APRACTICAL GUIDES MANPUTEES



limbs 4 life



Mission: To provide information and support to amputees, their families and primary care-givers while promoting an inclusive community.

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Introduction

In Australia people face the challenges associated with limb loss every day.

In fact, every three hours a limb is lost due to diabetes(1), and it is the most common cause of non-traumatic amputations in this country.

Some people lose limbs due to vascular disease or cancer, while other individuals face limb loss as a result of accidents and infection. Regardless of the cause, amputation is life changing for each individual and their family.

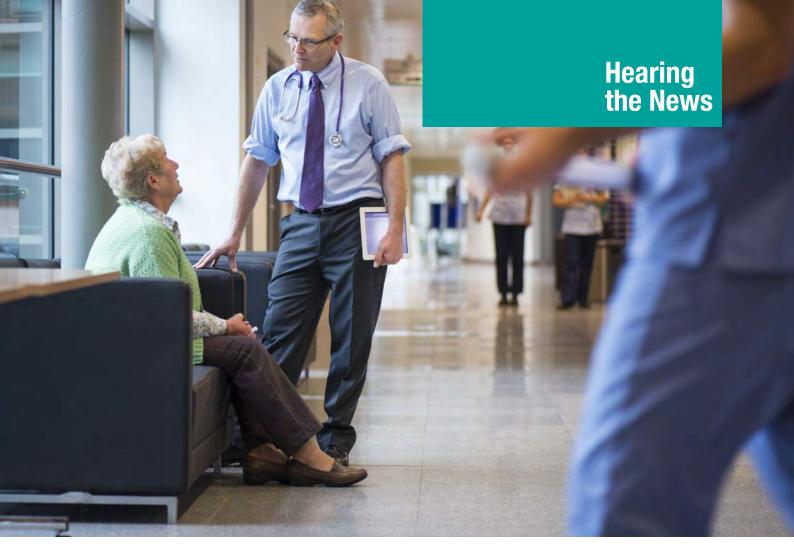
The aim of this resource is to provide you with some practical information to help guide you through the journey ahead.

We hope you find this guide helpful and that you are encouraged and empowered to ask questions, seek answers and find the right support to suit your needs, and those of your family.

Limbs 4 Life operates under the philosophy that no individual should go through the experience of limb loss alone.

We believe that individuals should have access to an organisation that understands their circumstances, can facilitate connections with others in a similar situation, and provide up to date information to assist you to navigate the healthcare system.

(1)www.mja.com.au/journal/2012/197/4/limb-lost-every-3-hours can-australia-reduce-amputations-people-diabetes



Learning that you are facing an amputation can be a frightening prospect. Coming to terms with the idea of surgery is not always easy and can lead to many questions.

To assist with your preparation try to access as much information as possible so that you can understand what lies ahead. Make a list and write down any questions you have. Arrange a time to discuss these questions or concerns with your healthcare provider. It can sometimes be helpful to take a family member or friend to medical appointments with you for support.

Some recommendations prior to surgery may include:

- Visiting a rehabilitation centre to find out what services they provide
- Speaking to a prosthetist or physiotherapist about your mobility options
- Speaking to a rehabilitation consultant (doctor) or physiotherapist about the rehabilitation process and your care plan.
- Requesting to meet an amputee peer support volunteer
- Speaking to your surgeon or doctor about pre-surgical therapy

Rehabilitation facilities usually have printed information about their services.

If you are unable to attend a 'rehab centre' ask one of your family members or friends to collect the information for you. Alternatively if you are away from family or friends ask a member of staff at the hospital to provide you with the information.

In some states and territories rehabilitation centres are located in the same building as the hospital; while in other states, rehabilitation centres are stand-alone facilities.

For a list of rehabilitation centres in your state or territory, refer to the supporting documentation on the Limbs 4 Life website or contact us directly for assistance.



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The Decision to Amputate

For some people the choice to have an amputation is completely out their hands. Whether it is due to disease, infection, cancer or trauma; the opportunity to save a limb is not always possible.

This does not make the decision any easier and it is normal to fear the outcome.

Usually at that time people are faced with a number of questions.

Will a prosthesis give me back my quality of life?

Will I be able to do the things I used to do?

How different will my life become?

How will I manage day to day tasks?

It is normal to seek answers to the questions above and you should try to access as much information as you can. After all, the more equipped you are with knowledge and information the more confidence and control you will have over the outcomes of your future.

For others the decision to have an amputation is sometimes to achieve better outcomes especially if the limb is compromised by a deficiency or as a result of on-going failed surgeries.

Over the years we have met a number of people who suggest that while it was a difficult decision, it ended up being the best decision of their lives. They have been able to restore their overall body function with the use of a prosthesis and get back to the things that they used to do.

Becoming an Amputee

Becoming an amputee is a life changing experience for each individual. This experience does not have to mean the end, just a new beginning and a time to learn different ways of doing things.

Adjusting to Limb Loss

Everyone reacts differently to the loss of a limb. Limb loss can leave you feeling anxious, vulnerable and uncertain about the future.

Your body has experienced a significant change and it is important to remember that your ability to adapt to the changes will become easier over time.

Some common difficulties that you may experience include:

- The ability to complete everyday tasks
- A change to your level of independence
- A difference in your mobility
- Concerns with your body image and sexuality
- General changes to your lifestyle

It is completely normal to feel strong emotions. Some people grieve for their loss.

You may feel scared, angry, frustrated and even sad. Working through your feelings may take time.

Remember, you don't have to go through this experience alone. Support is available. Make sure you ask for assistance if you need it, whether it's at the beginning of your journey, several months, or years down the track.

Emotional Health and Wellbeing

Your emotional health and mental well-being is equally as important as your physical health. If you are having trouble dealing with your emotions there are a number of supports that you can tap into including:

- Get involved with a peer support program. Being with others who share a similar experience can help to reduce feelings of isolation. Peer volunteers understand your feelings about adjusting to changes in your day-to-day life.
- Join a local support group. Amputee support groups provide a friendly and comfortable environment to share experiences with one-another.
- If you don't wish to meet with a peer face to face, take part in an on-line discussion group. Online groups can provide a connection with the wider community.
- Seek professional help. If you are experiencing depression, anxiety, denial or grief following your amputation it is important to talk to your care team.

Emotional reactions can often change as you go through the period of adjustment. You may like to speak to a trained counsellor to help you to manage your emotions.

Your doctor can assist you with a care plan or refer you to a professional. These visits can be subsidised via Medicare.

Talk to the people in your life about how you are feeling. Stay connected to your friends. Share your thoughts with others, this will help you to deal with the changes of how your body looks and feels.

Support can be accessed through:

Beyond blue – 1300 22 46 36 Lifeline – Crisis Support 13 11 14 SANE Helpline 1800 18 7263

Or a mental health support organisation in your community.





The Benefits of a Peer Support Network

"Meeting other amputees really helped my husband. It also made a huge difference to me. I had no idea what to expect and what our lives would be like after he lost his leg. The support and information was wonderful."

