

Kia Kaha - BE STRONG
COPING WITH AMPUTATION
A Manual for the New Amputee

**Published by the New Zealand Artificial Limb Board for
the assistance of amputees and their support people**

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1. FOREWORD

In their own words

Hepi Maxwell, 19/01/1950, Rotorua

“I have had both legs amputated, one at the knee and one just above, as the result of a truck accident in 1974. The fitters at the Artificial Limb Centre in Hamilton are long suffering and very patient. I drive a hand controlled car, have peace of mind knowing I can support my family with my jade carving and have the encouragement of my family and friends. I have had a good run from the Limb Centre and am content with myself, knowing they have done all they can for me.”

Margaret Wilson, Tauranga

Margaret Wilson became an amputee after developing cancer in the knee of her left leg when she was 16.

“My leg was amputated above the knee and I suffered the pain and difficulty associated with that. You have no choice but to get on and learn to live with it - and that is what I have tried to do. I was lucky in that I had a good education and was the first member of my family to go to university. I was driven by the need to look after myself financially and my education and enjoyment of law has allowed me to do a variety of things. In 1990 I went to Waikato University to set up the school of law there. Prior to that I lectured in law at Auckland University. The Artificial Limb Centres have been superb and I have received excellent assistance from them. I don't dwell on my disability - I get on with life.”

2. INTRODUCTION

The prospect of amputation can be an immensely daunting one.

Where amputation results from illness, there is often a history of pain and a battle to save the limb. For accident victims, their first knowledge of this drastic change to the order of their lives may be in the post-operative ward as the fog of anaesthesia clears.

Either way, the loss of a limb can bring shock and grief.

Modern medicine, surgery and rehabilitation procedures give the amputee every chance and hope of a return to a relatively normal pattern of life. We also live in a country which cares for those with disabilities and doesn't attach a stigma to those with a disability.

For the amputee, however, the toughest battle is often in the mind.

This booklet has been written to give new amputees, and those facing the prospect of losing a limb, a guide to understanding their new state and preparing physically and mentally to cope.

It isn't intended to be an encyclopaedia on amputation, or substitute for the medical and personal advice and support of health professionals, family and friends. But we hope it's a useful start.... If it isn't, we trust you will write to us and let us know how we could improve it for future editions!

The Editors
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3. AMPUTATION - THE FACTS

About 1 person in 1,000 in New Zealand has lost a limb; that's around 4,300 amputees living in our communities.

Amputations result from two main causes: diseases such as diabetes or peripheral vascular disease; and accidents, particularly traffic accidents, but also industrial and farm accidents.

Where disease is the cause, amputation is often necessary to save the person's life.

People with congenital disorders or birth defects, where one or more limbs are not fully developed, are not amputees in the full sense, but they do face similar difficulties and challenges.

There are four main types of amputation:

- removal of the arm above the elbow (transhumeral amputation)
- removal of the arm below the elbow (trans-radial)
- removal of the leg above the knee (trans-femoral)
- removal of the leg below the knee (trans-tibial).

4. THE FIRST DAYS

Surgery

New Zealand surgeons amputate only when there is no way to save the limb, or where removing a limb is necessary to save a life, as in the case of a serious disease like advanced diabetes.

When they do amputate, our surgeons do so skilfully and safely and with the fitting of a prosthesis in mind.

Post-surgery

Hospital staff may initially use a rigid dressing to reduce swelling of the stump, prior to preparing for the fitting of a prosthesis. Immediately following amputation a dressing is applied and the stump bandaged.

Bandaging

An elastic bandage (usually an Elset bandage) is applied, or sometimes a “stump shrinker” (an elastic sock) is used to serve the same purpose. The elastic bandage controls the swelling in the stump, and shapes it so that it is well formed and suitable for a prosthesis. It also reduces the inability to straighten joints, which is known as flexion.

The ways of bandaging a stump differ slightly according to the type of amputation, and at the outset of your rehabilitation, a physiotherapist will show you the right way to bandage your stump.

To assist you, a guide to the bandaging techniques suitable for your particular amputation may be seen under “Resources” on this website.

