

**AMPUTEES FEDERATION OF
NEW ZEALAND INCORPORATED**

PURPOSE

**Newsletter of the
Amputees Federation of New Zealand Incorporated**



JULY 2010

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EDITORIAL

No. 90 – July 2010

On looking back, I found that it is almost two years since I last wrote the Editorial for *Purpose*. Handing over this responsibility to others who have contributed Guest Editorials has been huge for me, particularly over the last 12 months as I have come to terms with the tremendous loss in my life.

Not all of you will have experienced the loss of someone close, but all of you will have had to deal with the loss of a limb and will know that coming to terms with this and the changed feelings about yourself is not easily done.

The importance of good friends and support at such times cannot be over-emphasised. Peer support comes in many different forms and at various times throughout our lives. Such support can be given by friends, neighbours, family members and others we turn to for help along the way. When faced with a life-altering event such as amputation, a peer with a similar background brings invaluable insight to the new situation.

Amputee Societies are a valuable form of peer support and are a great resource for any amputee, new or experienced. Amputees who are members of an Amputee Society benefit in various ways, but most commonly by the encouragement and companionship provided by fellow amputees. Our National Conference held earlier this year was living testimony to how personal interaction can be so uplifting, inspiring and enjoyable.

Whether you are a new amputee and learning to live with the differences in your life, or an “old hand” who has overcome the hurdles and now just gets on with it, I hope you find it worthwhile to belong to our organisation; we certainly value your support.

Enjoy your read of this issue of *Purpose*.

With Best Wishes

Lorraine Peacock

NEWS FROM THE REGIONS

Auckland & Northland - Representatives of the Society enjoyed the Queenstown conference in March and have photos to prove that Vice President, Lois Mackenzie, bungee jumped. The committee is looking at visiting Whangarei and has asked Northland members to express their interest in such a visit.

Waikato, Bay of Plenty & Districts - An enjoyable day was spent in Ngatea where 17 had lunch at The Copper Kettle, followed by a visit to the Ngatea Water Gardens. The gardens were fully wheelchair accessible and not too strenuous for the walkers.

Hawke's Bay/East Coast - Welcome to new President, James Ward. We look forward to hearing how things are going in the Bay.

Taranaki - Secretary Judy says that they are hoping to increase their membership by having the Limb Centres send out information leaflets to non-member amputees in their area.

Manawatu - The mid winter lunch planned for June was set to be well attended. Of concern in their area is a cut-back of services by the District Health Board and there has already been a public protest march with further events planned.

Wellington Regions & Wairarapa - The AGM scheduled for 11 April had to be cancelled due to the lack of a quorum. We hope that things get up and running again soon.

Nelson & Marlborough - They continue to provide information to new amputees and service providers but would like the assistance of members with arranging meetings and visiting.

Canterbury & Westland - For a mild thrill seeking adventure, Secretary Ava recommends a visit to the Clip'n Climb wall which she managed with a little assistance. At a mid-winter Xmas function on 27 June, Parafed Canterbury was to talk to members about the advantages of regular exercise and participation.

Otago & Southland – Things have quietened down following a busy start to the year - 37 attended the AGM and 20 O/S members were at the Federation's conference in Queenstown. Southland committee members, Wayne & Teresa Vass, successfully promoted the Society at a May Day Expo in Invercargill on 1 May.

Newsletters of District Societies are displayed on the Federation's website (www.af.org.nz), along with plenty of other useful information.

**SUPPORT YOUR DISTRICT AMPUTEE SOCIETY
IT SUPPORTS YOU**

6th ANNUAL CONFERENCE - MARCH 2010

The venue was without doubt a significant factor in this being one of the most successful conferences in recent years. Amputees, partners and friends (approximately 50 in all) gathered at the Copthorne Hotel in Queenstown for a full and productive weekend of business, information sharing and socializing.



