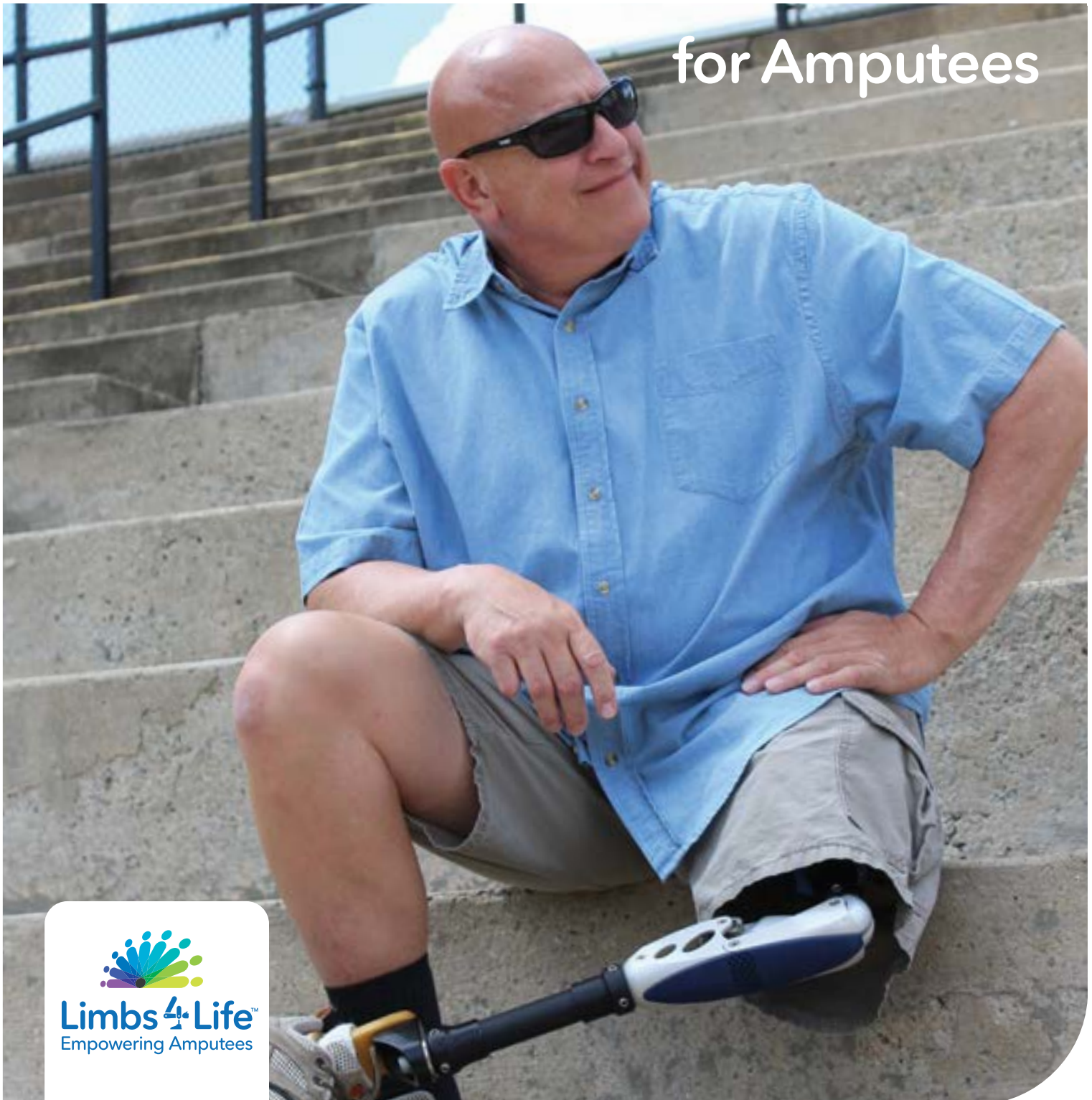


A Practical

Guide

for Amputees



Limbs 4 Life
Empowering Amputees



We empower amputees with knowledge and support to make a real difference, because no one should have to go through limb loss alone.

Limbs 4 Life would like to acknowledge and thank the peer support volunteers, our members and the healthcare providers who generously contributed to this publication.