Some basic points to remember about bandaging any stump are:

- Every stump bandage is “anchored” by taking turns above the next highest joint.
- Apart from the anchoring turns and the turns around the tip of the stump (which are circular), all the bandaging should be diagonal and spiralling.
- The only turns applied under tension (tightly) are those towards the end of the stump to taper the stump. The anchoring turns in particular must be loose - they are intended to anchor not constrict.
- If a bandage is tending to slip off, the anchoring turns can become tight and constricting, causing pain in the stump. You don't have to put up with that pain. The bandage should be removed and reapplied.
- It is very hard for an amputee to bandage an above-knee or above-elbow stump himself or herself. A carer (such as a family member) needs to be trained to do it.
- Bandaging a below-elbow stump yourself can be difficult, but most below-knee amputees learn to bandage well on their own.

Pain

Like any operation, an amputation will be followed by some degree of pain till the wound heals. Most amputees, however, report that the post-operative discomfort was less severe than expected. In many cases the pain experienced in a diseased limb before it is removed can be considerably greater than the pain experienced after the operation.

But there are some particular and unique types of pain and unusual sensations which may be experienced by amputees. These are discussed more fully, along with ways of coping with them, in section 5.

Prosthetics

A prosthesis is the medical term for an artificial body part.

Prosthetics is the science of making and fitting prostheses.

All amputees have the right to be assessed for provision of a prosthesis under the New Zealand health system.

After your operation, hospital staff will arrange for you to visit a Limb Centre where a team, including a clinical prosthetist, will identify the right prosthesis for you. The prosthetist and a physiotherapist will train you to use it. The timing of this referral will depend on your particular circumstances - including your general health and the condition of your stump. But the visit will generally be arranged for some time between three and six weeks after the amputation.

The processes around assessment for a prosthesis, its fitting and training in its use and maintenance are covered in section 6.

Looking after yourself

A stump presents an entirely new surface of the body to care for. Stump hygiene is particularly important since your stump will spend a good deal of time in close contact with a prosthesis.

Some hygiene guidelines:

- wash the stump daily with a mild or anti-bacterial soap
- rinse the soap residue off the stump and dry it carefully
- do not use oils, creams or talcum powder unless advised by your clinical prosthetist
- change your stump socks daily
- inspect the stump at least daily, and more often if it is sore. Use a hand mirror so you can see all of it
- if you notice any skin loss, soreness or signs of infection (such as inflammation) in the stump, contact your clinical prosthetist as soon as possible. If you are a diabetic, it is important that you take special care of your other limb as well.

The guidelines are:

- inspect that other limb daily

- wash the foot carefully, dry it thoroughly and inspect between the toes
- don't use talcum powder as it can be abrasive on tender skin
- if the skin looks dry, apply a bland oil or moisturiser
- keep your toenails trimmed, and if you have difficult nails - thick, brittle or in-growing - arrange to see a podiatrist
- if you notice any skin loss, blisters or infection on your other limb contact your doctor promptly.

Depression

It is quite natural for amputees to experience some degree of depression after surgery. However, for those who have experienced intense pain in a limb leading up to the operation, this is not so frequent.

Depression can be treated and should be discussed with your health professionals. Friends and family, of course, are also important in helping you adjust to your new circumstances.

Physiotherapy and exercise

Loss of a limb can clearly restrict or curtail the amount of physical activity you can participate in.

The good news, however, is that for many people a properly fitted, well maintained prosthesis can be less inhibiting to their mobility than imagined.

Learning and maintaining a daily routine of exercises is really important, to ensure that muscle strength is kept up and mobility of joints is retained.

If you are a leg amputee, see the exercises listed under Resources on this website.

Your allies

A number of medical and community care professionals will be involved in your rehabilitation:

- your doctor, who will be there to assist with any general health matters associated with your amputation
- the team at the LIMB CENTRE, including the orthopaedic surgeon, the clinical prosthetist (responsible for fitting the

prosthesis) and the physiotherapist (who looks after your exercise regime and training)

- Work and Income NZ (WINZ) can advise on what financial support is available
- your local District Health Board, whose Disability Support Services staff can advise on other services and benefits which may be available
- Your ACC case manager can advise on entitlements covering prosthesis, rehabilitation and back to work issues
- the Amputee Society, which is an organisation of fellow amputees and carries out a number of activities on their behalf
- the Health and Disability Services advocacy service (see under Your Rights).

Details of your local contacts are available on this website.

5. PROSTHESIS - YOUR NEW LIMB

As noted earlier, “prosthesis” is a term to describe an artificial limb.

Every amputee automatically qualifies for referral to a Limb Centre where the prosthetic team assesses the amputee’s requirements and arranges for the prosthesis to be fitted, along with training in its use.

Your first visit will be to a clinic where you meet with an orthopaedic surgeon, a clinical prosthetist and a physiotherapist. This team will develop a prosthetic management plan and discuss it with you.