The conference was officially opened on the Friday evening with an address by Mr Alan Brady, pioneer of the wine industry in Central Otago. In his talk titled “Visions, Dreams and Making Things Happen”, Mr Brady spoke about his early life as a broadcaster and his later successful venture into the wine-making industry.

*Alan Brady with President Wally
(Photos courtesy of Jane Smith)*

This session was followed by some good open discussion, with District Societies reporting on activities and accomplishments within their regions.

During the business part of the weekend on Saturday morning, the Election of Officers resulted in two new appointments - Simon McMillan as Vice President and Janis Bourne as a Committee member.



On Saturday afternoon, Libby Blackley and Ross James of Adaptive Snowsports gave an interesting talk and visual presentation on the Winter Paralympics and the success of Adam Hall. This was followed by an address from Mr Mervyn Monk,

Chief Executive of the NZ Artificial Limb Board (see next page).

During the dinner on Saturday evening, a presentation was made to Jenny Thompson to mark the conclusion of her 12 year term as the Federation’s nominee on the NZ Artificial Limb Board and on the Sunday morning delegates and observers were treated to a coach sightseeing tour of Queenstown and Arrowtown.

All in all, a successful and enjoyable weekend!

CHALLENGES FACING LIMB SERVICES IN NEW ZEALAND

(A summary of Mervyn Monk’s address to the Federation’s Annual Conference)

It is not quite 12 months since I took up my role as Chief Executive with the NZ Artificial Limb Board, and an interesting 12 months that has been. But before I proceed any further, I would like to acknowledge the work of the previous General Manager of NZALB George Mitchell. George was a greatly experienced practitioner, giving 33 years of service to NZALB, 12 of those years as General Manager. Frankly, one of the things that greatly impressed me when I was considering the prospects of coming to work for the Board was the great wealth of experience and collective talent and skill possessed by this small group of Prosthetists, Technicians, support staff and Board Members. Arguably the limb service provided to amputees in this country is one of the best anywhere in the world; this is not just my opinion. I am not just saying this because I am present at your Conference.

So what makes the limb service in this country this good?

- All amputees can access the service and the service is delivered nationally;
- The service is fully funded;
- The limbs provided are consistent with the needs of the amputee, with regular follow-up easily accessible;
- The service is very well resourced given the number and location of amputees throughout NZ - 5 Limb Centres where full fabrication and repairs are available, often without even an appointment required; and regular Regional Clinics in 12 other locations in NZ.
- The level of staff commitment is simply extraordinary - not only are the staff greatly experienced, they are almost fanatically committed to amputees. I have to tell you, this is now quite unique in allied health and health services generally these days.

So we have much to celebrate! Yes - but also let me share with you what this fresh pair of eyes has also noticed. Three things.

- Firstly, the current service is quite well funded, but NOT necessarily in the best position to meet the new demands of emerging technologies.
- Secondly, there are three different stakeholders with potentially three different objectives.
- Thirdly, there is an opportunity.

FUNDING for the service is largely from two sources: ACC for amputees with limb loss as a result of trauma and MOH for amputees with limb loss as a result of illness and the like.

While these funding streams are provided according to quite different criteria, I am delighted to assure you that each limb is provided according to the amputees need and not according to the source of the funding.

Both these funding sources are unlikely to increase in the next three years and the messages we are hearing everywhere at the moment is “provide more with less”! And so we need to consider how we might remind our stakeholders, and the funders, why it is important to maintain funding levels commensurate with funding needs. I am not for a moment suggesting amputees protesting in the streets for more funding, but I am suggesting the proliferation of “good news” stories - and there are many, as I was indicating before. You are representing an amazing group of people, and clearly not one of you has not had to overcome challenges, the like of which most of us can not really imagine.

Ideas: Keep politicians and Local Authority leaders on your mailing lists; invite them to join your social activities whenever and wherever possible; provide the local newspaper(s) with whatever news you can imagine involving amputees. Everyone likes to be involved with good news or assisting someone in genuine need.

