

NEWS FROM LIMBS 4 LIFE

limbs4life

amplified

WINTER 2016

Health & Wellbeing Edition

*Meet Fay Keegan
- Hiking to the top*

How important is a healthy diet?

How to cope with amputation?

*Are you getting the best out
of your prosthesis?*

*Making prosthetic choices
work for you*



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Fay hikes to the top

I was eleven-years-old and the 'sporty' child in a family of four children when I fell from a train at Sutherland Station, just past the end of the platform. My left foot was mangled in a turning wheel. The accident didn't make me who I am today - but I wouldn't be 'me' without it.

In the days following the accident I was told that, unless I got gangrene, the foot was saved; but I'd never walk again. From that moment I was determined to prove them wrong. It took six months of grueling physiotherapy to walk again, but walking was forever restricted.

I grew up in a Sydney suburb adjacent to the Royal National Park and loved bushwalking and sport. Those days were over. My foot would never again meet my demands upon it. My foot couldn't physically cope with attending school and I completed the majority of high school by correspondence.

Around me I felt there was little understanding of the complex impacts of trauma. I felt isolated and battled for years with feelings of denial, anger, grief and loss; not understanding (as I do now) that one can never truly understand situations unless one has had the same experience oneself.

After three years of rehabilitation and repeated hospitalisation for infections and plastic surgery my Orthopaedic Surgeon recommended amputation, saying I would live a more normal life. It was impossible to imagine being separated from my foot. I was terrified, feared the unknown, and refused.

The years that followed saw me frequently hospitalised with infections or surgery; pain was a constant companion. The legacy of the accident changed the course of my life. My foot was like an active volcano, always rumbling away and sometimes erupting. Months and months accumulated into years and years of hospital stays for unrelenting infections which were suspected to be osteomyelitis. Chronic ulcers stubbornly refused to heal - the foot was covered in skin grafts. I had surgery for decades to come.

On the October long-weekend in 2011, almost



forty-three years after the accident, I decided to investigate amputation. All that year, and most of the previous, I'd battled severe infection. My husband was doing all the shopping, cooking, everything. All I could physically manage was to go to work and sit. My foot had whittled my life and health away.

Medical investigations queried chronic osteomyelitis and I had seven weeks of IV antibiotics at home. During that time I consulted a Rehabilitation Specialist, an Orthopaedic Surgeon, a Vascular Surgeon and a Prosthetist. The Prosthetist reignited my hopes when he said I'll be able to hike further. I had never lost my desire to be able to hike again.

I searched for information and found the Limbs 4 Life website. I called and had a long conversation with Melissa Noonan, who sent me information and gave me references on elective amputation. My Rehabilitation Specialist gave the name of a Peer Support Volunteer and encouraged me to meet her.

I weighed up so many things. It was a hard time. Once I'd gathered and considered as much information as I could I felt there was only one thing to do; I booked a date for surgery in January 2012.

Without peer support, my two month wait for surgery would have been hard; I didn't know what to expect or how hard it was to have a prosthetic leg. As I listened to my Peer Support Volunteer share her experience of day to day life as an amputee, I began to count the days down to surgery as if it marked the start of a positive new beginning. I could see how well she coped and I became confident.

Before surgery, my Rehabilitation Physician advised me to have counselling throughout the decision-making and surgical process. As a Clinical Social Worker, I had regular Clinical Supervision and I worked through the issues in those sessions. I think my supervisor was concerned how happy and excited I felt because I'd finally given myself permission to let my foot go.

After surgery, I was prepared for a backlash to strike, for depression to kick in. It didn't. One day, in the rehab hospital, I realised that I'd done my grieving a long time ago – it cast a pall on my teenage years. Even so, I was not prepared for the emotional change when my new leg arrived and I started to walk again. I became happy, energised.

I had my goals firmly in sight: to be able to walk around our farm, walk in Sydney when I visited our children, to travel, and to start hiking again. My goals motivated me to work hard. In just under five weeks post-surgery, my new leg arrived. It took time to build tolerance to wearing my prosthesis, it was hard work, but from the first day I wouldn't let it out of my sight. By the time I arrived home I was walking with only the aid of a stick, and quickly gave that away within a few weeks. I was like a kid with a new toy; I didn't want to take the leg off at night, and I no longer had pain.

It was time to start walking, and I worked on a program developed with a physiotherapist who supported me over several months. On day one I walked 200m and that proved to be a lot of hard work. I gradually increased week by week until I could walk further and further and started hiking again.

Setbacks struck hard a few months after I reached a goal of hiking eight kilometers. The skin broke down on the stump and it took over a month to be able to use my leg again. There are always frustrations and setbacks in all rehabilitation; the path onward and upward is never in a straight line. In the early days progress seemed slow. I was still working, and noticed my energy levels were easily depleted.

With the setback, doubts arose. I began to question myself and my dreams. Will I achieve my goals? Will I be able to travel? Do I have the stamina to go flat out all day, every day as travelling demands? What if it is always as hard as it is now? Will I be worse off than I was before?

Those fears settled once I was wearing my prosthesis again.

Without the support I received from the amputee community my adjustment to amputation could have been a lot harder. Whatever comes our way, the traumas or illnesses or challenges, I have always believed it helps to have a sense of belonging - to know we are not alone, to be informed and to advocate for systemic changes to meet our needs.

We thank Fay Keegan for sharing her personal story in this edition of Amplified.

The importance of a healthy diet

Dietitians Association of Australia (DAA)

Balancing food intake and physical activity to avoid unwanted weight gain can be challenging for amputees, and especially lower limb amputees. But with a little know how (including knowing where to go for expert advice and support), you can strike the right balance.

Maintaining a healthy weight and waist measurement will cut your risk of diseases, such as heart disease and cancer, limit the need to have prosthetics adjusted and, importantly, help you feel your best.