Leanne wife to Graeme 61 (below knee amputee)

"Peer support gave me hope. Just knowing that there are others like me, helped to reduce my fears."

Rodney 49 years (below elbow amputee)

Peer support is an important part of the recovery and rehabilitation process. Early on in your journey to recovery you may experience uncertainty, have doubts and questions. Peer volunteers can help to ease the burden and provide support along the way. Receiving a visit from a peer can be a rewarding experience and a wonderful way to gain an understanding of your new situation.

Peer Support Volunteers are amputees like you; people who have experienced and lived with limb loss for a number of years. They have successfully adapted to their amputation, re-engaged with their community, and live independently.

Building a network of peers will enable you to share your own very personal experiences with people who understand. Peer networks can provide practical and emotional support in a group setting which will enable you to be listened to and heard.

It may help you to develop confidence and feel more secure about your situation. Peer networks can be wonderful sources of information; they can give you tips, share knowledge and in some cases help to guide you to services and activities in your own community.

A peer may be able to answer some of the many questions you may have with regard to day to day activities; this may include using a prosthesis, sports and activities along with addressing concerns of a personal nature.

There are a number of ways you can access amputee peer support through Limbs 4 Life:

Face to face support will enable you to meet with a peer volunteer. Often the volunteer you are matched with will: be someone of a similar age; have lost their limb for the same reason; have the same level of amputation; and, in most cases be someone who is the same gender. Peers can visit you in hospital and/or at your rehabilitation centre. All you need to do is contact us to request a visit or alternatively ask one of your family members or your healthcare provider to arrange a visit on your behalf. If you are not in hospital, a peer can meet you in a public place.

Phone support can be provided to anyone at any time. If you would like to speak to a volunteer you can contact the toll free number and we will match you to a volunteer who will contact you by telephone, at a time to suit you.

Virtual support is for those of you with internet access. You can register to join the online AMP-Link forum. The forum is moderated by amputees who will welcome your comments and provide feedback. You can post questions or simply share your experience in a safe and friendly environment, or you can sit back and read comments from other people.

To visit the forum go to: www.limbs4life.org.au/forum/index.php. Limbs 4 Life also operate a number of social media pages and you can find the organisation on Facebook and Twitter.

Group support

There are a number of support groups operating throughout different states and territories of Australia. Some groups meet on a monthly basis, while others meet less frequently.

Some meet for lunch while others have their meetings around an activity. If you would like information relating to a group in your area visit the Limbs 4 Life website or contact us directly.



GETTING THE BALANCE RIGHT

























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Amputation

Site of Amputation **Common Terms Shoulder** Shoulder disarticulation **Below elbow** 3 Transradial **Above elbow** Transhumeral 2 **Through Wrist** 4. 4 Wrist disarticulation 6 5. **Partial Hand** Transmetacarpal **Hipdisartic** 7 Hip disarticulation 7. **Above knee** Transfemoral amputation 8 Thru knee 8. Knee disarticulation 9 9. **Below knee** Transtibial amputation 10. Symes 10 11. Partial foot

The Surgery

For most people, the purpose of amputation surgery is to remove enough of the infection, or disease to enable the limb to be healthy. At the same time surgeons try to save as much of the limb as possible so that an artificial limb can be fitted.

After the Surgery

Each hospital will have a different system in place for managing your residual limb after surgery. It is very important that stump bandaging and wound dressing is done correctly. This applies to both upper and lower limb amputees. It is normal (following surgery) for stump bandaging to be checked and (in some cases) reapplied up to two or three times per day.

The purpose of re-bandaging is to ensure that the dressing is firm but not tight and that it stays in position to effectively manage swelling without causing any discomfort in the limb.

Pain

Pain in the area of the wound is common following any operation, especially as you start to move around and the tissue starts to heal. This pain should improve over the first few weeks and will usually require some medication in the short term.

If you suddenly experience new pain that does not settle down with your current treatment notify the medical staff immediately.

It is best to be sure that there are no underlying problems (for example your bandages or dressings being too tight).



Movement Therapy

Following any lengthy stay in bed your muscles and joints can start to become weak and stiff. As you recover from surgery, hospital staff (usually the physiotherapist) will start to help you to regain some mobility.

The staff may arrange a wheelchair for you so that you can begin to move around. You may also start a gentle exercise program which will help to prepare you for the transition to rehabilitation.



If you have had an amputation below the knee you will (most likely) be fitted with what is commonly called a Removable Rigid Dressing (RRD). This dressing fits comfortably over the top of the stump bandages and/or stump socks.

Removable Rigid Dressings should be worn all the time unless otherwise discussed with your carers - RRDs are most effective when they are worn as much as possible as then they help to reduce swelling which makes wound healing faster, are more likely to create a stump shape good for a prosthesis and allow your first leg to fit longer and more easily and then it can protect you from any unexpected knocks or falls.

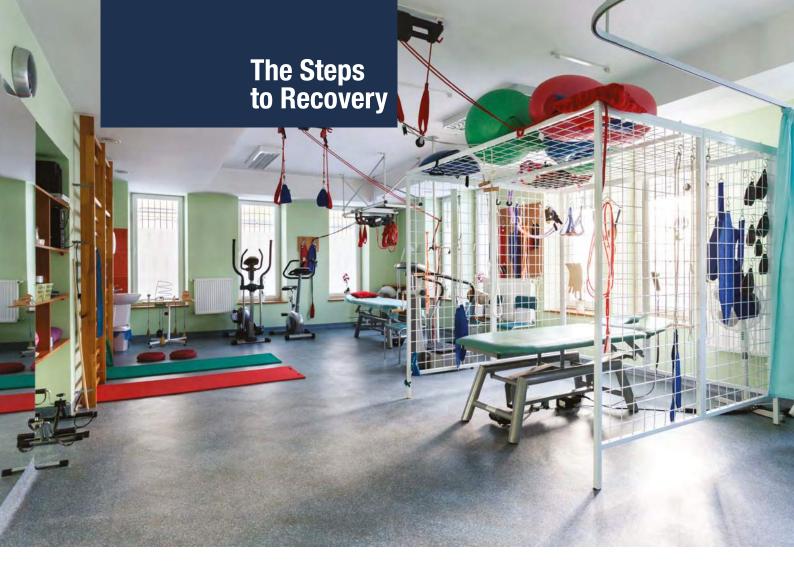
RRDs are tailor made to suit each individual. In most cases hospitals will engage the services of prosthetist to manufacture this for you.

Below knee amputees can be more prone to swelling in the stump if the knee is bent for long periods of time. This can also lead to shortening of the muscles and less movement in the knee joint.

For this reason it is important not to hang your leg over the side of the bed or over the edge of your seat for more than a few minutes when transferring or showering or doing your exercise program.

Make sure you use a suitable stump support at all other times.





Following surgery there are usually **three major stages** to your recovery:

Acute care stage Rehabilitation stage Returning home

- > care provided to you, while you are in hospital
- > care provided to you in a rehabilitation centre
- > regaining independence and mobility

Amputation Surgery

Rehabilitaton Centre Discharge Home

Leaving hospital and going to rehabilitation is the first major step in your recovery.