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Contents

Introduction	4	How your Prosthesis is Made	27
Hearing the News	5	The importance of socket fit	29
The decision to amputate	7	Caring for your Residual Limb	31
Becoming an amputee	7	Increased body temperature	33
Adjusting to limb loss	7	Hair removal	33
Emotional health and wellbeing	8	Prosthetics Explained	34
The Benefits of a Peer Support Network	9	Funding for a prosthesis	36
Amputation	12	National Disability Insurance Scheme (NDIS)	38
Sites of amputation – Common terms	13	Selecting your service provider	38
The surgery	14	Assistive devices	38
After the surgery	14	Returning to your Place of Residence	39
Pain	14	Going home safety	40
Movement therapy	14	Tips for lower limb amputees	40
Removable Rigid Dressings	15	Tips for upper limb amputees	40
The Early Stages of Recovery	16	Driving	41
Who is involved in your care?	17	Employment	41
Rehabilitation Consultant (doctor)	17	Parking and travelling	41
Occupational Therapist	17	Health Matters Preventing Future Problems	43
Physiotherapist	17	Physical health	44
Prosthetist	19	Feet	44
Social Worker	19	Weight management	45
Nursing team	19	Managing change	45
YOU	19	Emotional Health	46
Managing Pain	20	Sexuality and intimacy	47
Phantom sensation	21	Body image and self esteem	47
Phantom pain	21	Family and friends	47
Reducing the pain	21	Finding your new Normal	48
Developing Good Habits	23	Appendix	50
On-going complications	24	Glossary of Terms	50
Sockets and socket fit	25		

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, 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. In addition, some children are born with limb differences. Regardless of the cause, amputation or limb loss 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 the needs of your family.

At Limbs 4 Life 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 when you need it the most.

Hearing the News





Learning that you are facing an amputation can be a frightening prospect. Coming to terms with the thought of surgery is not always easy and can lead to many questions. Spending time in hospital is usually stressful for everyone.

To assist with your preparation for surgery, try to access as much information as you need so that you can understand what lies ahead of you. Make a list, and write down any questions or concerns you have. Arrange a time to discuss these questions or concerns with your doctor or healthcare provider.

It can sometimes be helpful to take a family member or friend to medical appointments with you for support. Friends and family members can help you by taking notes during these appointments especially if you're concerned that you may not remember all the information you are given.

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

After surgery, some people may complete the healing process at home. 'Hospital in the Home' (HITH) or 'Rehabilitation in the Home' (RITH) are both services which are comparable to what you would receive in hospital. These services provide access to a range of healthcare staff who will assist with your recovery. Options will vary depending on where you live.

They can also ask questions on your behalf.

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 and/or functional outcomes
- Speaking to a rehabilitation consultant (doctor) about your recovery process, your 'treatment care plan' and what will happen after surgery
- Requesting to meet another amputee (peer support volunteer)
- Speaking to your doctor about pre-surgical therapy and what you can do in the lead up to your operation

If your treatment care plan includes sending you for rehabilitation after your surgery, ask about the programs and services that the rehabilitation facility have in place. If you are not going to be admitted to a rehabilitation facility, find out where you will be going and what supports will be available for you.

The decision to amputate

Whether your amputation is due to disease, infection, cancer or trauma; the opportunity to save a limb is not always possible. For some people, the choice to undergo an amputation is completely out of their hands. While for others, the decision to amputate can be a very difficult decision to make, and it is normal to fear the outcome.

The decision to have an amputation to achieve a better outcome, especially if the limb is compromised by a birth deficiency or as a result of failed surgeries and long-term pain, can be the best decision you will make in your lifetime.

Many people are able to regain their physical function with the use of a prosthesis or mobility device, and get back to the things that they used to enjoy, without the pain that they were once experiencing.

At this time, people usually have questions. These questions may include:

- How will I manage day to day tasks?
- How will I look after myself?
- Will I be able to regain my independence?
- Will a prosthesis give me quality of life?
- Will I be able to do the things I used to do?
- Will I still experience pain?
- How different will my life become?

It is normal to seek answers to the questions you have. Ask as many questions as you need to, and access as much information as you can. After all, the more equipped you are with information, the more confidence you will have over decisions in your future.

Becoming an amputee

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

Adjusting to limb loss

Everyone reacts differently to the loss of a limb/s. Limb loss can leave you feeling anxious, vulnerable and uncertain about the future. Your body has experienced a significant change. It is important to remember that your ability to adapt to these 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/functionality
- Concerns with your body image and sexuality
- General everyday changes to your lifestyle

It is completely normal to feel strong emotions. Some people grieve for their loss. You may be feeling 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 later, or years down the track.





Emotional health and wellbeing

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

- 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 how you are feeling and can help you to adjust 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 online discussion group. Online groups can provide connections to the wider community.

- Seek professional help. If you are experiencing depression, anxiety, anger, denial or grief following your amputation it is important to talk to a member of your healthcare team or your local doctor. You may like to speak to a trained counsellor to help you deal with 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 as this will help you deal with the changes of how your body looks and feels.

Support can be accessed through:

Lifeline - Crisis Support 13 11 14

SANE Helpline 1800 18 7263

Beyond blue - 1300 22 46 36

or a mental health support organisation in your community.