New technology is constantly emerging and many of these new developments are already having, or have had, a positive impact on the provision of limbs, with many limbs lasting a lot longer and limbs being light and yet stronger. Other more advanced technologies are also “available” but clearly cost prohibitive at this time. Hence our need to achieve efficiencies, and show the cost/benefit of providing more of this technology over time.

STAKEHOLDERS - there are three principal stakeholders in the provision of Limb service in this country. They are Government, Amputees and the Board and staff of NZALB - and each of these stakeholders have expectations. Government currently has a financial challenge; the Government expects more “front-line services” for the same or less cost. No additional funding is likely within the next three years, and maybe longer. This does not make the situation any easier, and hence my reference to “good news” stories - the social, economic and personal benefit of amputees having an appropriate limb to met their needs cannot be over-emphasised, and the more that becomes the public perception, the better.

Amputees also have expectations, and you and I both know they are about as many and as varied as there are amputees. The evidence I have seen since commencing in this role suggests that our staff are generally very good at meeting that expectation. That is not to suggest that they could not do better, but the feedback I am receiving is very positive and supportive of the limb service provided. And I can tell you that staff are committed to continuing that support in the best way they can. As technology advances, we are all going to be challenged by the knowledge of some amazing developments in prosthetics, and the impact they may provide for some amputees - the reality and affordability of these developments will clearly be the issue, and a challenge for us all.

STAFF - Amputees and NZALB are both very fortunate in that many of the staff have over twenty years experience with the Limb service. Maintaining the knowledge, professional expertise and interest of these people is obviously a critical factor in the continuing development of our service - and certainly not inexpensive. Currently staff are being supported in undertaking more of their own Continuing Professional Development and this year four Clinical Prosthetists and a Physio will be attending a large International Conference in Leipzig in May. Two other Clinical Prosthetists and the National Prosthetics Manager will be travelling to Australia in April. Attendance at various international forum is seen as essential in maintaining staff knowledge, given they are one of the smallest groups of clinical professionals in NZ.

OPPORTUNITY - Clearly anyone and everyone attending here today, has an opportunity to promote the cause of amputees. They also have the chance to work collaboratively to highlight the potential of amputees, despite whatever the level of limb loss. Equally each and everyone of us can continue to identify how the Limb service in this country can continue to grow by enhancing the opportunities of amputees. Frankly, there is no one solution but many incremental improvements to be made if we are to maximize the future opportunities of amputees. They exist in sport, community, business and education - to mention but just four areas where our energies might best be focused. Ladies and Gentlemen, I do not have the answers here and now, but I can assure you the team at NZALB is committed to achieving positive outcomes for you.

Thank you again for allowing me to talk and meet with you. In closing, I would just like to acknowledge again the work of the Amputees Federation - its leadership and its commitment.

PUBLICATIONS available (no cost) from the National Coordinator or District Society Secretaries

A New Challenge - Advice for New Amputees (a 32 page booklet)

An Ongoing Challenge - A 60 page publication which covers a wide range of topics and includes personal profiles of 10 amputees.

A Challenge with Purpose – A History of the first 50 years of the Amputees Federation of NZ Incorporated (275 pages)

The Amputee Society of Otago & Southland Inc. –The first 60 years (146 pages)

VISIT the Federation’s website at www.af.org.nz It contains a wealth of useful information and “visitors” to the site number around 3,000 every month.

SPORTS MATTERS

Congratulations to the following recent “achievers” from within our ranks:

- 2010 Swimming NZ Awards - Sophie Pascoe (Swimmer of the Year with a Disability)
- 2010 SportConnect Recipients - Paula Tesoriero (Cycling) and Sophie Pascoe (Swimming)
- Alpine Snowboarding - Carl Murphy (Gold in Slalom and Giant Slalom at USASA National Championships)
- British International Disability Swimming Championships in Sheffield - An impressive array of Gold, Silver and Bronze Awards won by Cameron Leslie and Sophie Pascoe
- Australian Athletic Championships in Perth - Kate Horan (Silver in the 200 metres) and Rory McSweeney (Gold in the Men’s Javelin)

(My apologies for any which may have been inadvertently missed - Ed.)