Some people feel a level of anxiety when told that they are being discharged from hospital to commence rehabilitation.

The news that you are ready to begin rehabilitation is a positive sign. It means that you are well enough to move on and progress with your treatment.

Choosing a Rehabilitation Centre

Amputee rehabilitation centres are located in each state and territory around Australia. You can choose the rehabilitation centre that you would like to attend. Most people prefer to go to a centre close to their home, family and friends. If you are unsure if there is a centre in your local area, ask your healthcare provider or contact Limbs 4 Life and we will let you know.

Amputee Rehabilitation

A rehabilitation centre is similar to a hospital with access to around the clock care. Medical staff will continue to provide you with assistance and support. When you arrive at the rehabilitation centre you will be introduced to your new medical team.

The medical team is made up of a group of health-care professionals who will assist with your recovery process. The team will work with you to help you regain your independence and increase your level of confidence. Together you and the medical team will discuss your goals and develop a care plan to suit your needs. Each member of the team has specific skills and plays an important role.

"Rehab was the next stage of my recovery.

After speaking to a representative from the rehab centre I knew that they would help me to get my independence back".

Mary 49 years (below knee amputee)

You

The most important member of the rehabilitation team is YOU. From the onset, you will be encouraged to play an active role in your rehabilitation and care. It is important that you are happy and comfortable working with all other members of the medical team. They will support, guide and help you to achieve your goals. Members of the rehabilitation team can include:

Rehabilitation Consultant (doctor)

The doctor appointed to you while in rehabilitation is commonly referred to as a Rehabilitation Consultant. Their role is to oversee your medical team, ensure that your health and medical needs are being met. You should discuss your rehabilitation goals and aims with your doctor. This is called a 'client led' approach. It is up to the doctor and the rest of your rehabilitation team to ensure your goals are guided and realistic. The doctor will also attend to other medical issues associated with your amputation and healthcare. The doctor together with the team will assess if you are fit and able to use a mechanical/assistive device, such as a prosthesis.

How long will I be in rehab for?

This is a common question. In most cases it will depend on your health and any health related issues. Upon arrival at your rehabilitation centre your medical team will conduct an assessment and develop a personal treatment plan. The plan will include a date for discharge. This will give you a timeline relating to your length of stay.

Occupational Therapist

Helping you to adjust to daily living is the role of the occupational therapist. They assist you to overcome limitations with day to day activities, like personal care, education, leisure and work. Occupational therapists help to measure and fit you with wheelchairs and arrange for home modifications such as ramps, grip and grab bars in wet areas and hand rails where required. They also assist with return to driving and vehicle requirements.

Physiotherapist

Your physiotherapist will design an exercise program tailored to your requirements. They will assist you to regain your balance, flexibility, strength and stamina. Your program may include the use of gym facilities and sessions in a hydrotherapy pool (when all wounds are healed). They will assist you with the use of mobility aids such as wheelchairs, walking frames, crutches and other assistive devices that are suitable for your abilities. If you are fitted with a prosthesis (artificial limb); your physiotherapist will play a major role teaching you how to walk again.

Prosthetist

The prosthetist will conduct an assessment to decide if a prosthesis is right for you. They look after the design, manufacture, supply and fit of the prosthesis. Together you will discuss and decide on the best prosthetic components to suit your needs and lifestyle. In the early stages of rehabilitation most amputees require regular prosthetic adjustments due to on-going changes with your residual limb (stump) and general strength and fitness. Over time you will gain a better understanding of what feels right for you.





Social Worker

Confidential counselling assistance for you and your family can be provided by your social worker. They can assist you with emotional support and any concerns you may be experiencing in relation to coping with an amputation.

Social workers will provide assistance with any lifestyle problems including adjustment issues, financial matters (e.g Centrelink), transport, disabled parking permits, multi-purpose taxi cards and accommodation requirements. Prior to discharge they can advise you on local support in your community including carer support services.

Maintaining a healthy attitude and sound exercise program can help **YOU** to achieve better outcomes.

"Taking part in regular exercise, feeling stronger and fitter helped me to feel more confident about starting my prosthetic training."

Greg 27 years (below elbow amputee)

Nursing Team

Members of the nursing team will assist you with medications, personal hygiene like bathing and dressing and any wound care and diabetic management required.

They will liaise with the appropriate team members about your specific needs or any referrals you may require.

Remember, if you don't understand something ask. Your rehab team is there to help you.

Your rehab doctor or a member of the team will discuss the option of additional healthcare professionals being involved in your care during your in-patient stay.

Depending on the reason for your amputation, other people involved in your care may include:

Diabetic educator

Dietician

Exercise physiologist

Pastoral Care

Podiatrist

Psychologist (clinical or neuropsychologist)

Sexual health counsellor



Managing Pain

Everyone's experience of pain is different. Some pain is worse than other pain. Unique to some amputees is phantom pain and or phantom sensation - pain or feeling in the limb that is no longer present.

Phantom Sensation

Phantom sensation is a feeling in the limb which is now absent. Some people feel as if their limb is still there, even after surgery. This is quite normal.

You may also have feelings or sensations in parts of the limb such as the toes or the fingers, the shin, elbow or even the knee. You may experience feelings such as pins and needles and or feel the need to scratch an itch in an area which is no longer there.

Phantom sensation is common following the amputation of a limb. One theory to explain this is that the brain has developed a recorded image of the limb and when normal messages from the limb are lost (due to amputation) the brain attempts to reconstruct an image of the limb, and send messages; hence phantom sensation.

The good news is that the brain has an amazing capacity to re-learn and this is greatly helped by increasing normal input. Example include: moving,

touching; or, (best of all) using the residual limb (with the help of a prosthesis) to enable a new image of the limb to be created in the brain.

If you do experience the sensation that your limb is still there, take care. Many lower limb amputees report trips and falls especially during the night. It is easy to think that your limb is still there if you're feeling sleepy or when it's dark you may try to use it.

In the early stages of amputation it's important that you concentrate when moving from your bed to a wheelchair. If you don't feel confident, ask for assistance.

Phantom Pain

Phantom pain sometimes occurs in the weeks following amputation and, like phantom sensation, can reduce over time. Some people find this pain debilitating. It can be similar to a shooting or sharp pain, cramp, burning or feel like a mild electric shock. Phantom pain can usually be managed by a variety of treatments and medication. If you experience phantom pain speak to your healthcare provider so that they can work with you to decide which pain management option will work best.

Phantom pain may return on occasions. Examples include: when you are generally unwell; over tired; if your prosthesis is not fitting correctly; or, if there are particular problems with the residual limb (stump).



Reducing the Pain

One of the successful ways to manage phantom pain is diversion therapy. Examples include: trying to focus your attention on doing something different such as moving, if you have been sitting still or touching and massaging the residual limb.

