

amplified

edition 1 | 2017

Leading the way
Meet Lyn Johnson

A leg up for the NDIS

How to choose the right
prosthetist for you

An insight into shared
decision making



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Welcome to the 'new look' Amplified magazine. We hope you like the new format.

Limbs 4 Life is currently in the process of re-branding and changing the way we look. In coming months, we will be launching our new website, along with updating all of our resources and magazines.

Don't forget that National Amputee Awareness Week is fast approaching. Contact us today to receive your ribbon.

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Never too late to try something new! Meet Lyn Johnson



"I didn't have the chance to speak to any amputees before the surgery. Information on the internet was non-existent, and I really wanted insight to what life would be like."

Lyn's journey as an amputee began in 2001, when she had a cyst removed from the top of her foot which turned out to be an aggressive sarcoma.

"When I was diagnosed with cancer, my life took an unexpected turn. I was working in antenatal clinic at the time, and all my years of medical training and the language that I had used, didn't help me to understand the meaning behind the biopsy and bone scans; and then the word - amputation. It was like entering a whole new world," Lyn said.

After the initial diagnosis, everything moved very quickly for Lyn. Within two days, her surgery had been planned and Lyn boarded a plane to Melbourne to start treatment.

During a brief discussion with her doctor, Lyn was given three options: the removal/amputation of her foot, intense radiation therapy which would lead to a non-functioning foot, or a below the knee amputation.

Lyn researched as much as she could in the short time between her diagnosis and boarding the plane to Melbourne and believed that an amputation would result in the best possible outcome.

"I didn't have the chance to speak to any amputees before the surgery. Information on the internet was non-existent, and I really wanted insight to what life would be like."

"I just really wanted to talk to someone who had walked that path. I knew that when I left Devonport I would return as an amputee," Lyn said.

Thanks to the prosthetist that Lyn was seeing at the time, she finally found the information she was



For almost 15 years, Lyn has been involved with the Tasmania Amputee Society (TAS), an organisation established to provide Peer Support to amputees and their families. TAS advocates for better funding for prosthetics for amputees.

Currently in Tasmania, there is only one public prosthetic service provider something that TAS has been lobbying to change for over a decade. "We have examples where people travel to the mainland to receive prosthetic treatment because they want the opportunity to choose their provider," she said.

There is a private service in Tasmania however that provider is unable to manufacture prosthetics under the public system and it means that amputees need to pay out of pocket costs to access their prosthetics should they choose to visit the private service. "It's frustrating that in this day and age there is limited choice," Lyn said.

"We all know how important the relationship between an amputee and their prosthetic provider is. Naturally there will be times when for whatever reason, people just don't get along. This is why our community needs choice," Lyn affirmed.

Now as President of TAS, Lyn and her team hope to create a partnership with Orthotic Prosthetic Services Tasmania (OPST) and the Department of Health and Human Services (DHHS), to expand the Peer Support Program across all hospitals in the state.

"The Peer Support Program is something that should be promoted among healthcare providers. Not every amputee may wish to receive Peer Support, and that's fine, but those who do, should have the opportunity to meet with someone who has 'been there before'. It's important to build community connections and provide support for people facing this life changing challenge," she said.

Lyn thinks that Peer Support just makes good sense. "Our Peer Support Program is designed to assist amputees and we believe it is critical to their health and wellbeing, and that of their families."

"We are experiencing some difficulty getting in touch with new amputees which is a shame because I think the sooner a new amputee has contact with us (TAS) the quicker a lot of their fears can be put aside, and they can start moving forward in their journey," Lyn said.

The Tasmanian Amputee Society (TAS) currently has 11 trained amputee Peer Support Volunteers all of whom are dedicated to make a difference to those in

the community facing amputation and/or living with limb loss.

"The Peer Support Program is something that should be promoted among healthcare providers."

In her spare time, Lyn enjoys gardening and is fortunate to have some wonderful friends who will get on the end of a shovel if asked. "I have tried to use a shovel but my balance is not the best and a few times I have ended up on my bottom, not a good look," laughed Lyn.



Lyn is also kept busy by her three children, five grandchildren and one great granddaughter. Another great grand-child is due in December. She cites the ongoing support received from her family and friends during her journey to be extremely valuable. Lyn's young grandson Thomas, and great granddaughter Nevaeh like to help her to put on her leg. Lyn has also been to 'show and tell' at her eldest grandson's school, not long after she first lost her leg.