The Benefits of a Peer Support Network





"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 insight to your new situation.

Peer Support Volunteers are amputees like you; they are 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 hard earned knowledge and 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 about day to day activities; this may include using a prosthesis, using a wheelchair, driving a modified car, sport/s and community activities, along with addressing concerns of a personal and private nature.



Accessing supports

There are a number of ways you can access amputee peer support through Limbs 4 Life. 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, the rehabilitation facility and/or in a public location. All you need to do is contact us to request a visit or alternatively ask one of your family or your healthcare team members to arrange a visit on your behalf.

Face to face support will enable you to meet with a peer volunteer, prior to or following surgery.

Phone support can be provided to anyone at any time. If you would like to speak to a volunteer you can contact Limbs 4 Life and we will match you to a volunteer who will contact you, at a time to suits you.

Virtual support is for those of you who would prefer to chat to someone online. You can join the conversation in our Facebook group. 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. Visit **'Amputees - Limbs 4 Life.'**

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 a particular activity. If you would like information about groups in your area contact us directly.

"Meeting other amputees really helped my husband. It also made a big 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 years
below knee amputee

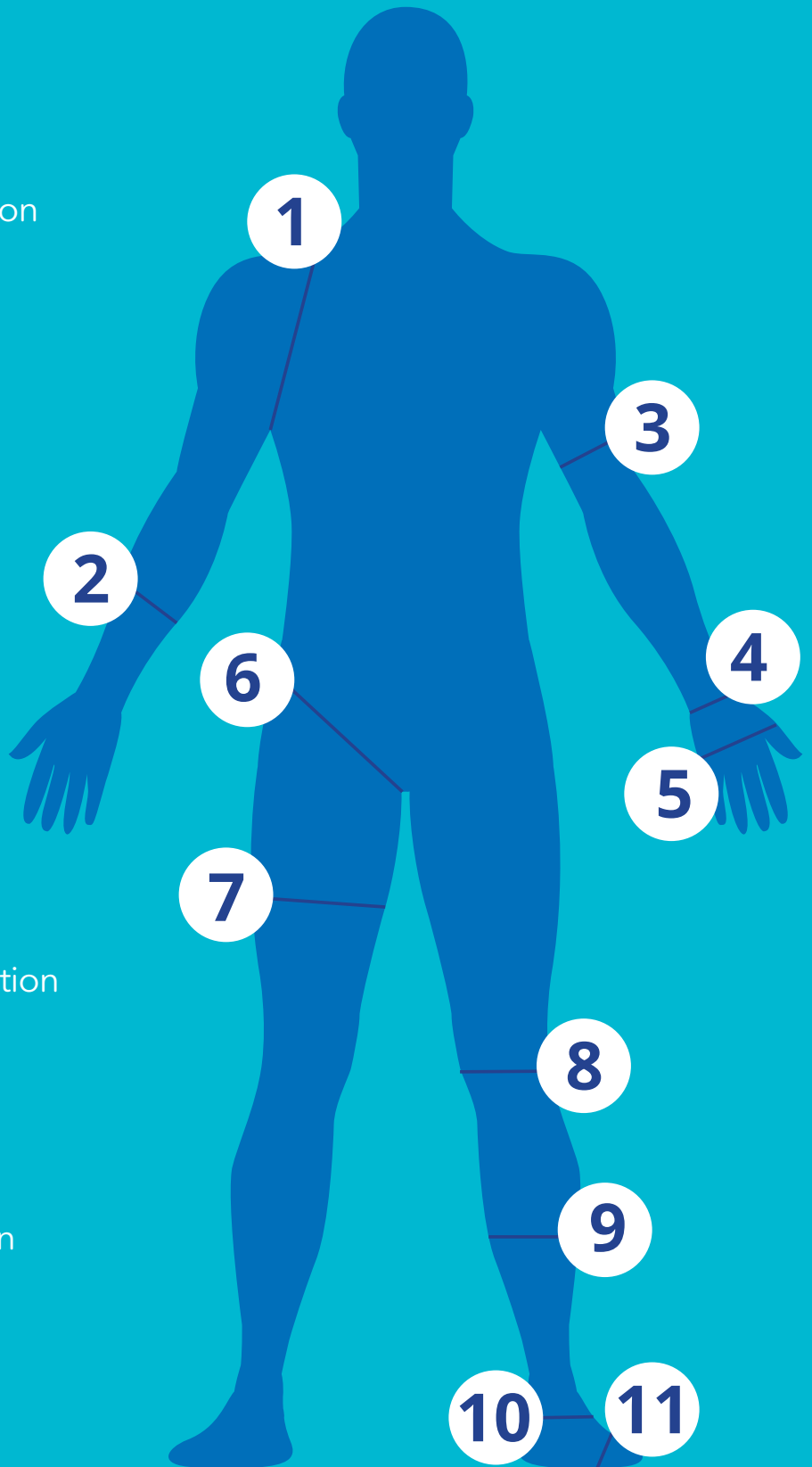


Amputation



Sites of amputation Common terms

1. **Shoulder**
Shoulder disarticulation
2. **Below Elbow**
Transradial
3. **Above Elbow**
Transhumeral
4. **Through Wrist**
Wrist disarticulation
5. **Partial Hand**
Transmetacarpal
6. **Hipdisartic**
Hip disarticulation
7. **Above Knee**
Transfemoral amputation
8. **Thru Knee**
Knee disarticulation
9. **Below Knee**
Transtibial amputation
10. **Symes**
11. **Partial Foot**



The surgery

For most people, the purpose of amputation surgery is to remove the infection or disease to enable the limb to be healthy. At the same time, and where possible, surgeons try to save as much of the limb so that it may be possible for an artificial limb (prosthesis) to be fitted.

After the surgery

Each hospital will have a different system in place for managing your residual (stump) limb care 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) re-applied 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.

TIP

If you suddenly experience new pain that does not settle down with your current treatment notify the healthcare team immediately. It is best to be sure that there are no underlying problems, for example your bandages or dressings being too tight.

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 during the first few weeks and will usually require some medication in the short term.

Movement therapy

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

If you are a:

lower limb amputee

- the staff may arrange a wheelchair for you so that you can begin to move around.

upper limb amputee

- the physiotherapist will assess your balance and leg strength and start you walking with or without appropriate supports.

upper and lower limb amputees

- it is important to maintain your flexibility and strength in the joints above the level of your amputation and your therapists will assist you with this.



Removable Rigid Dressings