Try the following tips from the Dietitians Association of Australia for maintaining a healthy weight throughout life.



Breakfast booster

We often hear about the importance of breakfast for maintaining concentration levels throughout the morning. What people are often surprised to hear is breakfast eaters are more likely to maintain a healthy weight than breakfast skippers. One of the reasons for this is that if you start the day with a source of filling protein and fibre, you are less likely to overeat later in the day.

Top tip:

Try a bowl of porridge during winter. Add ½ cup rolled oats and ½ cup of reduced-fat milk to a bowl (if cooking in the microwave) or the stovetop. Mix it up by adding different fruits for sweetness and a small handful of nuts or seeds for texture once cooked. For an on-trend twist (and a delicious combination), try adding mandarin segments and chopped almonds to your porridge.

Too much of a good thing?

One place where well-intentioned Aussies can unwittingly slip up is portions sizes. Start with a regular-sized dinner plate and imagine that it is cut into quarters. Aim to fill one quarter of the

plate with lean meat or meat alternatives like legumes, eggs and tofu; fill one quarter with grains like wholegrain rice, quinoa, cous cous or wholegrain pasta; and fill the rest (half your plate) with vegetables. And when it comes to fruit, a good guide over the day is around two serves. If you drink fruit juice limit your intake to a maximum of 125mL a day, as it provides a concentrated source of kilojoules.

Top tip:

Often restaurants and take-away outlets don't stick to these portions, which means that you need to be aware of how much you are eating, particularly if you eat out often. Ordering a side salad is an easy strategy, or you might choose to share your meal with a friend.

Go wild for veggies

There are a couple of reasons to focus on vegetables at main meal times. Non-starchy vegetables are very low in energy (kilojoules or calories) which means you can fill up on these with a lower likelihood that you'll put on weight. They are also a great source of fibre which is important for digestive health, but will keep you feeling fuller for longer. This is another way to make sure you aren't overeating higher energy foods.

Top tip:

You don't have to wait for lunch or dinner for a veggie-fix. We know that if you don't eat your first vegetable before 4pm, you're unlikely to get enough in your day. Try chopped veggie sticks for a snack, add some sliced tomato or mushroom to wholegrain toast for a different breakfast option, opt for a veggie soup at lunch (great during winter!), and look for new ways to include both raw and cooked veggies at lunch and dinner.

Snack wisely - Aim for nutrient-packed options

High energy (kilojoules or calories) snacks tend to be higher in saturated fat and added sugar, and lower in the vitamins and minerals that the body needs. These are the foods we tend to go for if we haven't eaten enough throughout the day (think 3pm chocolate cravings or the hot chips with dinner!).

While it is okay to include 'discretionary' foods occasionally, if they are a regular part of our day it can mean weight gain will creep up on you. So choose nutrient-rich snacks, such as fresh fruit, vegetable sticks and dips like hummus or tzatziki, unsalted mixed nuts or nut bars, tubs of low fat yoghurt, or wholegrain crackers and cheese, instead.

Top tip:

Don't forget alcohol in this category of discretionary foods. Alcohol is very high in energy – higher than both carbohydrate and protein – and provides very little nutrition. A schooner of beer provides almost the same energy as two slices of bread. So make sure that you factor in your alcohol intake when thinking about weight management.

Accredited Practising Dietitian (APD) – they're the experts in food and nutrition. APDs provide practical, tailored advice based on the latest science, and can help motivate and support you to take charge of what you eat.

Visit the 'Find an APD' section of the Dietitians Association of Australia (DAA) website at www.daa.asn.au to find an APD in your area.



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LIMB-itless Conference

Limbs 4 Life, in conjunction with Ottobock, hosted LIMB-itless, Australia's national amputee conference in April. This year's conference attracted an attendance of over two hundred people and provided delegates with the opportunity to hear from presenters covering a wide range of topics aimed at educating and empowering the amputee community.

Dr Lloyd Walker, National Disability Insurance Agency (NDIA) Director of Assistive Technology, shared valuable information about amputees transitioning into the National Disability Insurance Scheme (NDIS). Dr Natasha Layton (NDIA) also presented, with a focus on the 'user' experience of the NDIS.

In addition, there were a variety of speakers sharing tips and information about prosthetics covering topics such as socket alignment, socket technology, and learning how to develop a common language between amputee consumers and prosthetic clinicians. Other presenters shared information about managing phantom pain, ways to deal with skin conditions and learning about self-advocacy. Amputee physiotherapists enlightened the audience with information about the importance of gait patterns for lower limb amputees and posture for upper limb amputees. Presenters with specialities in childhood limb difference also spoke about education, paediatric prosthetics and building positive body image.

The conference closed with a moving personal story from Mike Rolls.

With disability conference funding support from the Australian Government Department of Social Services, Limbs 4 Life was able to pay for 36 amputees and parents of children with limb difference from around Australia to attend the Conference at no cost. Conference funding also enabled Limbs 4 Life to film a large majority of the presenters.



Watch out for the LIMB-itless conference presentation videos which will be available on the **Limbs 4 Life YouTube** channel very soon.





Practical coping strategies to help amputees and their families

Sarah Fitzgerald (Clinical Psychologist from Royal Talbot Rehabilitation Centre)

The loss of a limb can be devastating and is likely to cause significant disruption to many aspects of a person's life. As well as the expected effect on a person's mobility, independence and participation in day-to-day activities, it can also have a significant impact on one's occupation, relationships, community and leisure involvement. Moreover, for some, an amputation can disrupt plans for the future and affect how they view themselves and the world. Amputees are often required to cope with ongoing health issues (eg. pain), learn new skills and sometimes even modify their expectations in relation to their capabilities. Therefore, the loss of a limb requires major adjustment, both for the person and their family/friends.