Lyn is always seeking to try new challenges and since becoming an amputee Lyn has spoken publicly about her journey. "If you had told me early in 2001 that I would be public speaking, I would have laughed at you, and said no! The very idea of speaking in public terrified me. However, I hoped that by sharing my story, other people would feel more comfortable about the thought and/or fears of amputation," Lyn said.

Lyn has addressed 'World Cancer Day' lunch in Devonport, the Lions Club Change-over dinner, addressed 'Educational' Dinner meetings for

Nurses and Midwives and spoke at the International Women's Day celebrations. Lyn's presentation is titled, 'Does success bring change, or does change bring success?' Quite an apt title, considering Lyn's circumstances.

In 2016, Lyn was able to tick a few things off her 'bucket list.' Along with her friend Sue, Lyn travelled to Alaska and Canada. The pair rode on chairlifts, flew in a helicopter and travelled on the Rocky Mountaineer Rail Journey.

"It was a wonderful experience...all of the accommodation facilities were disability accessible and I never had to worry once," Lyn said. For Lyn, it was the trip of a lifetime.

Another highlight for Lyn was attending the Ottobock 'Get Active' event in Sydney, where she had the opportunity to try on some of the latest advancements in prosthetic limb technology. "At the event, I had the opportunity to run, using a blade prosthesis. It was such an incredible feeling and something that I never thought that I would be able to do."

"It reminded me that there are always new opportunities in this wonderful wide world of ours and that we should embrace new opportunities when they come along.

"Life continues after you become an amputee, you just have to be creative at times, and make the most of it," she said.

Lyn has been nominated to carry the baton in the Queen's Baton Relay, leading up to the 2018 Commonwealth Games. We wish Lyn every success with the selection process.

If you would like to find out more about the Tasmania Amputee Society (TAS) and how they can help you, please visit:
www.tasamputee.org.au

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The Athlete's Foot



Mark Turner Defying the Odds

"After discussions with a dedicated Peer Support Volunteer from Limbs 4 Life and care from doctors, physiotherapists, and occupational therapists coupled with seeing how other amputees were coping and managing, I could see that it was not all doom and gloom."

At 87 and despite having lost one of his legs to cancer, Mark is showing no sign of slowing down.

For most of his life, Mark has been a very active and passionate sportsman. His love of sport has seen him involved in golf, Aussie Rules Football, tennis, as well as umpiring with the VFL (Victorian Football League) and suburban football leagues in Victoria.

When he was 55, doctors discovered a melanoma under his left heel and recommended surgery to remove the lymph glands in his left groin and radiation to minimise the risk of cancer coming back in the future.

Unfortunately for Mark, the radiation treatment didn't achieve the desired outcome, resulting in limited blood supply to his leg and foot. So, in 2013, Mark underwent a second operation to implant a bypass from the iliac to the femur, in an attempt to help increase the blood supply to the leg. But two years later, he was back in the operating theatre - this time for an above the knee amputation as the bypass had blocked, stopping any blood flow to the leg.

According to Mark, losing his leg shook him up a bit mentally but he gained the upper hand.

"After discussions with a Peer Support Volunteer from Limbs 4 Life and care from the team of physiotherapists at Caulfield Rehabilitation hospital, coupled with seeing how other amputees were coping and managing, I could see that it was not all doom and gloom," he said.

With the help of his physiotherapist, Mark started regular exercise and a balanced diet. "I have a daily exercise regime designed to maintain muscle strength for both the affected leg and the good leg and a set of exercises, using weights for upper body and arms. I have reduced my food intake with smaller meal sizes - although a bit hard with cake sometimes," he said.

When Mark is not driving his wife to the local shops, getting himself to the doctors or enjoying the sunshine driving his electric scooter, he would be at the home of sport - the mighty Melbourne Cricket Ground (MCG).

Two to three days per week, Mark volunteers as a guide and welcomes local, national and international visitors to the stadium and the MCG Cricket Museum.

"At the MCG, I get to meet and greet locals, national and overseas visitors, provide them a brief description of their walking tour and introduce them to a guide. I also get to show people around the MCG Cricket Museum and chat to them about the 180 years of history of the Melbourne Cricket Club," he said.

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Is it OK to Ask about Limb Difference? Five tips!

It's OK to ask me what happened to my leg, but not in the supermarket please! Sometimes I'm rushing.

It's not unusual for people to ask me how I lost my leg and, without sharing the gruesome details, my answers vary. In specifics, not facts. It's different for different people and places.

Sometimes I give a pat reply, I've had years of practice. And, other times, I might sit down and have a long chat and feel good about talking. The difference is often in the other person, the context and what seems the reason for the question. Do I know them? Are they just curious? Are they caring? Are they a new friend?