ATTENTION GOLFERS!

There are two tournaments later this year which may be of interest to you.

The 2010 Tournament of Amputee Golf New Zealand
at the Nelson Golf Course on 19-21 October



And the 4th Annual Otto Bock
Victorian Amputee Golf Championship 2010
at Sandhurst, Australia, on 24-26 November

Further details and registration forms available from the Editor

A chip on the shoulder indicates there is wood just a little further up

IS WEARING A PROSTHESIS BAD FOR YOU?

(By Geoff Hill. Reprinted with permission from Limbs 4 Life)

We all know using a prosthesis can be a good thing. Mobility, independence, image, all these things come from being able to use a prosthesis. However, like all good things there is also a cost. Renowned physiotherapist, Robert Gailey*, has reviewed the evidence of what long term physical damage can result.



(Photo courtesy of Matt Buedel)

The heart of the matter is that the human body is well designed to move around, but the design is very complex. So when a change such as amputation occurs there are flow-on effects through the rest of the body. These effects can, over time, contribute to degenerative skeletal and soft tissue conditions.

Most amputees favour their intact leg when walking. This means the force going through their intact leg may be up to 23% greater than their amputated side, a situation not normally found in non-amputees. There is some evidence that the better a person’s prosthesis fits, the less the force difference between the legs, that is, the more normal the situation. A better fitting prosthesis may allow better walking simply by being more comfortable, or by giving better control and feedback on where their limb is. The wearer may walk more confidently.

The theory goes that when a good fit is not maintained the person tends to make a lot of small compensations and adaptations to how they move in order to stay as comfortable as possible. Individually these adaptations may be insignificant but added up they stress the rest of the body and in the long term may cause degenerative arthritis. Certainly studies have found that osteoarthritis is more common in the sound limb than the amputated side in amputees. This may be why amputees often walk slower than non-amputees - they are trying to reduce the forces on their sound limb. Compared to the general population, long term amputees may be up to three times more likely to have knee pain in their intact limb if they have a below knee (BK) amputation, and five times more likely if they are an above knee (AK) amputee. Hip joints also suffer. One study found three to six times more osteoarthritis in the hips of veterans with amputation than veterans without, with above knee amputees being three times more affected than below knees. Interestingly the differences between amputated and intact sides were not clear.

Low bone density, or osteoporosis, is also common in amputees. Commonly the tibia (shinbone) of BK amputees and femur (thighbone) of AK amputees has reduced bone density. As bone tends to work on a “use it or lose it” basis, this is probably due to the bone carrying less force than is usual as it is no longer transmitting weight directly down to the foot. However, for the same reason, this is rarely a problem. Possibly more significantly AK amputees often have reduced bone density in the neck of the femur, the bone involved in breaking your hip. Whether this is due to reduced forces through the femur, reduced activation of the hip when walking or reduced exercise is not known. There is no clear evidence that amputees are more likely to break their hip if they fall than non-amputees. Back pain is common throughout the community, but even more common in the amputee community. Some studies suggest over 60% of amputees suffer moderate to severe back pain. Of course, some of these would have had back pain anyway, regardless of their amputation. It might seem obvious that the uneven loading and altered way of walking of amputees would contribute to back pain, but this is unproven. However it does seem to be musculoskeletal imbalances that may cause back pain with differences in back muscle strength and endurance being important. This is probably one of the flow-on effects caused by amputation mentioned earlier and is different to the osteoarthritis issues that affect the knee and hip.

Most of these things are subtle and hard to change. One factor that can be controlled is having the correct height in the prosthesis. If your prosthesis is of a different length than your intact limb then your pelvis will be tilted and may be twisted, contributing to back pain. It may also cause the spine to curve higher up (compensatory scoliosis) as the body tries to rebalance itself. As little as 5mm prosthetic shortening for BK’s and 10mm for AK’s can cause this compensatory scoliosis.