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. The purpose of this hard-cased dressing (which looks similar to a helmet) is to protect the wound and prevent increased swelling. A RRD should provide protection if you have a fall, bump or knock your residual limb (stump). Once fitted with a RRD it is important to wear it for all transfers in and out of bed and any time you are using crutches, a wheelchair or moving around.

RRD's are usually tailor-made to suit each individual. In most cases, hospitals will engage the services of a prosthetist to manufacture this for you.

In the early stages following an amputation, below knee amputees can be more prone to swelling in the stump if the knee is bent for long periods of time. This can lead to shortening of the muscles (also known as contractures), increased pain and reduced movement in the knee joint.

During the beginning of your recovery it is important not to hang your leg over the side of the bed, or over the edge of your seat/wheelchair for more than a few minutes at a time, and/or when transferring, showering or doing your exercise programs. Make sure you use a suitable stump support at all other times.

Upper limb amputees may have the limb bandaged or fitted with a light compression garment to control any swelling. For below elbow amputees, it is important to maintain good movement at your elbow and shoulder level.

TIP

Even though you have had an amputation it is not unusual for you to feel like your leg is still there. Take care when getting up out of bed, and think about what it is that you are going to do, prior to doing it.



The Early Stages of Recovery





Acute hospital

Discharge destinations

- ⇒ Rehabilitation facility
- ⇒ In/outpatient rehabilitation
- ⇒ Hospital/rehab in the home
- ⇒ Supported care facility

The pathway to your recovery can vary depending on where you live. The length of your recovery time may depend on the cause of your amputation together with other physical factors, your medical condition and your general health.

The news that you are ready to begin the rehabilitation phase of your recovery is a positive sign. Whichever pathway your journey may take, it means that you are well enough to move on and progress with the next phase of your recovery.

Everybody's recovery journey is different and can follow a different treatment pathway. When we talk about treatment pathways we mean: the people involved in your care, the people that will help you along the way, how you will be cared for, what supports you will receive and where your discharge destination will be.

Who is involved in your care?

The amputee rehabilitation and recovery process is different for everyone, and can vary between facilities, states and territories. There may be a number of different healthcare team members involved in your care. Your healthcare team will work with you to help you to regain your independence and increase your confidence and help you to develop and achieve your goals. It is important to have recovery goals.

You should discuss your goals with your healthcare team and work with your team to develop a plan for your recovery.

The healthcare team who may be involved in your care can include:

Rehabilitation Consultant (doctor) - oversees to ensure that your health and medical needs are being met. Your doctor together with your team will assess if you are fit and able to use a mechanical/assistive device, such as a prosthesis.

Occupational Therapist - helps you to adjust to day to day activities, like personal care, domestic tasks such as: meal preparation, accessing your place of residence, education or work readiness. If you are an upper limb amputee the Occupational Therapist will assist you with the functional training of your prosthesis.

