 2 legs and foot was chosen for me and in hindsight were not appropriate for me and my lifestyle'* and *'More information of limbs available to suit me rather than given what was offered'*.

Again, meeting with another amputee was preferred method of receiving information and support *'Speaking to an amputee in my age group with the same degree of amputation and of similar activity level, which would influence any choices and might have helped'* and *'Being and meeting someone who had experienced this'*.

20 percent of participants remain dissatisfied with aspects of their prosthesis. 64.7 percent reported they were not able to choose a prostheses or aid that matches their lifestyle. Many participants report not being offered a choice, for example, *'In my case there was no alternative'* and *'standard leg'*.

There were mixed experiences with prosthetists, for example, a participant had *'great faith in what the prosthetics team told me and recommended for my situation'* while another didn't get a prostheses that suited *'until I went to another provider'*, another did their own research and advocacy, *'Yes, after I pushed the situation to a head and because I found the appropriate prosthesis for me, I contacted the company and spoke to them directly'*.

Most people indicated that they received their first prosthesis or aid within three months of their rehabilitation stay. A further 20 percent waited up to six months, 14 percent waited up to 18 months. In some cases this delay can be attributed to healing time. The above results indicate that the ability to have the correct prosthesis is key to emotional wellbeing, efficient mobility, improved energy levels, better job prospects and general life choices.



### Cost of prosthetics

In order to receive a prosthesis that was satisfactory for them, a number of participants indicated that they paid tens of thousands of dollars to achieve what they deemed to be a better quality of life.

Participants reported paying sums including \$100 to \$3,000, \$13,500, \$15,000, \$50,000, \$65,000 and \$70,000. One participant paid '\$23,000 for an arm and \$4,000 x two for legs'.

The explanation from one participant regarding why he chose to pay for the cost of his prosthesis: *'the basic "standard" prosthesis was pretty ordinary, so I had to pay [lots] to upgrade'.*

### Public and private systems

Participants raised inadequacies within the public system. Some comments related to funding for prosthetics, for example, *'government funding for prosthetics is totally inadequate'*. *'Only provides for basic limbs'*. *'People who 'happen to get sick' are significantly disadvantaged compared with those who are compensable'* and *'Being a public patient I feel I am not able to access the best type of prosthetics available'*. Other comments related to the quality of the prosthesis and service within the public system, *'Public provider inadequate'* and *'When I changed over to a privately run prosthetic service I got much better information/service/options'*.

Some participants commented on being rejected for a prosthesis. Examples include an 87 year old and an 18 year old each from a different states. *'We were very disappointed that I didn't get the option to have a prosthesis. I am 87 and in good health I could have managed if I was given a go'*. *'We were never given the option to receive a leg - my son is 18'*. *'They said it was too hard to fit something for him'*. *'Please help us'*.

### Case Study – Mary's story

This story is about Mary who consented to have it included. Mary is a 23 year old woman and is a triple amputee who contracted meningococcal disease. Mary was in hospital for nearly five months, while doctors worked to save her life – as Mary states:

*'The hospital system spent hundreds of thousands of dollars ensuring my survival'. 'I was left with one arm, and no legs'.*

*'Why does the health system bother to put so many resources into keeping me alive when the funding provided for prosthetic limbs is so basic?' 'In order for me to contribute to the economy, (gain university skills), and be independent, I have needed to take a loan in excess of \$50,000 to purchase suitable limbs to regain my independence'. 'I would never have been able to move on with my life with the limbs provided by government funding'.*

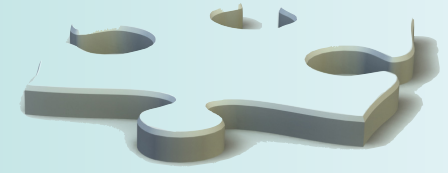
(\*Name has been changed to protect the individual)

### Keeping up to date with advances in prosthetics

An overwhelming 90 percent of participants would like to know more about advances in prosthetics and related products such as water/shower legs and new technology. However, 60 percent said they were not aware of new prosthetic products and aids as they become available. For those keeping up to date, they nominate their prosthetist as the main source of information, followed by the Internet, Limbs 4 Life *Amplified* magazine and website.