Your prosthesis will become a valuable part for returning you as near to your normal life as possible. It’s important that you work closely with your prosthetic team to develop a prosthesis that suits you.

This will mean fully discussing your daily activities, goals and needs, with your clinical prosthetist. You should make an appointment to see your clinical prosthetist if at any stage you wish to discuss any problems or issues concerning your prosthesis.

You should also advise the Limb Centre if you change your address or phone number.

Prosthetic principles

The prosthesis is designed to:

- fit and function as comfortably as possible
- provide maximum mobility

- allow maximum involvement in a normal lifestyle.

A number of factors determine the choice of a prosthesis (these factors can alter over time dependent on age, weight, activity and lifestyle):

- the shape and condition of your stump
- your overall physical condition
- your lifestyle and level of activity.

Making a prosthesis

Most modern prostheses are made from a combination of modular components. There is a broad variety of prosthetic feet, ankle joints, knee joints, elbows, split hooks and hands to choose from, each with special characteristics to suit individual needs and circumstances.

A prosthesis can either have a hard outer shell made of laminated material (an exoskeletal) or gain its strength from an internal metal frame (an endoskeletal).

Both types have a socket which fits your stump. This is formed from a mould of your stump made from plaster of Paris bandage or a digital image with Tracer CAD.

The prosthetist then modifies the mould to allow for weight-bearing requirements, but also to ensure comfort and stability in the socket - particularly taking the bony areas of your stump into account.

The mould is then used to create a socket out of plastic material - this is the socket you try on at the first fitting. It is mounted on an adjustable alignment jig to enable the prosthetist to align it correctly for walking. Following this, the prosthesis is ready for the final touches.

The whole process may take about three weeks, involving two or three visits to the Limb Centre.

For first time amputees, it's important to make a follow-up appointment after receiving your prosthesis to ensure the fit is maintained - minor adjustments are often required in the first few weeks.

Straps

The straps on your prosthesis are part of a suspension system that helps keep the prosthesis fitting snugly on your stump. It is important to keep these straps done up firmly to reduce "pistoning" (the

tendency for the prosthesis to slide up and down your stump) which can lead to skin abrasion.

Shoes

Leg amputees often have problems in choosing shoes.

A large and varied range of prosthetic feet is available and these are selected to suit your individual requirements, ie. the height of the heel can be selected to suit you personally.

Once you set the heel height, of course all other shoes you wear on both feet must have that same heel height. Difficulties can be experienced if either heel is too low or too high.

As a new amputee you should choose shoes which are:

- comfortable - ones you will wear most of the time
- lightweight
- virtually new and preferably unworn
- preferably high-cut, ie T-bar, ankle strap or easily adjustable (laces, velcro or straps).

Stump socks

Stump socks are a key accessory to the prosthesis.

Stump socks do two important things:

- they maintain comfort in the prosthesis. Extra socks or sock thicknesses are used to make up for any stump shrinkage over time, thus maintaining a proper fit
- they remove sweat from the skin, ensuring dampness and rubbing does not damage the skin and cause abrasion.

They come in various sizes and thicknesses, and several will be given to you when you get your first prosthesis.

Clean socks should be used every day. They have a limited life, however, and new ones can be obtained free from the Limb Centre.

It's worth noting down the sizes of socks issued to you, in the personal information page (inside front cover of this booklet).

Prosthesis care

Your prosthesis is like any piece of equipment - it's important to keep it clean and in good working condition or it will not work well for you.

If your prosthesis has a plastic socket it should be cleaned by wiping first with a damp, soapy cloth, rinsed by wiping with a clean damp cloth and then dried using a dry cloth.

It should never be immersed in water.

Do not adjust any of the screws, joints or other parts of the prosthesis unless you have been shown how to do this by your clinical prosthetist.

It's a good idea to arrange an appointment with your clinical prosthetist every six months to have your prosthesis checked.

Learning to use the prosthesis

During the initial fitting period, your clinical prosthetist will show you the basic principles for using your prosthesis, as well as fine-tuning it and aligning it as necessary for your particular circumstances.

Your physiotherapist will then provide the extensive training needed, especially by lower extremity amputees, to get used to it. This includes assistance with daily actions such as walking on different surfaces, climbing stairs and ramps and getting in and out of vehicles.

Upper extremity (arm) amputees will receive training to perform daily activities such as dressing, eating and handling objects.