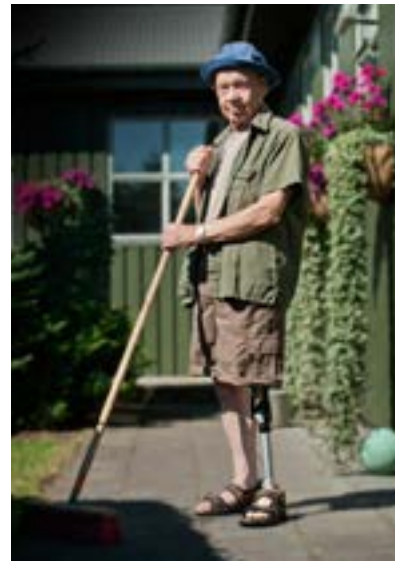
Physiotherapist - will design an exercise program tailored to your needs. They will assist you to regain your balance, flexibility, strength and stamina. They will help you to use mobility aids such as: wheelchairs, walking frames, crutches and other assistive devices suitable for you. If you are a lower limb amputee they will assist you to use a prosthesis.

TIP

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

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Prosthetist - will look after the design, manufacture, supply and fit of the prosthesis. Together, you will discuss and decide on the prosthetic components to suit your needs and lifestyle. They will also teach you how to 'donn and doff' (put on and take off) your prosthesis, and start your prosthetic training.

Social Worker - will provide confidential counselling assistance for you and your family. They can assist you with emotional support. Social workers will provide assistance with financial matters (e.g Centrelink), transport, disabled parking permits, multi-purpose taxi cards and your accommodation requirements.

Nursing team - assist you with medications, personal hygiene like bathing and dressing and any wound care and diabetic management that is required. They will liaise with your healthcare team about your specific needs or any referrals you may require.

YOU

The most important member of your recovery team is YOU. From the onset, you will be encouraged to play an active role in your recovery and care.

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

Diabetic educator

Dietician

Exercise physiologist

Pastoral care worker

Podiatrist

Psychologist (clinical or neuropsychologist)

Sexual health counsellor



TIP

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."

Peter 62 years above knee amputee

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 feelings in the limb that is no longer there.

Phantom sensation

Phantom sensation is a feeling in the limb which is absent. Some people feel like their limb is still there, even after surgery. This is normal. You may have feelings or sensations in parts of the limb such as: the toes or the fingers, the shin, elbow or even the knee which have been amputated. You may experience sensations such as: pins and needles, an itch or tingling sensations.

Phantom sensation is common following amputation. 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 way to re-learn, and this is helped by increasing normal input, for example; 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 phantom sensation, 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 and when you're feeling sleepy, or when it's dark, you may try to use it. (For example: getting out of bed during the night (like you did before) to go to the toilet.

To prevent falls in the early stages following amputation, it's important that you concentrate when moving from your bed to a wheelchair. If you don't feel confident moving or transferring, ask for help.

Phantom pain

Phantom pain sometimes occurs in the weeks following amputation and, like phantom sensation, can reduce over time. Some people find this pain very uncomfortable. 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 team so that they can work with you to decide which pain management solution will work best for you.



Phantom pain may return on occasions, for example: when you are unwell, over tired, feeling 'stressed' if your prosthesis is not fitting correctly and if there are problems with your residual limb (stump). Some amputees experience more pain due to a change in weather conditions and surrounding environments.

Reducing the pain

One of the successful ways to manage phantom pain is diversion therapy. Diversion therapy is when you try to focus your attention on doing something different. Such as: moving if you have been sitting still for a while, or touching and massaging your residual limb. Some people use things like: listening to music, talking to a friend or playing a game, to help take their mind off the pain. Basically anything that takes the focus of your mind away from the phantom pain can be a useful way for the pain to stop.

The use of other therapies can be helpful, these can include: massage or stretching and mirror therapy. Other people are comforted by the use of heat or cold packs; (these should only be used if you can feel hot or cold sensations well).

Transcutaneous Electrical Nerve Stimulation (TENS) machines generate electrical impulses through the skin surface that are transmitted to the spinal cord and brain. These different messages from your residual limb (stump) can create a diversion and therefore disrupt and reduce the pain. It is always recommended to speak with your healthcare team to discuss the use of other treatments for phantom pain to make sure you are using a method that is safe for you.

Don't be alarmed, your healthcare team can assist you with techniques to manage phantom pain. Most amputees report a reduction in phantom pain over a period of time.

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Developing Good Habits



Losing a limb/s will impact the balance of your body. Whether you are an upper or lower limb amputee, the best thing that you can do is to make every effort to have good posture and (and if you are using a prosthesis) a good 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.



If you are a lower limb non-prosthetic user it is important that the seating and back support on your wheelchair provides and promotes a good sitting posture. The seating/cushion needs to be comfortable and give you suitable pressure relief to prevent skin problems. 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.