Some people find that focusing their attention on something completely different can help, this could be a variety of things like listening to music, talking to a friend or playing a game of cards; basically anything that takes the focus of your mind away from the phantom pain.

Some people find the use of alternative therapies helpful, these can include: massage or stretching, mirror therapy and acupressure.

Other people are comforted by the use of heat or cold packs; however these should only be used if you have a good ability to feel the hot or cold sensation well.

Transcutaneous Electrical Nerve Stimulation (TENS) machine sends a different message to the brain which for some people helps to create a diversion from the pain message, which can assist with phantom pain relief. It is always recommended to speak with your healthcare provider to discuss the use of alternative treatments for phantom pain to ensure you are using a method that is safe for you.

Don't be alarmed, phantom pain can be treated by your healthcare provider. Most amputees report a reduction in phantom pain over a period of time.



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Developing Good Habits

Losing a limb will impact the symmetry (balance) of your body. Chances are you are going to be relying on a prosthesis or wheelchair for some time. The best thing that you can do for yourself is to make every effort to have good posture and gait (walking) pattern from early on. Your physiotherapist will help you to develop these skills initially; however it's up to you to keep up the good habits you learn.

Gait - a person's manner of walking **Posture** - a particular position of the body

On-going complications

In the case of a single-sided amputation, it is normal to put more stress through the sound or unaffected side of the body. People often do this to compensate for the absent limb/s in the early stages of prosthetic training; due to the lack of confidence and inexperience using a prosthesis. This additional stress can lead to long term health problems and can sometimes cause unnecessary pain.

Where possible it is necessary to make sure that you practice the good habits that you have been taught. Lower limb amputees need to be mindful of good gait patterns, and develop strength in the legs and trunk (stomach and back) muscles to assist with walking. This will support your ability to do everyday activities and help to prevent injuries. You should also be aware of the impact that the use of assistive devices such as walking frames, crutches and walking sticks can have on the rest of your body; especially the arms, hands, shoulders and upper back area.

People living with upper limb amputations need to take care of their neck, upper back and shoulder areas to prevent long term strain. Flexibility of the neck and upper back, along with neck and shoulder-blade control exercises will be very important in the long term. If you are experiencing pain of any kind, check with your healthcare provider to make sure that you are moving correctly. Seek additional medical advice if the problem persists.



Sockets and Socket Fit

The prosthetic socket is the device that joins your residual limb (stump) to the prosthesis. The socket is custom made for each individual according to the condition and shape of the residual limb. The prosthetic socket usually consists of a liner (or stump sock), a weight bearing outer wall (in the case of lower limb amputees), which forms the connection to other components such as knee joints and prosthetic feet.

Similarly the socket for upper limb amputees also forms a connection to other components such as elbow and wrist joints or hands.

The liner or stump sock acts as a buffer between the skin and the hard shell of the socket. The liner also works to minimise friction between skin and the socket.

When prosthetic sockets are fitted, clinicians will often make what is called a check (test) socket first; a clear see-through socket which enables the clinician to see any areas of pressure or redness. A check socket can easily be changed (modified) to suit your shape, wearability and comfort if required. That way, when the final socket is constructed the fit should be more suitable for you.

It is not unusual for sockets to feel strange at first — keep in mind that a movable body part is being housed in a hard shell. When first fitted with a prosthetic socket it is likely for it to feel unusual and it may take you some time to get used to it. In the early stages wearing a prosthesis may cause some discomfort and redness to the skin. However this should not be the case in the long term.

For a prosthesis to work well it is important that the socket is a precise fit. In fact, it is hard to think of anything else you might wear that has to fit as well, and for as long, as the socket of a prosthesis. This can simply be due to the fact that our bodies and stumps are living things which are constantly changing. Your prosthesis, however is an object which is fixed in size and shape.



A poorly fitting socket in LOWER limb amputees can:

- · cause skin breakdowns or blisters and ulcers
- affect your ability to walk well
- impact your balance
- · contribute to falls and
- be uncomfortable and painful to wear.

You should never wear your prosthesis if it doesn't feel right.

A poorly fitting socket in UPPER limb amputees can:

- cause skin breakdowns and irritations and
- impact your ability to successfully use the prosthesis.

So how do you manage to keep a good fit between something that changes (your body) and something that doesn't (your socket)? You do it in two ways:

Firstly, by trying to minimise changes in your stump. Including monitoring your diet and exercise. Secondly by constantly monitoring how you feel in your prosthesis, checking the skin and taking action if you notice a change.

Some people's residual limbs don't change. They wear the same arrangements day in day out without any problems, while others will need to make several adjustments over the course of the day.

Speak to your prosthetic provider about a list of problem solving techniques which may be helpful for you.

How Your Prosthesis is Made



Step 1.

Your prosthetist will take measurements of your residual limb



Step 2.

Plaster is wrapped around your limb to make a cast



Step 3.

A cast is then made of your limb



Step 4.

A lamination process is used to create the hard shell known as the socket



Step 5.

The socket is then attached to a pylon and foot or in the case of upper limbs the prosthetic component



Step 6.

Then the prosthesis is fitted to your limb and adjusted to your needs

Caring for your Residual Limb

Taking care of your residual limb (stump) is extremely important.

You need to get into a regular routine and check your limb on a daily basis, including when you experience any pain or changes in the way it fits:

- Use a hand mirror to check the back of your stump for changes before you put your prosthesis on
- It is also important to check your stump for markings or changes when you take your prosthesis off
- Check for skin breaks, ulcers, dryness or cracking. Any noticeable signs of change should be immediately seen to by your doctor.

Remember: A prosthesis should not cause pain.

The skin around your stump will always be fragile and it needs to be looked after. Prevention is better than cure; report any changes to your skin to your doctor or prosthetist immediately.

Residual limb pain can sometimes be caused by sensitive scar tissue, neuromas and other under lying issues such as; a poor fitting socket or a prosthesis which is not aligned correctly.

During the first year following your amputation, you will notice a number of changes.

Your stump may continue to reduce in size and change in shape as your body adjusts to wearing a prosthesis.

You may find that you need to visit your prosthetic provider more frequently during this time.

During the second and third year, your body and stump will start to stabilise and the need for adjustments to your prosthesis will become less frequent.

Any red marks or skin changes should be attended to if they do not fade after 15 minutes from the time you remove your prostheses.



There are a number of things that you should pay particular attention to:

- Skin hygiene is vital; prosthetic liners and stump socks should be cleaned daily with a gentle non-fragrant soap and rinsed well
- Stump socks and liners should be changed daily and more frequently if you sweat heavily during warmer months
- Stop wearing your prosthesis if you have any pain or discomfort
- Wear safe and comfortable shoes.

Increased Body Temperature

Amputees often report an increase in their body temperature. This can be due to a number of reasons:

- Less body surface area making it more difficult to reduce the body's temperature. The skin is our largest breathing organ and any amputation results in less skin surface area
- 2. A greater level of energy expenditure. Using a prosthesis (especially lower limb) requires more energy the more energy you expend the warmer the body gets. This can lead to a reduction of heat tolerance and excessive perspiration

If you are affected by increased body temperatures make sure you drink plenty of fluids to replace what has been lost by sweating. Try to limit the amount of caffeine and soft drinks and wear light breathable clothing.