This is further evidence that the amputee community has a thirst for information and has a desire to be pro-active in playing a role in maintaining their health and feeling empowered.

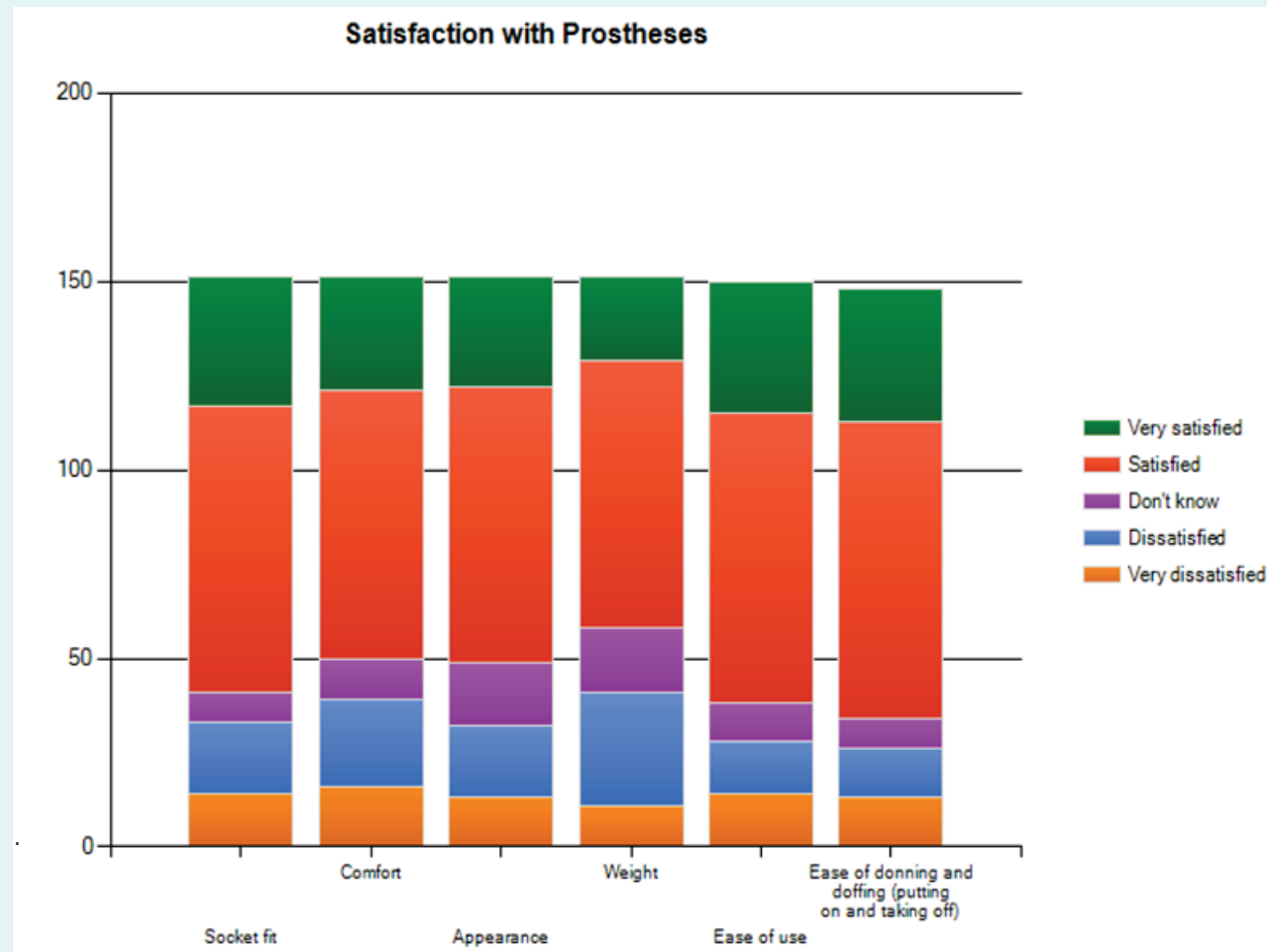
## Survey Findings continued



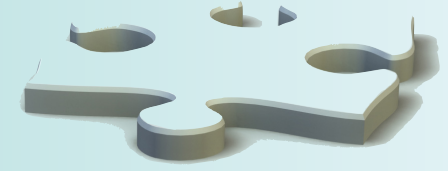
### Satisfaction with Prostheses

Overall the majority of participants were satisfied with their prostheses. However, there were around 20 percent of participants that are neither satisfied nor dissatisfied with aspects of their prosthesis.

86 percent wear their artificial limb every day, while 6.4 percent never wear it. 50 percent wear it for 13-18 hours per day, and 29 percent for 9 to 12 hours per day. Only 3 percent wear their prosthesis between 19 and 24 hours per day. One participant offered this advice for people unhappy with their prostheses: *'My advice to amputees, especially A/K (above knee) amputees is that if you have problems with an uncomfortable leg socket, DON'T blindly accept it'. 'Find a prosthetist who CAN produce a well-fitting socket'. 'It's no accident that I travel interstate for anything to do with my leg!'*







### Resettling at home

A majority of participants did receive support and information to help them prepare to return home. Allied health professionals including occupational therapists, physiotherapists and prosthetists were the most common providers for this assistance. Participants indicated that they were satisfied with the information and support they received.

A number of participants required modifications to their home following discharge from rehabilitation. These modifications most often involved the 'wet areas' such as the bathroom and toilet. In addition, entrances needed to be modified, for example, *'Ramps to replace steps and installed hand rails and grab rails to shower and toilet'*.

Participants reported the costs ranging from \$70 to \$90,000. Only 40 percent received financial assistance most commonly provided by either government or an insurance company. 11 percent paid for the modifications themselves.