Feelings of shock, anger, frustration, sadness and grief/loss are all common and normal, particularly in the initial stages. People also tend to experience increased stress and worry (eg. due to financial strain), along with feeling a lack of control and a sense of isolation. Given the challenges people face, it is not surprising that symptoms of depression and anxiety are common. Studies have found that after an amputation the prevalence of depression and anxiety is as high as 41 per cent. Therefore, it is important that people take steps to tackle

symptoms of depression and anxiety, as when left untreated they can have negatively impact on a person's recovery and rehabilitation, and physical and mental health.

There are a number of things people and their families can do that may help to facilitate the process of coping, with some coping strategies below.

Amputees experience various challenges and will have different reactions and needs dependent on the stage of their journey. For example, the challenges after surgery vary compared with challenges faced by someone learning to use a prosthesis.

In the initial stages, amputees may experience emotions such as sadness, shock and anger. It may be useful to discuss these feelings with others. This could be with a trusted family member, friend, or professional. Moreover, reminders that such reactions are normal and will typically pass with time are also helpful.

The initial stages can also be stressful. Therefore, practical strategies for self-care are recommended. This includes ensuring one has adequate sleep and is maintaining a good diet. Furthermore, relaxation, breathing

and mindfulness exercises are beneficial when experiencing increased stress. Should stress begin to disrupt one's life, it is important that they seek support from a qualified professional. And, the earlier the better as mental health issues such as depression are treatable.

When one is faced with health issues and associated life changes, countless research has shown the significant role that social networks play in facilitating coping. This is also true for people following an amputation. Therefore, staying well connected to family and friends is valuable. Family and friends can often provide practical and emotional support, and can reduce the sense of isolation that is commonly experienced. Additionally, peer support, whereby one can observe and talk with other amputees who have "successfully" managed challenges, may also help with coping and reduce the fear of the unknown.

A lack of control over the situation is also frequently experienced following an amputation. A useful tip to manage this is being involved in your care by asking questions of the doctors, nurses and therapy team.

This allows the amputee and their family to gather the information required to tackle any concerns, reduce uncertainty and plan for the future, thereby creating a greater sense of control. Remember there is never a silly question!

Having goals to work towards, particularly during rehabilitation, is imperative. Goals should be meaningful to one's life but also attainable and realistic and your therapists will be able to help develop such goals. Setting and achieving goals often provides people with a sense of purpose, structure, and improves confidence and self-esteem.

Similarly, having a daily routine and planned activities is a useful strategy that helps one to cope. It may keep people occupied, acting as a distraction, and prevents them from dwelling on their situation, which over time can be detrimental to physical and mental health.

However, one cannot always keep themselves busy. There will be times when worries pop up and may cause distress. Helpful tips for dealing with worrying thoughts include problem solving, taking action if able, relaxation, mindfulness and "letting go" strategies. It may also be useful to try to adopt an attitude of "taking things as they come".

Amputees have found that maintaining a positive/optimistic attitude can help with coping. "Put things into perspective" and reminders of one's achievements (both relating to rehabilitation/recovery and life in general) can encourage a helpful attitude. It is also beneficial to engage with a professional, such as a psychologist, to develop further coping strategies.

Finally, a key area in facilitating one's coping following an amputation is to ensure they are able to again participate in meaningful life activities, to re-establish a sense of normality and self-worth. This includes important life role, such as caring for themselves, being a family member and returning to work, driving and hobbies. Having a prosthesis can assist with one's integration back into such activities. Furthermore, we know from mental health research, participation in pleasant, community and social activities along with having a general purpose in life, are beneficial to one's physical and emotional wellbeing. Lastly, re-engaging in life's activities demonstrates to the amputee and their family that the loss of a limb does not define them.



Adjusting to an amputation takes time and people experience a variety of emotions throughout the journey. Utilising practical strategies such as self-care, staying in touch with support networks and being informed and involved in the recovery process can all facilitate the process of coping, leading to positive health outcomes.

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Cycling to support others

Since learning to walk on his first set of prosthetic legs as an eight-year-old little boy, Ray has never been one to take it easy. He's almost lost count of the number of legs he's worn through over the years, like he's lost count of the number of kilometres he's ridden on his hand cycle.

Ray, now 69, took up hand cycling when he retired from his successful business nearly ten years ago and these days he's seldom out of the saddle.

He's training for his sixth CyclePower ride, preparing himself for a 500km tour through the heat, humidity and rolling terrain of Cambodia and Vietnam.

CyclePower is a community development and fundraising initiative run by Victorian charity, Disability Sport & Recreation. Born from the belief that participation in sport and recreation is a basic human right, CyclePower is tangible proof that physical activity can empower and bring people together in unexpected ways.

Since its inception in 2011, the initiative has visited countries throughout South East Asia, supporting projects that improve the lives of people with disability across the region and at home. Ray has been part of every trip and has loved every kilometre.

This year, Ray and his fellow CyclePower riders are returning to Cambodia and Vietnam to continue the work they started there in 2012 with the Battambang Women's Wheelchair Basketball Team.

"Four years ago, the CyclePower initiative set up a pilot women's wheelchair basketball program for the local women with disability. "We donated wheelchairs and ran clinics. It really took off and now they've got themselves an American coach and are aiming for international competition. "I'm looking forward to catching up with the friends we made and to see how the wheelchair basketball team has grown," Ray said.

CyclePower challenges people's perceptions about what people with disability are capable of achieving and Ray loves nothing more than to raise a few eyebrows on his travels. "In the countries we visit, you seldom see people with disabilities in public places. "They see us zooming about all over the place and it freaks them out; they've never seen anything like hand cycles before. "We visit orphanages and the kids love to see us and give us high fives as we ride past," Ray said, with a grin.