You may undergo this training as an in-patient (while you stay at the hospital) or later as an out-patient attending day clinics.

Weight gain

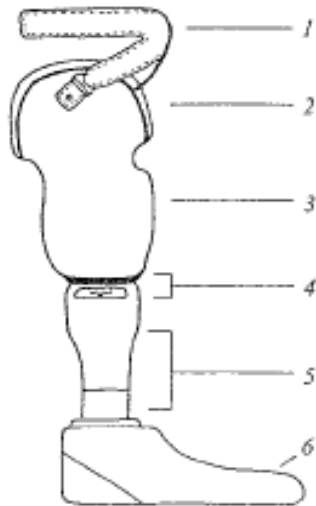
Variations in weight (especially gaining weight) is one of the biggest problems amputees face in getting good performance and maximum comfort out of their new prosthesis.

Fluctuations in body weight are reflected in the stump, resulting in poor fit, discomfort and difficulty in using the prosthesis. A reduction in the stump size can be accommodated by adjusting the socket, but the clinical prosthetist can do little to expand the socket size. Almost any increase in stump size will mean a new prosthesis has to be made. Significant weight gain can put additional stress on selected componentry and create a dangerous situation.

A sensible diet and reasonable exercise programme are therefore important in minimising this problem and allowing you to gain optimum performance from the prosthesis.

The Prosthesis

Trans-tibial Prosthesis (Below Knee)



1. The Strap (alternatively a sleeve)

To hold the prosthesis on.

2. The Liner

Soft insert for shock absorbing.

3. The Socket

Custom made to fit the amputee and distribute weight.

4. The Alignment Unit

Used to move the foot for optimal walking.

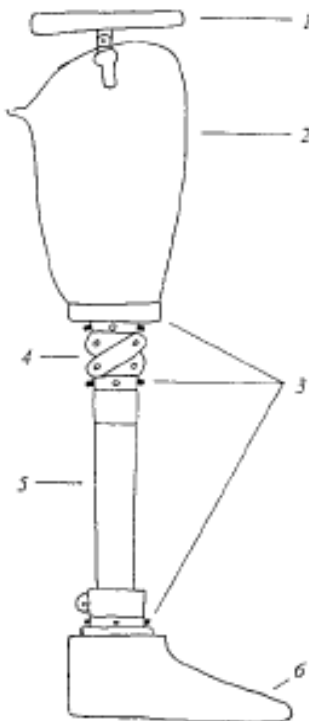
5. The Pylon

Distributes weight from socket to the foot.

6. The Foot

Made to imitate normal foot function.

Trans-femoral Prosthesis (Above Knee)



1. The Pelvic Band/Suspension Strap (alternatively a suction socket).

To hold the prosthesis on.

2. The socket

Custom made to fit the amputee and distribute weight.

3. The Alignment Units

Used by the prosthetist to alter the position of the knee and foot for optimal walking.

4. The Knee

Bends for sitting and swinging, but extends for standing and walking.

There are 3 basic knee types - locked, safety and free.

5. The Pylon

Distributes weight from the socket to the foot.

6. The Foot

Made to imitate normal foot action.

6. PAIN AND SENSATIONS - UNDERSTANDING AND COPING

Any surgical operation will be followed by a period of pain as the wound heals. Modern medicine provides several effective ways to cope with that pain till it subsides.

Amputees, however, can experience pains or sensations that are unique to them:

- phantom sensations
- phantom pain
- stump pain.

Phantom sensations

Most amputees experience a sensation as though the amputated limb is still there. This can happen after the operation or at any stage later on. It is felt as tingling, itching or the sensation of movement in the non-existing limb. It arises from spontaneous impulses in the nerves which have been cut in the course of amputation.

Phantom pain

A smaller number of amputees experience what is known as phantom pain, which happens in short bursts and is often described as sharp squeezing, burning or “electric shock”.

Phantom pain is not fully understood, but factors believed to be involved include the presence of persistent pain in the limb before it was amputated, and emotional stress.

Stump pain

Stump pain is a different condition and is felt in the stump itself. It usually has a local cause, and your doctor or clinical prosthetist should be advised as soon as possible.

Coping with pain

Apart from the medical treatments for pain of varying degrees, such as painkillers, analgesics and stronger drugs, pain can be reduced and managed in a number of ways:

- massage
- acupuncture
- certain prescription medications
- heat treatment
- treatment using a Trans-cutaneous Electrical Nerve

Stimulation unit (TENS)

TENS treatment

The TENS machine is used to reduce pain through the application of very mild electrical impulses to stimulate certain nerve endings. A TENS unit is available via your Limb Centre.