Only 18.4 percent of participants require a disability or personal support service to live at home. The vast majority of participants manage their health themselves or with their GP. A Rehabilitation Consultant manages only 16.5 percent of participants' health following discharge.

90 percent were able to continue driving a car, motor bike, truck etc post amputation. 44.5 percent needed vehicle modifications. Costs for these modifications ranged from \$180 to \$4,800. Some participants were unable to continue driving a manual car so traded it for an automatic. Only 19 percent received financial assistance which was provided in a majority of cases by an insurance company.

### Employment

62 percent were employed at the time of the amputation. 51 percent of those kept the same employment. Many participants explained they could not return to their previous role because of their amputation or injury. Some employers were not prepared to accommodate employees' new circumstances, for example, *'After I lost my second leg they put me off, they said that I would be more trouble than I am worth'* and *'Workplace was not prepared to build an extension with a disabled toilet'*.

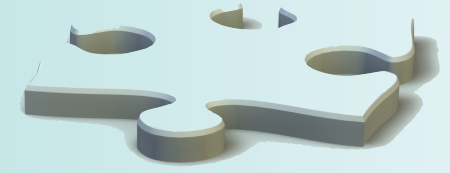
Modifications to workplaces was reported by 22 percent of participants. However, modifications were only undertaken in 20 percent of those instances. 20 percent of participants who sought new or alternative employment post amputation were given assistance which was most commonly provided by Centrelink. Although there was criticism of Centrelink, *'Finding work has been very tough, dealing with Centrelink has been difficult'*.

### Pain

Pain can impact on an individual's ability to undertake daily activities and if left untreated can lead to further disability. Almost two thirds of the participants experienced phantom limb pain *'every now and then'* or *'always'*. Only 16 percent had *'never experienced'* phantom limb pain. On a scale of one to ten with one being extremely mild and ten being extremely intense pain, 46 percent described experiencing this pain as between seven and ten.