Gait = a person's manner of walking

Posture = a particular position of the body

On-going complications

For those of you with a single-side amputation, it will be normal to put more stress through the non-amputated side of your body. People often do this to make up for their missing limb especially in the early stages of prosthetic training. This can be 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 by your healthcare team. **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.

People living with **upper limb amputations**, (whether they are using a prosthesis or not), need to take care of their neck, upper back and shoulder areas to prevent long term pain. Flexibility of the neck and upper back, along with neck and shoulder-blade control exercises will be very important in the long term.

TIP

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 made just for you, according to the condition and shape of the residual limb.

For lower limb amputees, the prosthetic socket usually consists of a liner (or stump sock), a weight bearing (hard) outer wall which forms the connection to other components such as knee joints and prosthetic feet. Similarly, the socket for upper limb amputees forms a connection to other components such as elbow and wrist joints or hands. The liner or stump sock helps to protect the skin inside the hard shell of the socket. The liner works to minimise friction and rubbing between skin and the socket.

When prosthetic sockets are fitted, your prosthetist will often make what is called a check (test) socket first; a clear see-through socket which enables the prosthetist to see any pressure areas 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 made the fit should be more comfortable 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 you are first fitted with a prosthetic socket it is likely that it will feel unusual. Adjusting to taking pressure through a different surface of your body when standing and walking, for example: the shin bone and back of the lower leg instead of the sole of the foot (for a below knee amputee) may take you some time to get used to.

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 'good' 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 is due to the fact that our bodies and stumps are living things which are constantly changing in size and shape. Your prosthesis, however, is an object which is fixed in size and shape.



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How your Prosthesis is Made



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

The Importance of socket fit

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.**

A poorly fitting socket in **UPPER limb** amputees can;

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

TIP

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

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. This includes; maintaining your diet and regular exercise; and, secondly by constantly reviewing how you feel in your prosthesis, checking the skin and contacting your prosthetist if you notice a change. Some people's residual limbs don't change. They wear the same limb and suspension system day in day out without any problems, while others will need to make several adjustments over the course of the day. Speak to your prosthetist about problem solving ideas which may be helpful for you.

How often will I need a new prosthesis?

In the early stages following amputation 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 additional sockets during this time. It's worthwhile to have an annual maintenance check to ensure that everything is working well.





PROSTHETIC SOLUTIONS FOR AN ACTIVE AND INDEPENDENT LIFESTYLE

At oapl, we understand that having an amputation can be a traumatic and challenging experience.

With over 30 years in the profession, patient care is our heritage and our inspiration. Seeing the real life difference we make in patient's lives for us, is what it's all about.

With an extensive number of prosthetic and orthotic professionals around Australia, you can rest assured that oapl clinical care is always within reach.



Need funding assistance?

Call us to discuss your options, including the National Disability Insurance Scheme.



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.
- 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 you 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.

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 prosthetist more frequently during this time. During the second and third year, your body and stump will start to stabilise and the need for adjustments (changes) to your prosthesis will become less frequent.



TIP

Any red marks or changes to your skin 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 think about:

- **Skin hygiene** is very important; you should wash, clean and dry your residual limb (stump) daily, when bathing or having a shower as part of your regular personal hygiene routine.
- **Stump socks and prosthetic liners** should be cleaned and changed daily with a gentle fragrant-free anti-bacterial soap, and rinsed well. More often if you sweat heavily during warmer months. Always dry your socks and liners properly.
- **Stop** wearing your prosthesis if you have any pain or discomfort.
- **Wear** safe and comfortable shoes.

Residual limb pain can sometimes be caused by sensitive scar tissue, neuromas and other underlying issues such as; a poor fitting socket or a prosthesis which is not aligned correctly. If you are experiencing pain, speak to your prosthetist immediately.



Increased body temperature

Amputees often report an increase in their body temperature. This can be caused by a number of reasons;

1. 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 use the warmer the body gets. This can lead to a loss of heat tolerance and greater amounts of perspiration/sweat

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

You may find that during warmer months you will need to change your stump socks more frequently. You may also need to take off your liner and dry it (if you sweat a lot) and re-donn or swap it with a clean, dry liner.

Hair removal

Amputees regularly ask about shaving or waxing their stump. Your healthcare team will discourage you from doing this. If you do decide to wax or shave your stump and 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.

Prosthetics Explained



Prosthetics come in many shapes and sizes. You, your prosthetist, physiotherapist and your doctor will work with you 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
- Any 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 limits 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 help 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 and/or other problems occur, some types of prostheses may be hard to put on properly. If you put on (donn) your prosthesis in the wrong way it can cause problems and be unsafe and uncomfortable, your doctor or prosthetist may suggest a simpler prosthetic system in order to keep you mobile and functioning.