You would expect that a poorly aligned prosthesis would cause more problems than a well aligned one. Certainly day to day observation would seem to support this. However, while alignment changes can be shown to change the forces through the amputated limb, there appears to be a wide range of alignments at which people feel comfortable. As the physical problems we are looking at here take a long time to develop it is hard to link them to a particular alignment, as most people will have a number of prostheses each with different characteristics over this time. It is more important that you are comfortable with how your prosthesis is set up.

So what does this mean for someone using a prosthesis now? Firstly, keep things in perspective. Most people have an amputation quite late in their life, while the studies here looked at changes that have occurred over several decades. If you are a fairly recent amputee these degenerative changes are a long way off. Secondly, there is little evidence that the amount or type of activity done has much affect on the progression of these changes – so don’t stop doing things. Thirdly, it is thought that if good habits are learned in the early stages of using a prosthesis by doing gait training and physio there are long term physical benefits. These activities are now much more common and easier to access than they used to be. Make use of them. Lastly, work with your prosthetist and doctor to get the most out of your prosthesis.

** Review of secondary physical conditions associated with lower-limb amputation and long-term prosthesis use. Journal of Rehabilitation Research and Development, Vol.45(1), 2008.*

HALF MAN - HALF PRICE STORE

The Story of Peng Shuilin

In life we keep complaining about what is or why we don’t have. Half the time we seem dissatisfied, though full-bodied and free to choose. Fat people say “I want to be slim.” Skinny people say “I want to be fatter.” Poor people want to be rich and rich are never satisfied with what they have.

PENG Shuilin is 78cms high. He was born in Hunan Province, China. In 1995, in Shenzhen, a freight truck sliced his body in half. His lower body and legs were beyond repair. Surgeons sewed up his torso. Peng Shuilin, 37, spent nearly two years in hospital in Shenzhen, southern China, undergoing a series of operations to re-route nearly every major organ or system inside his body. Peng kept exercising his arms, building up strength, washing his face and brushing his teeth. He survived against all odds.



Now Peng Shulin has astounded doctors by learning to walk again after a decade. Considering Peng’s plight, doctors at the China Rehabilitation Research Centre in Beijing devised an ingenious way to allow him to walk on his own, creating a sophisticated egg cup-like casing to hold his body, with two bionic legs attached.

(cont. next page)

It took careful consideration, skilled measurement and technical expertise. Peng has been walking the corridors of Beijing Rehabilitation Centre with the aid of his specially adapted legs and a resized walking frame. RGO is a reciprocating gait orthosis, attached to a prosthetic socket bucket. There is a cable attached to both legs so when one goes forward, the other goes backwards. Rock to the side, add a bit of a twist and the leg without the weight on it advances, while the other one stays still, giving a highly inefficient way of ambulation. Oh so satisfying to 'walk' again after ten years with half a body! Hospital vice-president Lin Liu said: "We've just given him a check-up; he is fitter than most men his age."

Peng Shuilin has opened his own bargain supermarket called the Half Man-Half Price Store. The inspirational 37-year-old has become a businessman and is used as a role model for other amputees. At just 2ft 7ins tall, he moves around in a wheelchair giving lectures on recovery from disability. His attitude is amazing, he doesn't complain. "He had good care, but his secret is cheerfulness. Nothing ever gets him down." His life is a feat of endurance, a triumph of the human spirit in overcoming extreme adversity.