If you would like to support CyclePower 2016 and help improve the quality of life for people with disability here and overseas, visit www.givematcher.com.au/cyclepower-2016.



The ArtLimb Team

In our day to day life we are constantly making decisions. When deciding on what bread to buy from the shop, we may spend seconds. When deciding on something that will impact on our lifestyle or health, we tend to take more time and effort. Usually we start by collecting basic information ourselves before speaking to different specialists to further develop our understanding and compare professional opinions.

This article explores the different situations for new and experienced amputees when making a meaningful choice about their prosthetic limb.

New amputees

For the new amputee, prosthetics can seem quite daunting and it is common to rely solely on the first piece of advice given. Leading up to and after amputation, there are many changes happening in life that can make prosthetics seem like a low priority. However, this first experience is very important for better recovery and begins with the gathering of information. Specialised websites, government organisations and amputee support groups should be the first origins of this information.

1. **Specialised websites:** can help explain the basics of modern prosthetics by providing information about modern approaches, technologies, components and introduce basic medical words related to prosthetics.

2. **Public and private facilities:** such as your local rehabilitation clinic can give specialised information about your individual situation.
3. **Amputee support groups:** can provide essential information, access to resources and opinions from other amputees who have already been through the rehabilitation process.

We have listed the sources of information above in this order for a reason. By having a basic understanding of prosthetics and knowing the meaning of some specific words (language) that health professionals use, new amputees will be able to have a more meaningful conversation with their health care provider. Once the new amputee has a basic understanding of prosthetics and their individual situation, they can then develop this understanding further by sharing experiences, thoughts and concerns with other amputees. The information gathered at this time starts to form an idea in the new amputees' mind of what the prosthetic limb will be like when it is finished. This expectation can sometimes be very different from the final result and it is important to understand why this can be a problem.

Expectations that are **too high** and unrealistic can lead to unachievable goals being set, resulting in the potential for a disappointing outcome. **Too low** an expectation can de-motivate a new amputee and end with the rehabilitation team settling for a lower result.

A realistic expectation will allow the amputee to focus on achievable goals and, it is more likely that they will be satisfied with their final (and first) prosthetic limb.

To help you develop a set of realistic goals, below are some examples of questions you can ask your prosthetist:

Why is this socket design recommended for me?
Why is this method of suspension/fixation recommended for me?
Why is this foot/knee/arm/hand recommended for me?
What other options are available?
What should I expect in the short term?
What is the plan for my future rehabilitation?
What do I do if I have problems with the prosthesis when it is finished?
How often will I need to see my Prosthetist for reviews?

During the early stages of rehabilitation, it is common for new amputees to experience a number of changes to both their body and their understanding of their prosthesis. The stump will change shape, the body will adapt to walking on an artificial leg and the individual will understand how to balance and/or control and use their prosthesis.

Experienced Amputee

An experienced amputee is someone who has successfully completed their prosthetic rehabilitation program and/or has some experience using an artificial leg or arm. Whether this happened last week or over 10 years ago, it is always worth taking the time to look at up-to-date information about prosthetics and see what new options may be available for you.

As we mentioned before, for the new amputee, this information can be gathered from several different sources. An experienced amputee would normally have an understanding of basic prosthetic principles, be aware of their local facilities and amputee support groups. For those who are not, it is always a good time to start.

When visiting your Prosthetist to review the results of a previous prosthetic design/treatment, it is a great opportunity to talk about your goals, discuss what new options may be available and ask the most important question "why?".

It is very important that you understand why something is being done. By actively asking questions, you will gain a better understanding of the prosthesis and allow your Prosthetist to support your future goals to meet your individual needs. We all learn and understand in different ways, so it is essential the answers make sense to you. If you are not sure, ask again. It is always a good idea to compare different professional opinions if things are still unclear.

Below are some examples of questions that can help you to understand your situation and set goals for your future prosthetic limb:

Did I achieve my previous goals? If not, then why?
Does my existing prosthesis meet my current requirements?
If there is an unresolved problem, why does it persist?
Is the technology used in my current prosthesis still appropriate for me? Why?
Would I benefit from a change to a different design/system?
What are my goals for the next limb?
What can I do if I have problems with the new prosthesis when it is finished?
How often will I need to see my Prosthetist for reviews?

Before starting the process of getting fitted with a new artificial limb it is important to clearly understand what your current physical condition is, what your new goals are and what advantages a new prosthetic design will give you.

Having a better insight into the principles behind prosthetics will make it easier to understand what is happening during prosthetic treatment. This in turn will help you to provide your prosthetist with clear feedback and help you both achieve a better prosthetic outcome.

ArtLimb is a non-profit, independent project dedicated to sharing knowledge and discussing information about artificial limbs.

If you are interested in reading more information about prosthetics, please visit ArtLimb online at www.artlimb.com



Is your Prosthetist and your prosthesis allowing you to be your best?

Jackie O'Conner BPO
(Bachelor Prosthetics Orthotics with Hons) - MAOPA
Policy and Advocacy Manager (AOPA)

When was the last time you thought about what else you need and what you would like to do in life but are having trouble doing it? You probably think about this a lot when things are not working out the way you planned.

Chances are it's annoying you. So let's pose the question "when was the last time you discussed the things you want to do with your Prosthetist and asked if they could help you to achieve these things?".

As a Prosthetist I often found that my clients didn't always discuss what they wanted to achieve. Having goals doesn't mean that they have to be visions of grandeur - it could be basic things such as wanting to be able to shower more easily when you're away from home or having the ability to stand up in your own shower. This may not have been something that you thought about, or even thought was necessary, in the early stages after your amputation but it might be something that you would like now.