7. QUESTIONS AND ANSWERS

Q1 How long will it take me to use my prosthesis successfully and return to a normal daily routine?

A The pace of rehabilitation is different for every amputee. It depends on overall physical health, muscular strength and personal motivation. Generally within a few weeks after beginning prosthetic training, you should be able to accomplish most of your routine daily tasks.

Q2 Will I be able to return to work?

A Many amputees can return to their current jobs without any difficulty. Others may need to alter their duties within their occupation or change jobs completely. It is important to talk with your employer about any changes to your ability to do your job.

Q3 How much will the prosthesis cost?

A In general, prostheses are free to New Zealand citizens and permanent residents. Special prostheses required for vocational and recreation purposes may be available under certain circumstances and can always be supplied at the amputee's own expense.

Q4 Will I be able to drive a car?

A Driving presents minimal problems for most amputees. Depending on the type of amputation, you may require an adaptive device for your car. Leg amputees may choose to have a left foot accelerator pedal or hand controls installed. An automatic car with power steering will benefit both upper and lower extremity amputees. If in doubt seek advice, an assessment can be arranged for you.

Q5 May I get my prosthesis wet? May I swim wearing the prosthesis?

A Your prosthesis is not designed to cope with excessive water. The water may damage the various components, although getting caught in the rain for a few minutes will not damage the prosthesis. Salt water

is extremely corrosive to the components of your prosthesis and must be avoided. If you are involved with water sports please talk to your clinical prosthetist regarding options available.

Q6 What type of shoes should I wear with my prostheses?

A See Prosthetic feet.

Q7 How often will I have to see my clinical prosthetist?

A During the initial fitting and training period you will probably see your clinical prosthetist several times. Follow-up appointments will be made by him or her. If you are having problems do not hesitate to contact them for an appointment.

Q8 How long will my prosthesis last?

A Your primary (first) prosthesis will need replacing within 12 months and possibly as soon as three months. Changes in the shape of the stump due to shrinkage make this necessary. Your second prosthesis should last considerably longer provided you take proper care of it and have it checked every six months by your Clinical Prosthetist.

The fit of your prosthesis is significantly affected by weight gain or loss. Changes in your weight will require adjustments to be made to your prosthesis, and in some cases may require a complete replacement.

If your prosthesis causes you pain or skin irritation, contact your Clinical Prosthetist, who will know how to advise you.

Q9 Are there any organisations for amputees?

A The Amputee Federation of New Zealand has branches throughout the country.

The Limb Centre that you visit initially will be able to provide the name of the contact person.

Q10 How should I deal with people who stare at me or ask me questions about my missing limb?

A First of all, remember that most people look a second or third time at any person who looks "different" for any reason. This usually stems

from curiosity, not one of pity or “making fun”. People may ask about your amputation or prosthesis, generally once again out of curiosity or interest.

If you have any further questions, please do not hesitate to ask your clinical prosthetist. He/she has had many years of experience and should be able to help you.

8. YOUR RIGHTS

Your rights when receiving Health and Disability Services:

1. **Respect.** You should always be treated with respect. This includes respect for your culture, values and beliefs, as well as your right to personal privacy.
2. **Fair treatment.** No one should discriminate against you, pressure you into something you do not want or take advantage of you in any way.
3. **Dignity and independence.** Services should support you to live a dignified, independent life.
4. **Proper standards.** You have the right to be treated with care and skill, and to receive services that reflect your needs. All those involved in your care should work together for you.
5. **Communication.** You have the right to be listened to, understood and receive information in whatever way you need. When it is necessary and practicable an interpreter should be available.
6. **Information.** You have the right to have your condition explained and be told what your choices are. This includes how long you may have to wait, an estimate of any costs, and likely benefits and side effects. You can ask any questions to help you be fully informed.
7. **It's Your Decision.** It is up to you to decide. You can say no or change your mind at any time.
8. **Support.** You have the right to have someone with you to give you support in most circumstances.
9. **Teaching and research.** All these rights also apply when taking part in teaching and research.

10. **Complaints.** It is okay to complain – your complaint helps improve services. It must be easy for you to make a complaint, and it should not have an adverse effect on the way you are treated.

All Limb Centres have a complaints process in place, details of which are available on request.

Rights when visiting a Limb Centre - You have the right to request a private consultation with any person providing a service to you, eg the prosthetist or surgeon.