Hair Removal

Amputees regularly ask about shaving or waxing their stump. Your healthcare provider will discourage you from doing this. If you do decide to practice hair removal and the base of the hair follicle becomes infected you may be unable to wear your prosthesis until the infection clears. Seek advice and a second opinion if you are worried or concerned.





TIP: If you are unsure how to explain a skin problem or red mark to your prosthetist - why not take a photo on your phone. A photo will help you to explain the problem when you see your clinician at your next appointment.



PROSTHETIC SOLUTIONS FOR AN ACTIVE AND INDEPENDENT LIFESTYLE

For us direct patient care is our heritage, our inspiration, it's where theory meets reality. It is where we see the real life difference we make in patients' lives. It's what sets us apart. With 13 clinics around Australia, and more on-staff Orthotists and Prosthetists than any other provider in the country, OAPL Clinical Care is always within reach.

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Prosthetics Explained

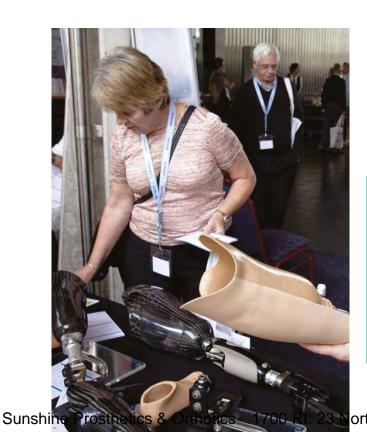
Prosthetics come in many shapes and sizes. You, your prosthetist, physiotherapist and your doctor will work together to choose the best and safest prosthesis for you.

This will depend on such things as:

- Your general level of mobility
- The condition of your residual limb (stump)
- Your weight
- Types of activities you do
- Your ability to look after yourself and manage your healthcare
- How comfortable you are with new ideas
- Other health issues

A prosthesis for an elderly person who is only going to walk indoors will be very different to a prosthesis for someone who works all day in a manual job.

Prosthetic components have weight restrictions and recommendations based on mobility.





Underestimating weight or activity levels could result in a prosthesis that is not strong enough to let you be active safely and this can be dangerous. However, overestimating weight or activity could result in you wearing a prosthesis that is heavier than it needs to be.

To achieve the best outcome you need to be honest in discussions with your doctor and prosthetist. The presence of a family member or carer can sometimes be critical in deciding on the type of prosthesis that will best suit you.

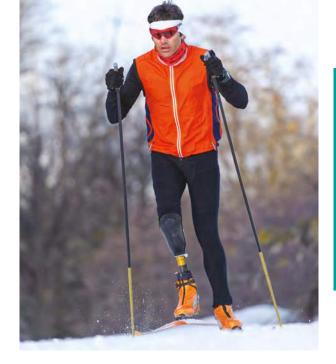
For example, as people age or other problems occur, some types of prostheses may be hard to put on properly.

If you put on (donn) your prosthesis incorrectly it can cause problems and be unsafe, your doctor or prosthetist may suggest a simpler prosthetic system in order to keep you mobile.

There are many other examples of how these factors can influence what is best for you. It is not always clear-cut. Sometimes a certain type of prosthesis looks like a great choice in theory, but unforeseen problems may occur.

Do I shower with my prostheses on?

Most people don't shower with their prosthesis on unless it has been specifically designed for use in water. Artificial limbs which are sometimes called water or shower legs are specifically built for that purpose and can withstand the effects of water. They have specialised parts which don't rust or malfunction in wet areas.



Sometimes prostheses, or the components, are referred to by their **'K'** classification. This is simply a measure of activity.

K1

Suitable for use on level surfaces at steady speeds. That is someone who only walks indoors and short distances outdoors for example to the car.

K2

Suitable for outdoor use but at a low activity level. For example someone who manages steps and slopes but walks limited distances and may use a stick or other gait aid.

K3

Suitable for general outdoor use, but not including sports and other high impact activities. i.e. someone who walks in most commonly encountered environments, at varying speeds, long distances when required and usually without a gait aid.

K4

Suitable for high impact use. For those people who have unrestricted mobility and may impose higher than usual forces on their prosthesis, eg; sports or manual work.

Componentry manufacturers often rate their components according to these classes or mobility grades. This is why your prosthetist will ask you about your activities, so they can choose componentry that is safe and effective for your lifestyle. Using a prosthetic limb takes a large amount of energy because you have to compensate for the loss of bone and muscle of the amputated limb.

How often will I need a new prosthesis?

In the early stages you may notice regular changes in the size and shape of your residual limb. Your residual limb can take up to 3 years to stabilise. Once you settle back into a regular routine your prosthesis may only need to be changed every 3-5 years. However you may find that you require new sockets during that time. It's worthwhile to have an annual maintenance check to ensure that everything is working well.

A person fitted with an above knee prosthesis (for example) may need to use up to sixty percent more energy to walk. For this reason you may choose not to use a functional prosthesis, and decide that it's not for you; in which case the option of a cosmetic-only prosthesis could be the best choice.

Remember, adjusting to limb loss is a big step and it takes time. Set yourself realistic goals. Be involved, and try to give your prosthetist feedback about the prosthesis so that they can assist you with the best outcomes. Be patient with yourself and take time out to reflect how far you have come as you work toward regaining your independence, mobility and confidence.

Prosthetic Componentry Companies

College Park Industries www.college-park.com

Endolite - www.endolite.co.uk

Fillauer - www.fillauer.com

Freedom innovations www.freedom-innovations.com

Hanger - www.hanger.com

Ohio Willow wood www.ohiowillowwood.com

Ossur - www.ossur.com

Ottobock - www.ottobock.com.au

Touch Bionics www.touchbionics.com

Trsprosthetics www.trsprosthetics.com

Some of the above websites have interesting stories and tips for amputees.

Funding for a Prosthesis

How your prosthesis is funded may depend on the cause of your amputation and/-or if you have the support of other organisations involved in your wellbeing, care and treatment.

Some people are often concerned about the cost involved in receiving a prosthesis.

During the course of your treatment and recovery, the supply and funding of your prosthesis will be discussed with you prior to its manufacture.

As the majority of amputations are due to contributing medical conditions such as diabetes, vascular disease or cancer, your prosthesis is generally covered by funding from the public health system.

How your prosthesis is funded will depend on the cause of your amputation. Generally speaking, the following categories apply:

- If you lost your limb due to disease or illness, you will most likely be covered by the public health system in your state or territory or the National Disability Insurance Scheme (NDIS) if you are under the age of 65.
- If you lost your limb in an accident for which there is no compensating body, for example at home or during recreation, then the public health system or the National Disability Insurance Scheme will cover the cost of prosthetic limb/s.
- If your amputation was due to traumatic reasons, such as a motor vehicle accident or workplace accident, and compensation is identified as a possibility, the insuring organisation will most likely fund your prosthesis and medical care as part of your rehabilitation needs.
- Veterans who either lost their limb as a result of injuries received while serving, or who have a Gold Card, will have their prostheses paid for by the Department of Veterans Affairs.
- Most Private Health Insurance companies do not allocate funding for prosthetics, however it is worth checking with your insurer if you are uncertain.