TRAUMATIC NEUROMAS

(Reprinted from inMotion Vol.20 Issue 2)

Nerves have a remarkable ability to regenerate and repair themselves after injury. Surgeons use this to their advantage when repairing transected (surgically severed) nerves via direct end-to-end attachment, nerve grafting or by using neural tunnels to guide the regenerating neurons to rejoin with the severed segment. On the other hand, stump neuromas are characterized by disorganized architecture with nerve tissue growing out in various directions, leading to a bulb-shaped thickening or "stump." The formation of a stump neuroma is a natural occurrence after nerve injury; however, not all neuromas are painful. The incidence of painful neuromas is thought to be between 10 to 30 percent. It is unclear why some are painful and others are not, but it most likely relates to the area and tissue into which the nerve regenerates. If the neuroma is located well above the end of the residual limb and is buried in adequate soft tissue, pressure and traction are unlikely to produce any local pain. Moreover, large neuromas located near the surface of the skin may not be painful when covered by a carefully fitted prosthetic socket. The pressure of the socket wall can be so well-distributed over a large surface area of the residual limb that no pain is felt at the neuroma site. If the socket does niggle discomfort, adjusting the socket will generally relieve the pain.

Pain from neuromas often varies in intensity and duration, and is described as aching, "cramping or shooting. Conservative measures are usually adequate for treatment. These include physical modalities (treatment methods), medicine and neurolysis

(temporary destruction of nerves for pain relief). However, if these fail, one should consider surgical intervention.

Physical modalities used to treat limb pain due to neuroma include ultrasound, massage, vibration, percussion, transcutaneous electrical nerve stimulation (TENS) and acupuncture, as well as modification of the prosthetic socket for pressure relief. Most physical modalities have had varying success in reducing pain.

Medical Interventions - Injection therapy can be a useful method for treating neuromas. Corticosteroids are widely accessible and are the most common injectable. However, overuse of injected steroids can lead to a number of side effects, including weight gain and high blood pressure, so patients usually receive only a limited number of injections. Other medical interventions for limb pain resulting from neuromas include nonsteroidal anti-inflammatory drugs, tricyclic antidepressants, and anticonvulsants. These treatments have had limited success. Most other medicine regimes have been the subject of sporadic case studies and have not been shown to be effective.

Neurolysis - Minimally invasive neurolysis with the use of cryo (freezing of the nerve) nerve blocks has been shown to be effective in pain control for neuromas. Radiofrequency neurolysis is effective but difficult to perform in many cases. Neurolysis is usually effective for 3 to 5 months, with longer results reported on repeated procedures.

Surgical Treatment - Large neuromas buried in a scar or located in an exposed position may be so painful that the amputee is severely impaired. Although surgical removal is the treatment of choice in these cases, this technique has failed to yield uniform results. Pain relief is often temporary due to the eventual development of a new neuroma. Most surgical treatments are geared toward reducing the abnormal interaction between regenerating nerves and surrounding connective tissue. Although multiple techniques are available for limiting regrowth, possibly the simplest procedure is to relocate the nerve. When possible, the surgeon will relocate the nerve away from weight-bearing areas and toward locations that will minimize pressure. Ideally, the surgeon will attempt to discourage regrowth at the end of the nerve. Although there is nothing clinically available that stops nerve regeneration completely, there have been many studies exploring techniques to minimize this. Surgeons have used epineural sleeves for many years with good success. Nerve capping has also had varying success. Various silicone caps are most popular, with success rates averaging at 70 percent. Nerve transplantation into local veins has garnered attention recently in attempting to slow down nerve regrowth. Transplanting the nerve into a vein has proven clinically effective in both upper and lower extremity neuromas. Researchers have also described using local bone or muscle as a transplant medium with good success in most locations throughout the body. Although both techniques yielded good results, implantation into bone was considered superior.

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**REMEMBER THAT YOU'RE NOT THE
FIRST PERSON TO HAVE LOST A LIMB -
MANY OTHERS HAVE PASSED ALONG
THE SAME ROUTE AND ACHIEVED
CONSPICUOUS SUCCESS.
IF YOU WISH TO DO THE SAME,
YOU ARE MORE THAN HALF-WAY THERE -
THE REMAINDER IS AS EASY OR AS
DIFFICULT AS YOU MAKE IT.**