Have you tried to do something like riding your bike on your current prosthesis? You might be finding it difficult because you are trying to hold on with one arm or you can't bend your knee enough because your socket is causing you pain. Does not being able to do these things make you question if it is possible? Maybe you feel defeated. Perhaps that makes you think "maybe I can't do this activity anymore?" rather than asking your Prosthetist if something can be done (to your prosthesis) to make it easier and/or pain free. There might be things your Prosthetist can help you with that you didn't realise. Perhaps technology has changed and now there are solutions available that didn't exist before.

Discussing your needs with your Prosthetist
 People's bodies and lifestyles change over time, as does prosthetic technology and

funding. So it's a good idea to make sure you talk with your Prosthetist about what you need and to ensure you are up-to-date with any changes in technology or funding.

When meeting with your Prosthetist it's also a good idea to discuss your current prosthesis and what you do or don't like about it, as well as talk about other options that would better suit you and your lifestyle.

When talking to your Prosthetist about your current prosthesis think about what you already know, which may include:

- that you know your skin reacts to a silicone liner, you sweat too much to wear a liner so you might like to talk about other suspension options
- that you need to kneel down to do your job and this often ruins your prosthesis
- that you need your prosthesis to be as light as possible and you don't care what it looks like as long as it lets you do everything you need to
- the things you like or don't like about your prosthesis and what is important for you (eg. look, feel, weight, length, function, type).

When speaking with your Prosthetist ensure that you talk about yourself more broadly, which may include:

- changes to your financial situation which may impact on your ability to pay for prosthetics (or parts) you have used in the past
- any other health issues you might be experiencing
- goals you would like to achieve (eg. return to work, driving, sport and recreation activities)
- difficulties in attending your prosthetic clinic for regular checks, which might indicate

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you need a prosthesis requiring minimal maintenance.

Before meeting with your Prosthetist also think about the activities you need to undertake or would like to be able to do in the future. It is a good idea to discuss these during your appointment as this will help to guide the decisions you can make with your Prosthetist. Such activities may include:

- changing a baby's nappy
- mowing the lawn
- getting up and down stairs
- cooking, showering, driving a car or anything else you may need to start doing on your own
- playing golf, going surfing, gardening or walking up and down a hill.

When speaking with your Prosthetist discuss changes to prosthetic parts, funding and emerging technology. While this information might not be relevant to you at the time, it may be of use down the track. You may want to:

- find out about changes to prosthetic funding, such as the National Disability Insurance Scheme (NDIS)
- learn about different prosthetics, prosthetic componentry and new technology that you have heard about, and ask whether any of these would suit you and your situation
- ask to trial new prosthetics.

Think of working with your Prosthetist as a 'team effort', one can't work effectively without the other. In order for you to make decisions and get the best outcomes:

- ask to take time to read about the componentry recommended for you before you go ahead and approve it
- discuss possible prosthetic options and their advantages and disadvantages of each part, so that you can work together to decide what will be best for you
- ask questions about any other expectations you have of your Prosthetist and/or the facility they work in, for example: "how long will it take from the time funding is approved until I receive my prosthesis?" or "I need to know about my appointments at least two weeks in advance so I can arrange to take time off from work" or "can we please book the next appointment now?"
- if you need to, ask for any information in writing and/or take some notes yourself so

that you can discuss these matters with family members or friends.

Having more specific discussions with your Prosthetist

Sometimes there are specific things that you might be worried about discussing for fear of offending your Prosthetist in some way. You should know that all health practitioners are required to be approachable about anything that you need to discuss and a good Prosthetist won't be upset if you ask questions. Most likely he or she will enjoy the opportunity to work with someone who is motivated to get the most out of their prosthesis.

A Prosthetist's skill is being able to discuss whether a component is suitable for you, and if not why not. A Prosthetist should also be able to assess and discuss whether the benefits listed in an advertising brochure are things that you will be able to take advantage of. Ask your Prosthetist as many questions as you need so that you can understand.

Some scenarios and ways of approaching each with a Prosthetist are provided below:

Mr Smith has been to see his Prosthetist for a similar problem every fortnight for the past three months. He really likes his Prosthetist who always sees him quickly and tries his best to help Mr Smith, but it's starting to feel like things are not going anywhere. Mr Smith is getting tired of needing so many appointments.

It would be a good idea and very appropriate for Mr Smith to ask any of these questions:

- Do you think it is worth seeing another Prosthetist for a second opinion?
- Do you think that I would be able to see someone else, just to get a fresh pair of eyes on this situation as this problem has been going on for a while now?
- Do you think this is a problem which I'll have to manage and put up with for life?
- We have tried to fix this same problem many times now, I have never had this problem with another prostheses - do you think it's time we considered a new prosthesis?
- Would it be a good idea for me to have this problem reviewed at the amputee clinic with the Doctor?

Miss Jones has been wearing the same knee

and foot componentry on her prosthesis for 10 years. Miss Jones likes her prosthesis and is comfortable with it, but it's not perfect. Miss Jones is starting to think that in the past 10 years things must have changed so maybe there is something new that would be better for her. Miss Jones sits down and thinks about the specific limitations (things she doesn't like and can't do) with her current prosthesis and starts researching new prosthetic knees on the internet. Miss Jones finds some prosthetic devices that she thinks might be good for her.

Miss Jones' next step should be to go to her Prosthetist and discuss the following:

- I have realised that my prosthesis has X,Y and Z limitations but what I love about my current knee unit is A,B and C, I am wondering if I can solve X,Y and Z without giving up A,B and C?
- I have found information about these components on the internet, I am wondering if you think that they will suits my needs?

Mrs Andrews has never had a prosthesis before and didn't realise what would be involved. She is feeling uncomfortable about seeing her male Prosthetist, due to cultural and gender issues. Mrs Andrews doesn't know any of the other Prosthetists in the clinic and is wondering if there might be someone more appropriate for her to see.