Because there are different funding sources, the type of prosthesis, and other rehabilitation services you receive, will depend on the cause of your amputation. Like many public health services, funding is limited. This means your prosthesis will be designed from a set range of components, with more sophisticated items not always available.

If it is determined you are eligible for ongoing prosthetic use and funding, all future prosthetic services ranging from your first (interim) prosthesis, replacement prosthesis, socket replacements, reasonable repair costs and supplies such as stump socks and shrinkers are included.

There is a set requirement for how often your prosthesis and socket can be replaced. Supplies and repairs also have set limitations based on manufacturers' guidelines and expected periods of use for a component. However, if the prosthesis or socket requires replacing before the expected time period, then your prosthetist may refer you back to the amputee clinic for further assessment.



In most cases you can make additional financial contributions toward your prosthesis if you desire particular componentry that public funding does not cover. It is also important to remember that you can trial certain prosthetic devices before facing out of pocket expenses. Most prosthetic componentry companies will allow you to have a foot, knee unit or hand/arm on loan for approximately two weeks.

This will give you the chance to see if a different prosthetic component gives you better outcomes such as:

- More energy at the end of the day
- Provides you with more stability and confidence
- Enables you to be more active
- Increases your functionality

Usually you will attend an amputee clinic as a public outpatient whenever you require medical attention associated with your amputation. Remember to have an annual review or prosthetic maintenance check every 12 months.

National Disability Insurance Scheme (NDIS)

The National Disability Insurance Scheme is a new way of providing individualised financial support for people with permanent and significant disabilities, their families and carers.

The National Disability Insurance Scheme was launched in a number of trial sites in July 2013. The Scheme will progressively be made available throughout each state across Australia.

If you are under 65 years of age and would like more information relating to eligibility free call **1800 800 110** for more information.

You can visit the NDIS website and complete the eligibility online assessment form and keep up to date about the roll out of the Scheme in your area.

Limbs 4 Life can answer questions and provide assistance in relation to the locations and funding streams, alternatively speak to your healthcare provider for information.

For information relating to state-based limb funding schemes please refer to the Limbs 4 Life website or contact us directly on **1300 78 2231**

Assistive Devices

An assistive device is the name given to equipment which aids your ability such as: wheelchairs and walking aids.

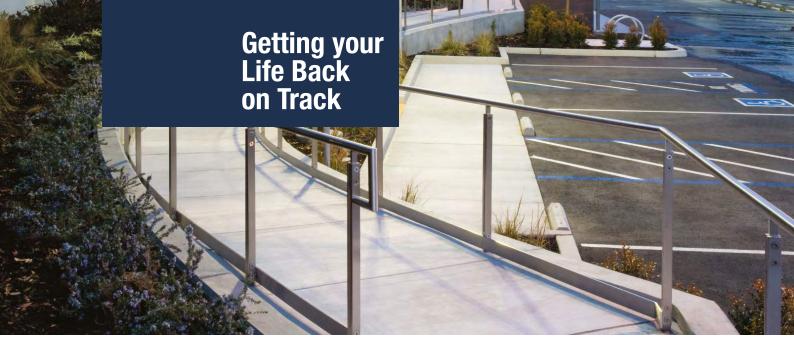
If you are a publically funded patient financial assistance for some aids and equipment style products including wheelchairs and home modifications like ramps, along with bathroom equipment and shower chairs and vehicle modifications (such as left foot accelerators or hand controls) are available from some state-based schemes. But there is likely to be a waiting period.

You should seek information relating to funding prior to purchasing any equipment. Speak to your healthcare provider for information relating to these items and others such as ramps and grip bars in wet areas.

There are a range of devices which can make life easier. If you have a special request, don't hesitate to ask your healthcare provider, chances are it may be available.

Tip: If you decide to purchase your own items prior to the waiting period, government reimbursements and funding subsidies may not apply.





Going Home Safety

Heading home for the first time can raise mixed feelings; excitement, anticipation and anxiety for both you and your family. Moving around a hospital or rehabilitation centre can be very different to navigating the way around your home. Many homes have lots of stairs to access the building, carpet instead of vinyl floors, toilets and wet areas that are not always easily accessible and doorways that are small and difficult to enter or exit.

Ensuring that your home is safe and accessible is important. Your occupational therapist will discuss options for modifications and assistive devices prior to your discharge. They may also arrange a home visit with you, to discuss your needs.

Here are a number of suggestions which can make that first trip home a little easier for you and your family.

Tips for Lower Limb Amputees:

- Remove mats on polished floors and tiles. They are a nuisance for wheelchairs and also trip hazards for prosthetic legs
- Request portable ramps to gain entry into the house (if you have only 1 or 2 steps)
- Hand rails for stairs can assist with balance and stability
- Furniture like coffee tables and hall tables can be challenging to navigate around; place them near walls and out of the way of the main thoroughfare

- Non-slip mats for the shower/bathroom floor are a safer options and the use of a shower stool, chair or bath-seat can help to prevent trips and falls.
 Your occupational therapist will discuss the option of grip bars in the wet areas (such as the shower, bathroom and toilet)
- Arrange things to be in easy reach so that you are able to do things for yourself

Tips for Upper Limb Amputees:

- Regular shoe laces can be exchanged for specialised laces or alternatively you can use shoes which do up with Velcro
- Devices such as a combined knife/fork can make eating easier
- Specialised computer keyboards are available for people with one arm
- Specialised boards are available to make things like cutting, chopping and opening jars easier to manage
- Some amputees will opt for Velcro instead of studs or buttons to enable them to change doona covers.

Although changes may need to be made and you will face some challenges, becoming an amputee may mean that you can do most of the things you used to do, but in a different way. Sometimes it's just a matter of careful planning, organisation and learning as you go.

Employment

Returning to work is yet another step toward regaining your independence. Some employers are very supportive when it comes to making the work place accessible.

In instances where accessibility is a problem, speak to your employer, local Member of Parliament or the local council in the area of your place of employment to find what funding support is available.

You may even like to engage the services of an organisation which can assist you to find employment and or transition into a different job role; especially if you are no longer able to fulfil your working requirements. Career advisers will work with you to develop a return to work plan.

Driving

Driving is an important part of an amputee's independence, especially if you have had a lower limb amputation. If you have medical approval and your health checks out you will be able to have your licence re-instated. In some states people are required to be re-tested for their driver's licence and have restrictions placed on their licences such as 'automatic only' vehicles.

Vehicles can be modified to suit your needs and there are a number of companies which specialise in the re-fit of left-foot accelerator pedals and the installation of spinner knobs or hand controls.