But, sometimes the look on people's faces when I tell them says they wished they hadn't asked. Perhaps I should have invented a less traumatising story? Maybe I got carried away and said too much?

Other people with limb loss have told me they sometimes wonder why people ask what happened to them. Is it curiosity or finding common ground?

Here are five things to think about before you ask.

1 How well do you know the person?

Are you a friend, an acquaintance or a stranger passing by? This speaks to the reason for asking.

A friend may never have heard the full story. Knowing a friend's history is part of understanding who they are, where they come from, what matters to them, why they

react to certain things and not others. It's an act of caring.

An acquaintance might be wanting to move towards friendship, or it might be curiosity. Ask yourself what's my motivation here. Am I after vicarious thrills? A good story to tell? Or do I care about this person and want to get to know them. You'll find your answer.

A stranger passing by? This is the hardest. Are you stuck together in a crowded bus and feel compelled to strike up conversation? Or are you asking for curiosity alone? Sometimes on a plane I will joke about my prosthetic leg when I am either struggling to step past another passenger or it's the other way around. Last time I flew, someone trod on my fake foot and apologised and I laughed it off, I felt nothing. I said it's a prosthetic limb. In that case I gave permission to talk. Take your cue from the other person and you'll know what's OK.

2 Where are you?

Social context is a significant consideration. Are you in a supermarket? Don't ask!

Are you picking your kids up from school? What if it's a gruesome tale you might hear? Do you want your children to have nightmares?

At a Party? Maybe turn to a book on social etiquette for ideas instead. Try icebreakers like 'What are you doing tomorrow?', or 'How do you know Sue and Bob?' Or, my favourite,

TIPS

'Would you like another drink?'
Are you sitting over coffee or lunch with a friend and never heard the full story? Not a bad time.
Are you sitting in the Amputee Outpatients Department of your local hospital waiting to see your rehabilitation specialist about your prosthetic limb? Go right ahead, you have a common interest.

3 How much time do you have to listen?

There are many causes of limb loss. Some people have congenital limb deficiency. Acquired limb loss can be the result of diabetes, vascular disease, cancer, trauma and infection. There might even have been forty four years between the trauma and the limb loss. That's a long story to tell!

Every person with limb loss has travelled a different path, no matter what's the cause. And they will tell their story in different ways. Some will give a one line reply, others a dissertation. If you have asked you might have to listen.

4 Do you really want to know?

Not all limb loss is pretty. Some tales are traumatic. Not just for the person who lived through the experience, for listeners as well. There are good reasons people who've experienced traumatic limb loss don't tell their stories - trauma overwhelms listeners as well as speakers. There are times I've been in the middle of telling the sanitised version of my story and I've had to stop to look after the

listener who's passed out on the floor at my foot.

5 Ask yourself why you're asking?

Have you got a great story to tell? Many people living with limb say it's not unusual for people to ask them how they lost their arm/s or leg/s only to be interrupted by the questioner - who seems eager to share their history of illness or trauma. I've heard many heartrending stories. Not all people with limb loss are trauma counsellors, especially in our spare time.

For a moment imagine four limbed people are a minority group in the world. Walking out your front door every day you can't help wondering how many people might ask you 'How come you've got four limbs?' Sounds crazy, right? Sometimes it can feel like that for us.

Those of us with a fraction of your limb total are not all alike, but many of us don't mind, at the right time or in the right place, being asked what happened to one or two or more of our limbs.

There are helpful and unhelpful ways to ask questions. Some open conversation, others shut it down. One of the best ways is simple. Try prefacing your question with 'Do you mind' or 'Is it OK if I ask?'

It offers us a choice and gives you a clear response.

Fay is an author and a below knee amputee. Read Fay's blog posts at 'Missing Foot Notes' www.faykeegan.com.au/blog/

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Have you transitioned into the NDIS, or are you about to?

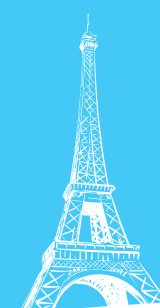
The **NDIS** is a new way of providing support and assistance to people with disabilities.

If you are an amputee or a person with a limb difference and about to move across to the **NDIS** there are a number of things that you should consider:

- Think about your goals prior to meeting with your Planner? Your goals will be used to help to create your plan.
- Think about what you will need in order to achieve your goals.
- Make sure you allow for a 4-hour prosthetic assessment as part of your plan (with your prosthetist).

If you need assistance setting your goals, contact Limbs 4 Life for a copy of the **NDIS Guide and Planning Workbook for Amputees and people with Limb Difference**.