Mrs Andrews should feel comfortable to ask:

- For cultural reasons I wonder if it would be possible for me to see a female Prosthetist? Is there a female Prosthetist available at your clinic?
- I am wondering if there is anyone here who speaks my language or whether we might be able to get an interpreter? My English is not too bad but this is all very new and important to me and I want to make sure I understand.
- The look of my prosthesis is the most important factor to me. I want it to be as normal looking and unnoticeable as possible, can you please help me with that and tell me what that means for the other parts of my prosthesis that I might have to compromise on?

Talking to others if you can't talk to your

Prosthetist

If you ever feel that your Prosthetist has said something inappropriate, makes you feel uncomfortable or unhappy, or you don't feel that you can talk about something important related to your care you should consider who else you can talk to. It is important to raise concerns you have because speaking up can help prevent it from happening again, either to you or to someone else.

Should this ever happen you should consider:

- Asking to speak to the manager of the clinic where you have received treatment. Raise your concerns in a factual way and consider what you would like the result of your discussion to be (eg. do you want an apology?, do you want reassurance that the manager will speak to the Prosthetist?, do you want to make sure you remain anonymous?, do you want a referral to another clinic?)
- Asking about the clinic's formal complaint policy. Every organisation is required to have this type of policy and explain the process involved in lodging a complaint.
- Checking to see if your Prosthetist is an Australian Orthotic Prosthetic Association (AOPA) member - you can check at www.aopa.org.au/findapractitioner. If your Prosthetist is an AOPA member, and you feel it is appropriate, you can make a complaint through AOPA. This will mean that AOPA will investigate whether the Prosthetist is practicing at the standard expected in Australia.



The sometimes hidden disability

Sam Spalding – Senior Orthotist (Austin Health)

These days, with the great work of organisations like 'Limbs 4 Life' and the 'Paralympics', being a prosthetic user is more obvious to outsiders. On the other hand, orthotic devices are more likely to be less visible (or 'hidden'). Sometimes others don't notice a missing leg or arm, because clothing or a cosmesis is hiding it, and similarly this can often be the case when it comes to orthotics.

So why are orthotics important to amputees? Traditionally sound side ('the good leg') limb management is often overlooked when treating a person with an amputation. This is why looking after your 'good leg' and investigating whether you need to use orthotics is important.

Simply put, an orthotic is a support, brace, or splint used to support, align, prevent, or correct the function of movable parts of the body. Shoe inserts are orthotics that are intended to correct an abnormal or irregular walking pattern, by altering slightly the angles at which the foot strikes a walking or running surface. Other orthotics include neck braces, lumbosacral supports, knee braces, and wrist supports. An orthotic device is often called an 'orthosis'.

Orthotic devices are made or fitted by Orthotists. Orthotists are tertiary qualified Allied Health Professionals who assess and treat the physical and functional limitations of people resulting from illness or disability. Orthotic management involves the assessment/fitting of 'orthoses' - which are externally, applied devices used to modify forces on the body.

As a lower limb amputee if you experience any of the following you may be a good candidate for an orthotic:

- Possible loss of function and weakness in the 'good' leg
- Increased pressure, skin break downs, blisters and callused skin
- A tight calf muscle or pain and muscle tightness underneath the foot
- Swelling and/or wear and tear on your joints
- Lack of sensation in the 'good' leg
- Increased weight bearing or strain on the 'good' leg.

Any problems or symptoms could be easily managed by using an orthotic device, for example:

- Improving mobility
- Reducing pain
- Managing musculoskeletal weakness
- The alignment of your prosthetic device with your 'good' leg
- Preventing pressure injuries
- Muscle tightness.

Lower limb muscle weakness

For people with lower limb weakness the benefit of using an orthosis could be worth exploring. If you have muscle weakness in your hips, knees or ankle, an orthotic device could help to support your day to day mobility and prevent trips, falls or injuries. Orthoses can be custom-made for each individual or fitted off the shelf.



Pain

Pain in your 'good' side may be due to a number of medical reasons, and if you have pain it is important to consult your doctor. Pain in your 'good' leg may be due to increased pressure causing swelling in your joints, or incorrect alignment of joints in your lower limb. If the joints are correctable then custom foot orthoses, footwear, footwear modifications, ankle foot orthotics (AFO) could help. When you immobilise a joint you reduce swelling in the joint-space and hence reduce pain. When you realign a joint you distribute the weight (load) within the joint over a larger surface area, hence reducing pain in the joint. Tight tendons underneath the foot or in the calf muscle could also contribute to increased pain under the heel, forefoot or at the back of the heel. To help reduce, and in some cases eliminate pain in these areas, an orthotic device may prove to be helpful.

Loss of feeling in your feet

Some people may experience numbness in their feet and legs, sometimes known as Peripheral Neuropathy. It can result in the inability to stand and balance confidently, clawing of the toes, and the development of bony areas under the feet. Any of these symptoms could cause increased pressure and discomfort under the foot when walking. Over time, this may lead to skin breakdowns, and worse still, open wounds. If you have reduced sensation (lack of feeling) in your lower limb you need to be extremely careful.

Your eyes must replace your feeling and you must check your feet every day for any signs of increased pressure or redness. So that you don't cause increased pressure on your 'good' foot you may need a foot orthosis. If you have a lack of sensation in your foot it may seem like

you 'can't feel the ground beneath you', which may lead to you feeling unstable in the dark when you can't see and even falling over. If you find that this is happening to you may benefit from some sort of orthotic device to help increase your stability.

Shoe fit

Make sure your shoe fits your foot. A really good way to check this is to trace around your foot using a pen and a piece of paper. Then, take the insert out of your shoe and put that on top of your foot tracing and see if your foot fits inside the insert tracing. If it does not fit then you need to seek professional advice regarding footwear. Make sure you also look for pressure marks on your foot; it is important to check all around your foot. If you are not able to see underneath your foot, use a hand mirror. You may need to seek professional advice and/or have a family member or friend have a look for you. If there are signs of pressure (eg. red marks or indents in your skin) you need to talk to your Prosthetist / Orthotist about what can be done to prevent this. A shoe that is too long can be equally as problematic - extra depth and width does not mean extra length!