Some states offer financial support via their respective aids and equipment programs. Likewise there maybe funding available for wheelchair hoists to assist with lifting the wheelchair into/onto the vehicle.

Parking and Travelling

Your social worker will help you with the application process to obtain state government concessions if you are eligible.
These can include:

Accessible Parking Permit Multi-Purpose Taxi Program Card Mobility Allowance (Centrelink)

The Multi-Purpose Taxi Program provides the user with a financial discount on the metered fare. The discount value can differ from state to state. If you plan on travelling interstate, the Taxi Directorate can allocate you interstate vouchers which can be used while you are away. Some states also provide taxi-vouchers which cover the costs of travel to medical appointments. Ask your healthcare provider for information regarding financial travel support.



MIS-MATCHED FEET?



XFII shoes can be purchased as a 'traditional pair (7 left & 7 right)', 'odd size pair (7 left & 9 right)' or 'individually (7 left)'. There is no waiting time, as the shoes are already in the store, and best of all, if you do need an odd size pair, you pay the same retail price as a traditional pair (or half the retail price if purchased individually!)

Whatever your circumstance or foot size (half size or greater in difference between feet), you can now walk into any of the 145 'The Athlete's Foot' stores in Australia and New Zealand and have each foot individually measured and fitted with the right size for each foot.









no III feet are the same

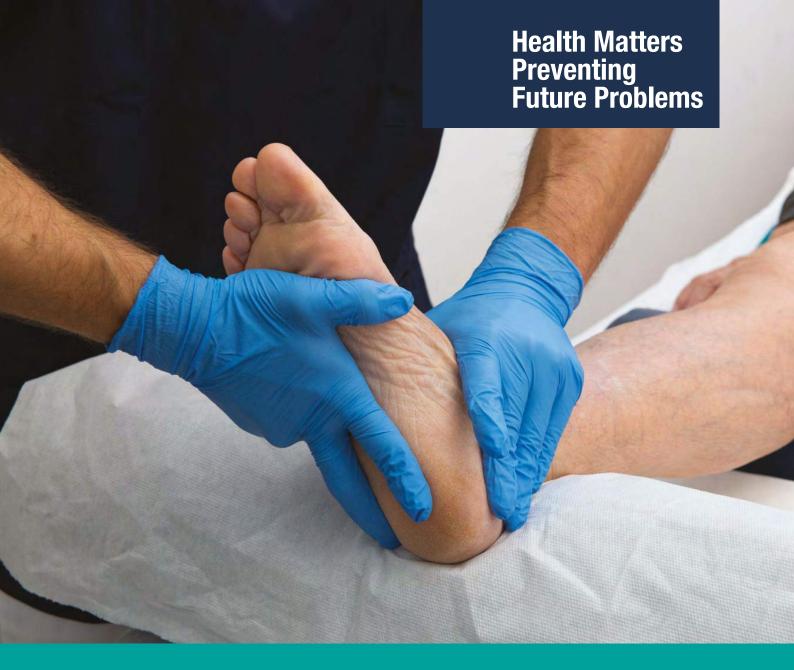


At the Australiasian Podiatry Council (APodC) we support Ascent's IIFit service to highlight its worth and efficacy - it represents great value and service for podiatry patients. We recommend the Ascent IIFit service, the only service of its kind endorsed by the APodC.









Physical health

Keeping as fit and as healthy as you can after your amputation is important. Effectively managing your long term health can assist you to prevent future problems. Below you will find some key areas that affect amputee's general health and wellbeing.

Foot health

The leading causes of lower limb amputations are complications resulting from diabetes and peripheral vascular disease.

Any injury to a foot with poor circulation will be slow to heal or may fail to heal at all.

If you have lost a limb due to diabetes it is important that you take steps to prevent this from happening to your remaining limb. Foot health tips include:

- Check your foot every day for any changes
- Use a hand mirror to see underneath your foot
- Check inside your shoes for foreign objects before putting them on
- Wear correct fitting shoes at all times and never go barefoot
- Wash and dry your feet properly every day
- Change your socks daily
- Have an annual foot check from a podiatrist
- Maintain good blood sugar levels.

Appropriate and early treatment of foot wounds increases the possibility of healing those wounds. DON'T WAIT. If you have noticed a change, contact your doctor, podiatrist or healthcare provider immediately.

Weight Management

Due to the reduced levels of activity, weight issues can be a problem for people with lower limb amputations. Try different forms of exercise and stay as fit as you can. A healthy body will assist your overall condition - mentally, physically and emotionally.

Keep your diet healthy.

People with diabetes should speak to their dietician or seek information from Diabetes Australia for further assistance with weight and diet management.

Your residual limb (stump) will reflect any changes that occur in your general body weight. If you gain weight your stump is likely to get bigger and your socket may become too tight.

If you lose weight your stump will get smaller and your prosthesis may become too loose. Generally changes of more than 2-3kg will show up in an altered socket fit, so try to maintain an even body weight.

Stump changes can happen for other health related reasons. For example anything that affects the fluid balance of the body can affect your stump size. Kidney or heart conditions can cause this, as can

some medications, particularly those which cause fluid loss. Other causes of changes in stump size include: weather (especially extreme heat); menstrual cycles; alcohol intake; activity; and, air travel.

If you have a large gain or loss in weight or a significant change in activity it is your responsibility to let your prosthetist know, so they can ensure the safety of your prosthesis.

Managing Change

In time, you should have a fairly good idea how your prosthesis should look and how it should feel when it is fitting properly. If you are unsure then talk to your prosthetist and ask them to explain it to you. You should learn to be familiar with how your stump looks so you can notice any changes in appearance, or skin markings.

The best way to deal with changes is to be aware of your own body and its responses, be informed on how your prosthesis should work and engage with your doctor and prosthetist if you ever have any questions.





Sunshine Prosthetics & Orthotics 1700 Rt. 23 North Suite 180 Wayne, NJ 07470 973-696-8100



Your emotional health is just as important as your physical health. Managing problems and addressing concerns sooner rather than later is an important part of your recovery process.

Sexuality and Intimacy

Intimacy and sexual expression are an important part of every person's wellbeing. Many changes can occur to your private life when you are affected by injury, illness or disability. Changes may be both physical and psychological.

For example you may be feeling tiredness and have a reduced desire for intimacy. You may also struggle with fears of rejection by your loved ones.

Some of the things that you can do include: focusing on your pleasure and your partner's pleasure. Don't keep thinking about how you want to perform. Sexuality, sexual desire and sexual functioning are often affected, which can have a significant impact on your quality of life, health and wellbeing.

Unfortunately, mainly due to embarrassment, we often don't receive or access help in this area of our health. Even if you feel embarrassed or uneasy, it is important that you seek assistance for your sexual health concerns.

We are all sexual beings. The term refers to all of the ways we express loving feelings and emotions. Our whole body responds to sexual attraction. Sexuality includes feelings of arousal expressed by touching, kissing and caressing.