Residual limb pain or phantom sensation was felt by 60 percent of participants *'always'* or *'every now and then'*. One third had never experienced phantom sensation. 21 percent recorded the pain intensity being between seven and ten on a scale.

A significant number of participants reported that pain interfered with their ability to do the things they would sometimes like to do.



## Summary

In summary the survey has led to the following conclusions:

- Amputees are a resilient group of people who mostly manage their own health.
- A number of publically funded participants report receiving prosthesis that are not suitable or of sufficient quality.
- Amputees want to speak with and be supported by other amputees during and after their hospital stay.
- Where possible amputees want to return to work and be informed of assistance that is available to them.
- Amputees want access to more information including:
  - living with limb loss
  - details of amputee support groups
  - government programs and assistance
  - advances in prosthetics

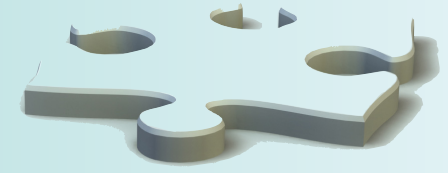
A number of amputees also stated that they are affected by pain and this limits their ability to undertake daily activities.

The single factor that stood out more than any other was that individuals either pre or post amputation wanted access to information and that there was a lack of information, prior to and following an amputation.



South Australian forum participants

# Implementation of Educational Forums



## Educational Forums

Following the collection and analysis of information Limbs 4 Life used the survey data to formulate the public education program. The education and awareness forums would highlight findings of the data and work to fulfill the gaps indicated by participants.

Pilot educational forums were held in Melbourne and Brisbane. Attendees were asked to provide feedback on the pilot forums which would assist with the revision and content of the final program prior to its implementation.

The education and public awareness forums were delivered in a number of capital cities and regional centres throughout Australia. The content for the forums was developed in line with the outcomes from the survey. In addition to this information and in response to participant's requests, Limbs 4 Life engaged the support from industry professionals to assist in the delivery of information.

Greg Strachan BP & O Business Development Manager from Ottobock Australia provided forum attendees with insight into K Class and Mobility grades. These two areas are used to define how prosthetics are rated depending on their functionality and a person's ability to ambulate in the community. These systems are used to choose prosthetic components for individuals, dependent on their level of function.

Matt Henderson works as the Technical Business Manager for Ossur Asia Pacific. He is also a below knee-amputee and certified peer visitor for the Amputee Coalition of America (ACA) and was engaged to provide both personal and professional insight into the forums. Matt gave illustrated examples showing how prosthetics can support 'what has been lost' and the basic differences in prosthetic functionality. He highlighted how different feet can provide significance increases to patient based outcomes, such as energy return and greater stability. Both presenters stayed on to answer questions from the attendees following each session.

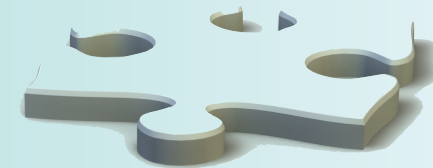
The forums were advertised and well attended in each state and regional centres. Feedback from the forums was generally positive, with participants requesting forums on a regular basis, to enable them to discuss their concerns and opinions and be updated with information and the progression of technology. It was also indicated that spending time with and meeting new amputees was a valuable experience.



Attendees at the QLD, SA and VIC forums



# Thank you



Limbs 4 Life would like to take this opportunity thank individuals and organisations who supported the public education forums and provided assistance in distributing the survey to their members.

Supporters of the Amputees in Motion  
Public Education Project;

Ossur Asia Pacific  
Otto Bock Australia  
Queensland Government  
Queensland Amputee Family and Support Group  
Amputees Far North Queensland (FNQ)  
Harrison Prosthetics & Orthotics  
NSW Amputee Association  
Sydney Amputee Association  
The Northcott Centre  
Repat Hospital Daws Park South Australia  
Orthotics and Prosthetics South Australia  
South Australian Amputee Golf Association  
APC Prosthetics Parramatta  
APC Prosthetics Newcastle