Pressure management

The best ways to manage pressure on your foot include, but are not limited to:

- A shoe that fits (shoes may need to be modified: stretched, patched, have the sole stiffened or altered, have a rocker sole 'roll off' added or altered in some other way)
- The addition of a custom made full length semi-rigid foot orthosis
- Wearing good socks (diabetic socks with minimal seams and no tight elastic around the top)
- Using a graduated compression stocking

for swelling (only if recommended by your doctor)

- Using silicone toe spacers.

Blisters and rubbing

If you find that you have had a rub on your foot and a blister or an ulcer has developed, you need to seek professional advice to stop any pressure on the area. Your doctor may then recommend that you see an Orthotist.

Partial foot amputation

Have you had part of your foot amputated? If so, there are many orthotic / prosthetic options available to you. The main aim is to make sure pressure is distributed evenly on the remaining part of your foot, as your foot function will have changed dramatically. If you have had the front part of your foot amputated (toes and/or partial foot), you may also benefit from something to help with your ability to 'push off' or propel

your body forward when walking. Cosmetic silicone feet which endeavour to replace the missing part of your foot are also available.



How orthotic devices can help

The use of an orthotic device can provide numerous benefits to someone with lower limb weakness. The main advantages may include:

- Improving your overall mobility
- Conserving energy and increasing endurance when walking
- Helping correct or maintain alignment of the legs
- Improve stability of weak or paralysed muscles, thereby improving balance and confidence
- Allowing you to stand up or walk for longer periods of the day
- Assisting with providing a smoother walking (gait) pattern
- Reducing muscular / joint pain in the feet, ankles and knees
- Making it safer to walk in the community with a reduced chance of slips, trips and falls
- Reducing the risk of wounds or skin breakdown, commonly caused by increased pressure.

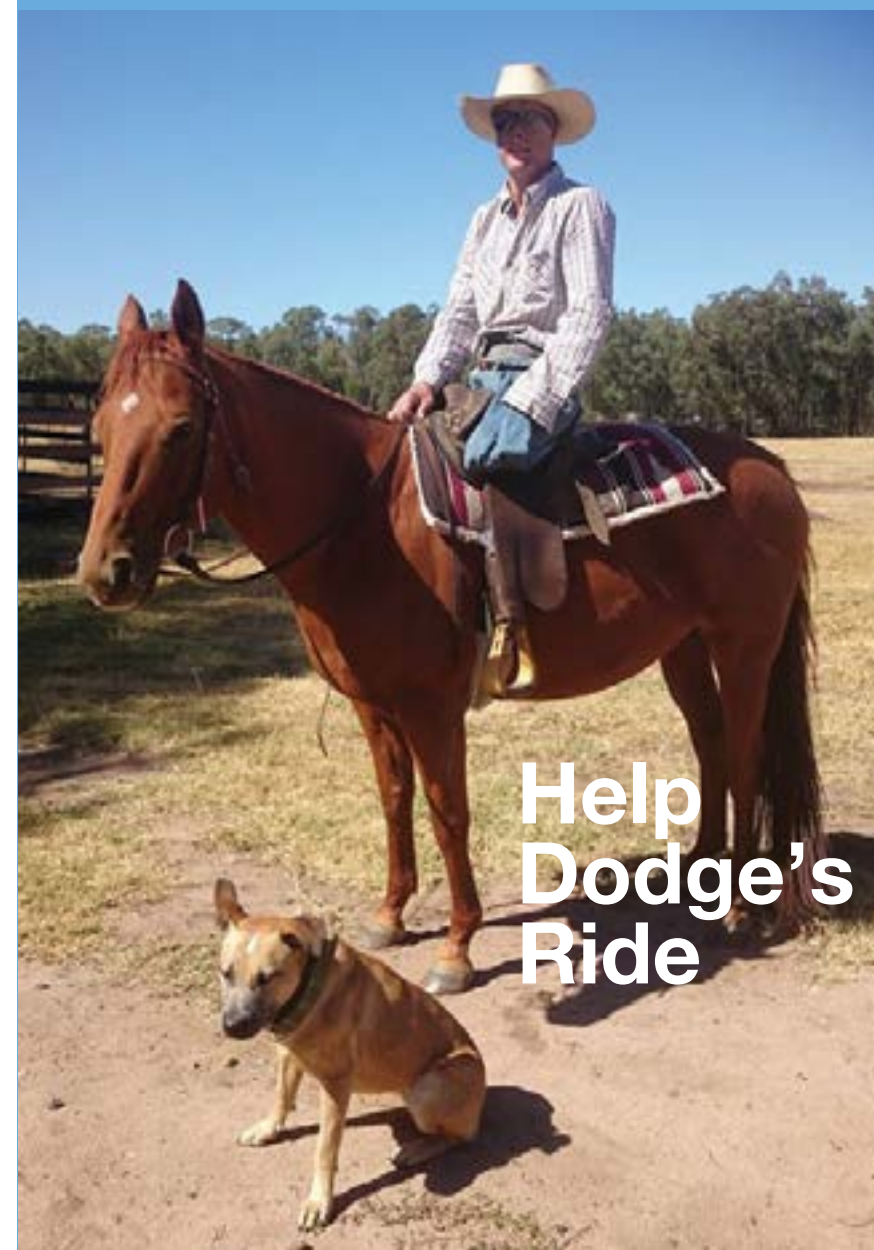
Where and how you can get help

If you, a family member or a friend would like further information about orthotic assistive devices, or if you would like to have an assessment to see if any orthotic options may be suitable for you, orthotics departments can be located within many public hospitals. There are also many Orthotists working in private clinics. Ask your Neurologist or Doctor to provide you with a referral.