After an amputation you may want to find new positions that are more comfortable. For instance you could add some pillows if you have problems with your balance. Explore and enjoy finding out ways that work best for you and your partner. (3)

(3) Houston S: Body Image, Relationships and Sexuality after Amputation, In: First Step Volume 4, 2005 (internet cited 2013 Nov 22) Available from http://www.amputee-coalition.org/easyread/first_step_2005/altered_states-ez.html.



Body Image and Self Esteem

Following an amputation, individuals are often concerned about their appearance and how this will impact upon family, friends and others. As human beings, we all think about how we look and how others see us.

Even though your body has changed physically, it's important to remember that you are still the same person inside. Focus on learning new ways to do things you enjoyed before.

As an amputee, you not only have to deal with changes in how your body works and feels, but also how it looks. The more you focus on what is missing, not just the limb but also things you could do before, the more likely you are to become depressed and angry.

Amputation will initially affect your self-confidence and confidence is a big factor in dating and maintaining relationships.

Males sometimes relate the loss of a limb to the loss of their manhood, while women tend to be more concerned about the impact it will have on their sexuality.

Amputees often worry about how people will perceive them or that others will stare, ask inappropriate questions or treat you as a lesser person. If someone asks a question or makes an

inappropriate comment, point out why you find it offensive. Hopefully they will understand. (3)

If you are learning to use a prosthesis, your body image is likely to change once you feel more comfortable with the limb. You will notice this when you begin to feel lost without it.

(3) Houston S: Body Image, Relationships and Sexuality after Amputation, In: First Step Volume 4, 2005 (internet cited 2013 Nov 22) Available from http://www.amputee-coalition.org/easyread/first_step_2005/altered_states-ez.html.

Family and Friends

Friends and family members often go through the process of grief and loss, similar to the person who has lost a limb. It is a major change for everyone. (4) You may find that family members and friends will try to do things for you and often have your best intentions at heart.

On occasions this can be frustrating, especially when you are trying to re-learn to do new things for yourself. Try not to get angry at those who are too helpful. Explain your situation to them and what you are trying to achieve in a passive tone.

Let them know that it's important for you to learn to do things for yourself, even if it takes longer for you to do them. Like anything, it's a process and you will need friends and family to be supportive. (5)

(4) Bani Saberi O: Feelings In: In Motion Volume 13, issue 6 (internet cited 2013 Nov 22) Available from: http://www.amputee-coalition.org/inmotion/nov-dec_03/feelings.html. (5) Custodio JS: How to deal with Rude People (internet cited2013 Nov 22) Available from http://www.relating360.com/index.php/how-to-deal-with-rude-people-3-24410/.







Finding Your New Normal

One of the most important things for people who face a life changing event is getting their lives back to the way it was prior to that event. The same applies for people who have had an amputation. Some people call it, finding their 'new normal'.

People lose limbs for a variety of different reasons. Adapting to limb loss can take time; especially due to the fact that it's permanent. For this reason it is common for people to seek out their 'new normal'. This may be taking part in day to day activities like going to work, meeting with friends, cooking dinner for the family or shopping at a local centre.

For some people finding their 'new normal' and knowing when that time has come means that they are back on track and starting to make progress in their world. When you find your 'new normal' and start to feel comfortable in your own skin, you can get on with your life, move forward, and start living again.



Appendix

Glossary of Terms:

You may find that your doctors, nurses and the medical team will use words which are unfamiliar to you. Here is a list of commonly used terms and if you don't understand something make sure that you ask.

AE above elbow amputation

AFO ankle foot orthosis
AKA above knee amputation
Abduction away from the body
Adduction close to the body

Alignment position of socket in relation to foot and knee

Amputation loss of part or all of a limb below elbow amputation

Bilateral double amputee

BKA below knee amputation

Check Socket a test socket which can be adapted for comfort and fit

Compression stocking an elastic garment to assist with swelling and blood flow

Cosmesis aesthetic covering of a prosthesis

Donning putting on the prosthesis

Doffing taking off the prosthesis

Dorsiflexion pointing foot upward toward the body

Eversion to turn outward

Extension straightening of the joint Flexion bending of the joint

Gait manner of walking or moving

Lateral outside of the leg

Liner the component which is worn inside the socket

Medial inside of the leg

Neuroma end of the nerve left after amputation
Oedema swelling of the stump or residual limb

Plantar flexion toe is pointing down

Prosthesis the artificial component of arm or leg

Residual limb the part of the limb which is remaining after an amputation

Rigid dressing the hard cast which is applied to the residual limb

Shrinker a compression sock to reduce swelling

Transfemoral above the knee
Transhumeral above the elbow
Transradial below the elbow
Transtibial below the knee

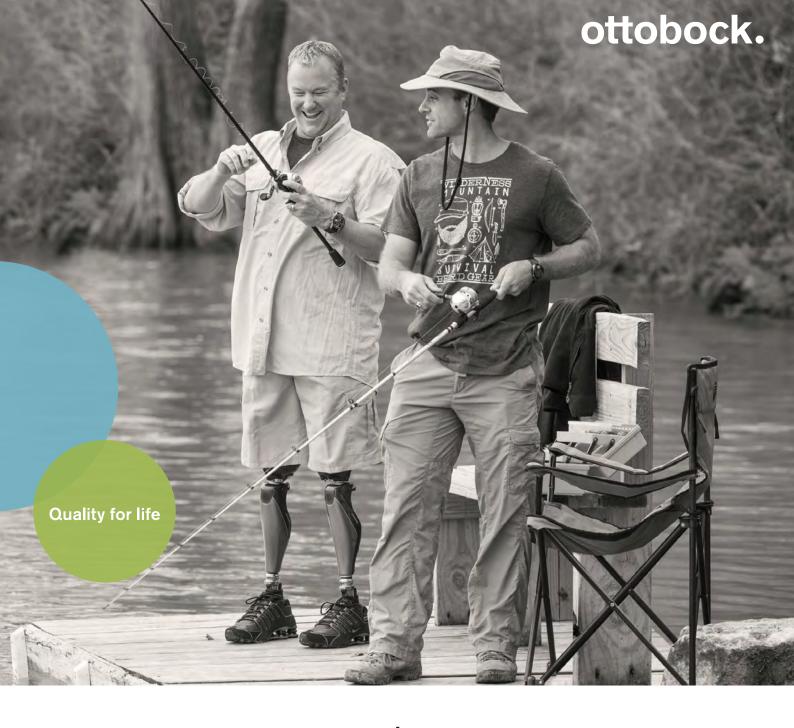
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The New Genium/X3

Reclaim your life

Whether taking the first trusting steps after an amputation to regain confidence or extensively hiking over rough cliffs in an exotic holiday destination, the aim is to move naturally, freely and safely. The new Genium/X3 knee joint opens up possibilities that were unthinkable a short time ago.

The Genium/X3 microprocessor knee combines unique technology, function and intuitive use to ensure the knee joint responds immediately in real time for amputees walking, running and even changing speeds suddenly.

For information on the Genium/X3 please visit **Ottobock.com.au**. Alternatively you can speak to your prosthetist or an Ottobock representative to find out more.





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