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



If you are a lower limb amputee sometimes prostheses, or the components of a prosthesis, are referred to by their '**K**' classification. This is simply a measure of activity, for example:

- **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, e.g. sports, manual work.

TIP

Regardless of your level of amputation; if you are going to use a prosthesis you need to use it regularly to maintain your skills.

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. A person fitted with an above knee prosthesis may need to use up to sixty percent more energy to walk. For this reason some people choose not to use a functional prosthesis. If this is the case the option of a 'cosmetic-only' prosthesis could be the best choice.

People with upper limb amputations may decide not to use a prosthesis at all and/or may only wear a prosthetic arm for certain activities such as: work around the home, riding a bike or doing a particular activity.

Funding for a prosthesis

People are often concerned about the costs involved in getting a prosthesis. During the course of your treatment the funding for your prosthesis should be discussed with you. 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 and/or if eligible, the National Disability Insurance Scheme (NDIS).

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 kind to yourself, and take time to think about how far you have come as you work toward regaining your independence, mobility and confidence.

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 (NDIS) if you are under the age of 65
- If you lost your limb in an accident and there is no compensating body, for example at home or during recreation, then the public health system or the National Injury Insurance Scheme (NIIS) will cover the cost of prosthetic limb/s. (Note the NIIS is still a work in progress, funding will be provided by the NDIS in the meantime)
- If your amputation was due to trauma 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 or the Defence Force.
- Most Private Health Insurance companies do not allocate funding for prosthetics, however it is worth checking with your insurer if you are uncertain as they may cover partial costs.

Because there are different kinds of funding, 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.

TIP

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



If 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 have set limitations based on manufacturers' guidelines and expected periods of use for a component. However, if the prosthesis or socket needs changing before the usual time period, then your Prosthetist may refer you back to your amputee clinic for further assessment.

If you are funded by the public health system, you can make personal financial contributions toward your prosthesis if you want particular componentry that public funding does not cover.

It is important to remember that you can trial most 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

to try before you make the final decision about which device is best for you. 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

You are not limited by the number of devices you can try; however, it is usually only two or three at the most. If you have an urgent issue related to your stump/residual limb organise a review with your GP or local emergency department immediately. If it is a persistent issue that could be related to your prosthesis a review with your amputee specialist would be beneficial. 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. The NDIS is progressively being rolled out across each state and territory, with the exception of Western Australia, who have adopted their own Scheme. (see WANDIS for more information).

If you are under 65 years of age and would like more information about the NDIS contact their office on 1800 800 110 or visit the website ndis.gov.au. You can also request a free copy of the 'NDIS Guidebook for Amputees and People with Limb Difference' from Limbs 4 Life to help you to navigate the transition and goal setting process. As a participant of the NDIS it is very important that you can clearly outline your goals, how you will achieve your goals, and how your goals will assist you to live an ordinary life. The NDIS refers to prosthetics as Assistive Technology or (AT).

Selecting your service provider

In each state and territory there is a variety of prosthetic clinics. You may decide that you would prefer to see a prosthetist who is close to home, or close to your workplace. It is entirely up to you

who you choose to make your prosthesis. You may even prefer to meet with a couple of different prosthetists to discuss your needs.

A list of prosthetic service providers can be found on the Limbs 4 Life website. Go to the '**Find a prosthetist**' section to find out more.

Assistive devices

An assistive device is the name given to equipment which aids your ability such as: wheelchairs and walking aids. If you are publicly funded, financial assistance for some aids and equipment including: wheelchairs and home modifications like ramps, bathroom equipment and shower chairs and vehicle modifications (such as left foot accelerators, hand controls or wheelchair car hoists) are available from some state/territory-based schemes. But there is likely to be a waiting period.

You should seek information relating to the funding available prior to purchasing any equipment. Speak to your healthcare team for information relating to these items.

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

Returning to your Place of Residence



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'.

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 can be very different to navigating the way around your home. Many homes have lots of stairs to access the property, carpet instead of vinyl floors, toilets and bathrooms that are not always easily accessible and doorways that are small and difficult to enter or exit.

Ensuring that you are going to a place that is safe and accessible is important. Your occupational therapist will discuss options for modifications and assistive devices prior to your discharge. They may arrange a visit to your place of residence (with you where possible), to discuss your needs.

There are a number of things that you need to consider prior to leaving hospital:

- Think about how you will access your home?
- Is your home accessible to move around?
- Can you get into and out of the shower/toilet?

It is important that your place of residence is accessible and safe.



Below are a number of suggestions that you may wish to consider:

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
- 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
- Anti-slip mats for the shower/bathroom floor are 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 shoes 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.



Driving

Driving may be an important part of your independence. If you have medical approval and your health checks out you will be able to have your licence re-instated. In some states/territories people are required to be re-tested for their driver's license and/or have restrictions placed on their licenses 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, wheelchair hoists and the installation of spinner knobs or hand controls. Some people even manage to ride their motorbikes again. Push bikes and motorcycles can also be modified if required.