Limbs 4 Life offers the Limbs 4 Kids program as a way of providing support and information to children and young people with limb differences and all who care for them.

For more information email kids@limbs4life.org.au or visit www.limbs4kids.org.au

limbs
4 kids



Jamie Manning is an incredible individual with drive and determination to literally get back up on the horse.

In March 2014, Jamie was in a serious car crash. The car hit a tree and caught on fire. Against all odds Jamie survived. Jamie had full thickness burns to 40% of his body and face, had head injuries that would leave him in an induced coma for 7 weeks, a broken back, broken hip, dislocated hip, internal injuries and his lungs were damaged by smoke and fire. Due to the burns Jamie lost his left leg above knee and his left hand.

Despite all this Jamie considers himself to be an extremely lucky person. "After all I should not be alive today," said Jamie. Supported by his loving wife and 3 great kids means everything to Jamie.

Early on in Jamie's recovery he was looking for a way to challenge himself and help others at the same time. "A major part of my life before the accident was horse riding. So what better way than ride from Tilpa in far western NSW to our home outside of Dubbo, a distance of 560km," explained Jamie. By doing this Jamie would like to raise awareness for amputees and Limbs 4 Life.

To donate or to read more about Jamie's story visit: give.everydayhero.com/au/dodge-s-ride-never-write-this-cowboy-off

Don Elgin One Foot on the Podium

Born without the lower half of his left leg, young Don Elgin never considered himself disabled until he was in high school - and even then, he had to be convinced. His story, of a boy from the bush who battled the odds and finally stepped onto the podium as a medallist at the Sydney Paralympics, is one of absolute inspiration. Driven by an inherited sense of grit, determination and pure guts, Don overcomes an abundance of obstacles to rise to the top of the sporting heap. His life's philosophy tells us that success is not a birthright - it's earned.

The way Don tells his story is the reason he's one of the most entertaining and engaging speakers on the Australian circuit today.

For more information or to purchase Don's book visit www.donelgin.com.au





The start of something new - the National Disability Insurance Scheme rollout

On July 1 the National Disability Insurance Scheme (NDIS) started being rolled out across Australia over the next three years. The NDIS provides all Australian's under the age of 65 with a permanent and significant disability with the reasonable and necessary supports to live an ordinary life. This life changing reform will mean that Australians with a disability will have access to a national scheme rather than a one-size-fits-all state based approach.

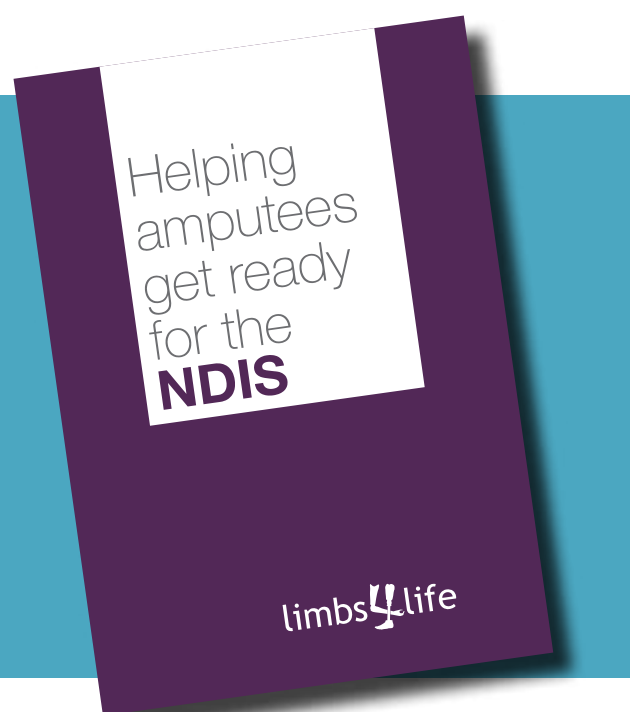
So what does this mean for you?

Amputees in all states and territories of Australia will be able to exercise choice and control when deciding on their prosthetic, assistive devices and lifestyle requirements. In the past, due to limitations on the state-based funding schemes, you and your Prosthetist may have had limited prosthetic options. Like before you will still be able to trial (most) prosthetic equipment devices prior to making your final decision.

How can Limbs 4 Life help you?

Limbs 4 Life is in the process of developing a workbook 'Helping Amputees get Ready for the NDIS'. This workbook will help to guide you through the process of transitioning into the NDIS, assist you to identify your goals, help you to recognise the things that are important to you and assist you to develop your plan. If you would like to receive a copy of 'Helping Amputees get Ready for the NDIS' please email us at info@limbs4life.org.au or call toll free on **1300 78 2231**. The workbook will shortly be available on the Limbs 4 Life website also - www.limbs4life.org.au

For more information about the roll out and to find out when the NDIS will be available in your area visit: <https://myplace.ndis.gov.au/ndisstorefront/about-us/our-sites.1.html>



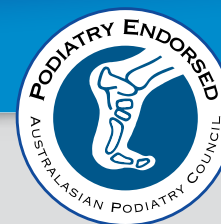
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THANK YOU

As another financial year draws to a close Limbs 4 Life would like to take this opportunity to thank all of our generous partners for supporting us to continue delivering support to the Australian amputee community - BankVic, nib foundation, PB Foundation, Allens and Collier Charitable Fund.

We would also like to thank all the generous individuals, schools and groups who have also generously supported Limbs 4 Life during the year.

Limbs 4 Life

Phone: 1300 78 2231 - toll free

Email: info@limbs4life.org.au

www.limbs4life.org.au

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