Everyone using a health or disability service has the protection, of the Code of Health and Disability Services Consumers Rights. If you are unhappy about the service you have received, you may take your concerns directly to the person or organisation that provided the service. If you want support to do this, a free advocacy service is available to help you.

Phone 0800-11 22 33 for contact details of your local advocacy service.

9. GLOSSARY OF TERMS

Alignment - The adjustment of the relationship of the socket to the foot to provide optimum comfort and the best possible function.

Amputation site - The actual site or level where the amputation has or will be performed.

Artificial Limb Centre - A clinic for treating amputees and where prostheses are prescribed and manufactured.

A/E Above Elbow or trans-humeral amputation

A/K Above Knee or trans-femoral

B/E Below Elbow or trans-radial

B/K Below Knee or trans-tibial

Check Fit Socket - A clear plastic socket from which the prosthetist will be able to determine the accuracy of the socket fit.

Clinical Prosthetist - A person trained in the fitting, fabrication, aligning and repair of a prosthesis.

Contracture - a contracture of tissue, usually muscle, tendon or joint capsule, which limits the range of movement of a joint. Joint cannot be straightened.

Cosmetic Cover - A shaped foam which covers the internal structure of the prosthesis.

Cosmetic Hand - A terminal device which provides a cosmetic replacement. They are usually non-functional or passive.

Cuff - Strap used to suspend a Below Knee prosthesis.

Disarticulation - Amputation through a joint.

Extension - The straightening of a joint.

Flexion - The bending of a joint.

Gait - The process of walking.

Jig - A device used by a clinical prosthetist to assist in the process of alignment of a prosthesis during manufacture.

Jig (Walking) - an adjustable jig which allows the Clinical prosthetist to try variations of alignment during prosthetic fitting, used at the stage when walking alignment is being built into the prosthesis.

Liner - A soft flexible lining insert worn between the stump and the socket.

Modular (endoskeletal) prosthesis - A prosthesis with an internal rigid structure and an external foam cover.

Oedema or Edema - Swelling of the limb, usually due to excessive accumulation of fluid.

Orthopaedic Surgeon - A surgeon trained in disorders of bone and joint, muscle and nerve, with a particular interest in correcting gait.

Parallel bars - Two parallel bars at palm height between which an amputee can walk during gait training.

Phantom limb - Awareness of the part of the limb which is missing.

Phantom pain - Pain felt in the phantom limb.

Plaster cast - The application of a plaster bandage to produce a cast or replica of the stump.

Pressure area - An area of tender or broken skin caused by pressure.

Limb Centre (Artificial Limb Centre) - A clinic for treating amputees and where prostheses are prescribed and manufactured.

Prosthesis - Artificial limb.

PTB - Patella Tendon Bearing prosthesis - attached by a cuff.

KBM - Modified Supra-condylar prosthesis - selfsuspending.

PTS - Patella Tendon Supra-condylar prosthesis - selfsuspending.

Range of movement - The distance a joint can be moved in its various directions.

Rigid Removable Dressing - A removable cast applied to the below knee stump to protect and shape the stump.

SACH foot - Solid Ankle Cushion Heel prosthetic foot.

Socket - A hollow replica of the stump which provides an interface between the body and the prosthesis.

Split hook - A functional steel or aluminium terminal device for the upper extremity prosthesis.

Stump/residual limb - Remaining part of arm or leg following amputation.

Stump sock - A protective sock to be used when wearing a prosthesis. They are made of various materials, the commonest being wool.

Stump pain - Pain felt in the stump (residual limb).

Suction socket - A socket which requires no external suspension as it is held in place by total contact adhesion.

Surgeon - A doctor who specialises in operative treatment.

Suspension - Harness or device which holds a prosthesis on.

Supercondylar - Above the condyle (which is the widest part of the knee joint)

Vascular surgeon - A surgeon specialising in operative treatment of blood vessel disease.

10. FURTHER INFORMATION

Video material available

- Zac's Story
- There's Nothing You Can't Do
- Other various in-service videos

Publications and Internet Sites

Consult your local centre regarding the various options available. They will best advise you on what material most suits your particular needs.

Auckland - <http://www.nzalb.govt.nz/auckland.html>

Hamilton - <http://www.nzalb.govt.nz/hamilton.html>

Wellington - <http://www.nzalb.govt.nz/wellington.html>

Christchurch - <http://www.nzalb.govt.nz/christchurch.html>

Dunedin - <http://www.nzalb.govt.nz/dunedin.html>