The modification of a vehicle can vary depending on the age of your car and the state you reside in. Some states offer financial support via their aids and equipment programs.

Employment

If you were employed prior to your amputation, then going back 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 re-train for a different job role; especially if you are no longer able to fulfill your previous working requirements. Career advisers can assist you to develop a return to work plan. If you are eligible for the NDIS, you might consider returning to work as one of your goals.

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

The Multi-Purpose Taxi Program provides the user with a financial discount on the metered fare. The discount value can differ in each state or territory. (Conditions apply). 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 travel vouchers to cover the cost of travel to medical appointments. Ask your healthcare provider for information regarding financial travel support.

While many hotels offer accessible rooms not all accessible rooms comply with the Australian standard, making it difficult for people to be independent away from home. If you have specific requirements relating to your accommodation needs, speak to a representative from the hotel rather than the appointed booking agent.

If you require assistance with air travel and support to go to and from the gate lounge and/or onto the aircraft, advise the carrier at the time of making your booking.



Health Matters Preventing Future Problems



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.

Physical health

Feet

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.

Here are a few tips to keep in mind;

- 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

TIP

Early treatment of foot wounds increase the possibility of healing. **DON'T WAIT.** If you have noticed a change, contact your doctor, podiatrist or healthcare provider immediately.

MISMATCHED FEET?

SIZE 7 LEFT

SIZE 8 RIGHT

NO PROBLEM WITH

IIFIT

With 60% of the population having different sizes between their left and right feet, the Ascent **IIFIT** range helps achieve the perfect fit!

IIFIT is a service from Ascent where you only pay for what you need, giving you the perfect footwear fitting solution. The **IIFIT** range can also greatly assist Polio sufferers, Diabetics and partial or full foot amputees.

Whether you need a traditional pair, mismatched pair or an individual shoe, the Ascent **IIFIT** range gives you a customised fit. **No wait, no extra cost!**

Only pay for what you need!



Traditional or Split Pair
Same price, no upcharge,
no waiting.



Half a pair.
Half price



ascentfootwear.com





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 2-3kilograms will be 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.

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.

There are so many types of prostheses and people are all individual. 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 a question.

Emotional Health



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.

Body image and self esteem

Following an amputation, individuals are often concerned about their appearance and how this will impact on 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.

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.

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. 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.



Finding your 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.

Some people adjust to the use of a prosthesis faster than others. Some people don't use a prosthesis and need to adjust to using crutches or a wheelchair, some people need to teach themselves new skills; like writing with their non-dominant hand. For this reason it is common for people to seek out their 'new' normal. A 'normal' way of doing the things you used to do; differently from how you did them before.



This may be things like taking part in day to day activities including: going back to work, meeting with friends, cooking dinner for the family or shopping at a local centre. It also may mean being able to move around your home and feeling confident and safe doing so, getting back out into your garden/your local community, spending time with your friends, or planning that holiday you have always dreamed of taking.

For some people finding their 'new' normal and knowing when that time has come means that you are back on track and starting to make progress in your 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

BE 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 for shrinkage, and to aid in swelling and prior to a prosthetic fitting

Shrinker a compression sock to reduce swelling

Transfemoral above the knee

Transhumeral above the elbow

Transradial below the elbow

Transtibial below the knee

Limbs 4 Life is the peak body for people living with limb loss in Australia.

As part of our mission, Limbs 4 Life aims to empower amputees with access to support and information.

We provide this via:

- Our Peer Support Program: connecting new amputees (and their families) with trained volunteers who have adapted to amputation,
- Access to our free publication Amplified magazine,
- Providing information and support regarding navigating the healthcare system, prosthetic funding and services,
- The provision of Fact Sheets about specific areas of interest for amputees and their families,
- Our information rich website limbs4life.org.au,
- Our online discussion groups such as: Amputees - Limbs 4 Life (on Facebook).

If you, or someone you know needs support, or you would like to join our mailing list to receive regular updates please contact us:

Phone: **1300 782 231 (Toll Free)**

Email: info@limbs4life.org.au

Web: limbs4life.org.au

Making a real difference together



Quality for life

Meridium Reclaim your way

- Automatically adjusts to allow foot flat for stable and safe standing even on slopes and uneven terrain
- Change footwear from sandals to stilettos without compromising safety, functionality or even pressing a button. It's self adjusting!
- Increased toe clearance for fewer stumbles and greater safety
- Real time adaptation to changes in walking speed. You don't have to "wait" for your leg anymore.
- Customise the foot performance from your smart phone

Experience a new level of comfort, control and stability with an obligation free Meridium trial.

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