You can download the **NDIS Checklists** on the Limbs 4 Life website: limbs4life.org.au



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A leg up for the NDIS

Let me start by saying, I LOVE THE NDIS. I remember marching in Brisbane in 2012 in support of the NDIS with a sign saying it's a "leg up for all Australians", which five years later and 12 months into NDIS life, I still stand by. I do understand the frustrations and complexity many people have experienced, and my own journey hasn't been perfect, but I am really happy with my outcomes and hope the NDIS is here to stay.

If you are not sure what the NDIS is about, I can sum it up in one word: GOALS.

Your goals might be to have independency at home, to return to work, to be trained for a new career, to get out into the community and experience new hobbies or social events. You don't have to achieve all of your hopes and dreams in the first year, you need to have a long term game plan, and figure out what goals should come first.

For me, as an amputee living in Canberra, the most exciting aspect of moving over to the NDIS was that I could access the new private clinic here, called Momentum Sports and Rehabilitation. This has made sure I can access appointments and supports when I need them instead of waiting for months, and I now also have access to innovation and technologies to improve my quality of life. How's that for a big plus to start with?

My goal for a long time has been health and fitness. In 2015 I went to the first running clinic held by Ossur in Australia and I really loved it. It was hard yakka, and it was an expensive experience for me (flights, hotel etc) but I still consider it to be the greatest investment I have ever made in both my physical and mental health. In 2016 I went to the first running clinic held by Otto Bock, and again, a brilliant investment. Getting to try a running foot, hanging out with likeminded people, and being out in the sunshine and exercising was all so wonderful.

When it came time to work on my NDIS plan, I said with confidence that I would like a running leg. I had shown my own investment (time and money) towards this goal already, and what was holding me back was the leg I couldn't afford. I am too old (!) to ever want to get into sprinting, but I'd really love to be able to go for a jog around the lake. My planner loved that I was able to prove my own work towards this goal, and I was approved for a running leg! In addition to this, I was able to access additional funds for physio to learn how to use it properly, and funds for a personal trainer to really help get me going and build the muscles I need. How amazing is this! Preventative health care at its absolute best.

As mentioned earlier, this hasn't been completely easy sailing. There were weeks where I felt like I couldn't get a call back from the NDIS, and my plan has been revised twice, but it has always worked out and I really can't complain at all. I feel very lucky to live in a country that is trying very hard to improve the lives of people with disability, and I am happy to work just as hard for this - for myself and for others in the community.

Here are some tips I thought might help in your own NDIS experiences:

1. You must self-advocate. If you are unable to do this, you must find someone who understands your every need and can help you. I don't have a case manager (an independent person to navigate the NDIS on your behalf), but if you want one, make sure they are someone you can really relate to, who understands prosthetics,

and will be available to represent you in the way you need.

2. Pace yourself and don't be greedy. If we all do the right thing and access the relevant and realistic supports we need the NDIS will be around for the long haul.
3. Be prepared. Read everything you can, talk to people who have experienced the good and bad, and go into your planning meetings with a clear idea about what the NDIS is, and how it can improve your life. Make a list of everything you have needed in the last few years - new/ spare liners, stump socks, socket replacements, padding, shower covers, shower chairs, and cosmetics.
4. Be kind. The Planners are not experts in every field, but they will do their best to help you. We all have to take some responsibility to know what we need. Every conversation you have with NDIS staff is an opportunity for you to teach them and for them to teach you. No one is perfect.
5. Be calm. You're going to get frustrated. It's a new system, a new way of doing things. New things always have issues, and it always take longer than we think it should.
6. If you can't get through on the phone or via email, don't forget they have shopfronts. You can go in and ask for help in person.
7. Track everything. I self-manage my personal training, and I have a basic spreadsheet to keep a track of how much funding I have, when and how I have spent it. If I am ever audited, I can provide the documentation straight away. You don't have to self-manage, but if you do and you're worried about recordkeeping, ask for help.

I truly believe that the NDIS is going to change and improve the lives of many amputees in Australia. I wish you well in your goals and I look forward to hearing more success stories as the years roll on!!

Priscilla Sutton, Canberra.



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IC2A and Assistive Technology for All

World Congress Report

The International Confederation of Amputee Associations (IC2A) joined over 2000 delegates from 106 countries at the World Congress of the International Society for Prosthetics and Orthotics in Cape Town, South Africa 8-11 May 2017. This was the first ISPO world congress on the African continent. The event included keynote lectures, 6 parallel scientific paper sessions, a scientific poster display and a major exhibition that included 120 exhibitors displaying products, services and initiatives with the theme being "Assistive Technology for All".

11 volunteers from 7 countries supported IC2A to have a strong presence at the event and to amplify the users' voice. IC2A activities included:

IC2A at ISPO Open Board meeting: As an official partner of ISPO with a Memorandum of Understanding, IC2A has a place at the ISPO Open Board along with other international partner organisations. IC2A President Nils-Odd Tønnevold presented on IC2A activities.

IC2A Inspirational Lecture: On 8 May 2017, Giles Duley, photographer was awarded the first IC2A Inspirational Medal after his inaugural IC2A Inspirational Lecture during the opening ceremony. Following a call for nominations from the IC2A Amputee Association members and the ISPO Board members, Giles Duley was selected from a shortlist of ten excellent nominations by a panel of two representatives of IC2A and two representatives of ISPO. The IC2A Lecture featured prominently and was a resounding success and set the tone for the entire conference, raising awareness about the importance of access to good rehabilitation services to enable someone to achieve their own goals.

IC2A Exhibition stand: Our 3 metre square deluxe exhibition stand was sited prominently in the exhibition hall adjacent to the international lounge. The stand was a fantastic networking point, drawing many delegates throughout all four days of exhibition, not least because for the first two days, Giles Duley was present signing copies of his book "One Second of Light". Giles was kind enough to take time to speak to a multitude of delegates drawn by his photography work.

IC2A AGM: On 10 May we had our IC2A AGM which went according to plan and we were delighted to welcome a newly forming member association from Zambia to the meeting.

IC2A Think Tank: On 10 May, we held our first ever, inaugural IC2A Think Tank with people representing WHO, ISPO, corporate members and association members gathered around the table. The Think Tank considered priorities for the future of prosthetics service provision presented by each invited delegate in turn and these were prioritised as follows:

- Promoting 60 WHO Standards for Prosthetics and Orthotics
- Cost benefit analysis/data
- Skills shortage (train more professionals and increase productivity of existing personnel)
- Safety and security
- Comfort, no pain – socket fit/comfort – phantom/stump
- Communications model – user/professional and information sharing
- Policy – improve contract models for services
- An up to date list of user association members and also corporate members are on our website www.ic2a.eu

WHO Standards for Prosthetics and Orthotics: We are linking our action points to new WHO Standards for Prosthetic and Orthotic Services Provision (publication pending). The IC2A president has been active on the WHO Standards Development Group. Combined with determination, resilience and entrepreneurial effort we will focus on doing what we can to ensure that the Standards are implemented so amputees' lives are better in all WHO member countries which include developed and developing countries all over the world. IC2A is now a member of the Global Cooperation on Assistive Technology, an initiative of the World Health Organization.

IC2A Growth: The feedback from users, health care professionals, user associations, industry partners and partner organisations such as WHO and ISPO is that IC2A is a very welcome initiative. Our activity in South Africa is already resulting in increased interest and membership.



ISPO World Congress 2017

The International Society of Prosthetics and Orthotics (ISPO) biennial Congress was held in Cape Town in May 2017. This was the first time the ISPO Congress was held on the African continent and was attended by over 2000 delegates from around the world.

The program boasted an extensive array of symposia, instructional courses, presentations, posters and exhibitor workshops focussed on improving the outcomes for consumers of orthotic/prosthetic services all around the world. Presentations were from a range of disciplines including clinicians, researchers, technicians, manufacturers, medical professionals, rehabilitation experts, biomechanists, and other allied health professionals.

There were over 30 attendees from Australia, many of whom were there to share updates from the profession in Australia. Australians featured throughout the scientific program including areas of partial foot amputation, occupational health and safety in the orthotic/prosthetic profession, the



setting of standards for the accreditation of orthotic/prosthetic education programs, rehabilitation and communication tools amongst others.

Consumer focus

It was fantastic to see consumers featuring more heavily in the program than ever before.

The International Confederation of Amputee Associations (IC2A) (<http://ic2a.eu/>) provided a key note address as part of the opening of the congress by Mr Giles Duley.

In 2011, Duley lost both legs and his left arm after stepping on an Improvised Explosive Device (IED) in Afghanistan whilst photographing those caught up in the conflict. He was told he would never walk again and that his career was over. However, Duley refused to give up on his goal to return to work as a photographer, and returned to work less than 18 months later.

Sharing his story of limb loss and journey of self-acceptance, determination and achievement was honest, inspiring and the perfect place for all attendees to begin their 4-day congress. Duley was awarded the inaugural **IC2A Inspirational Medal**.

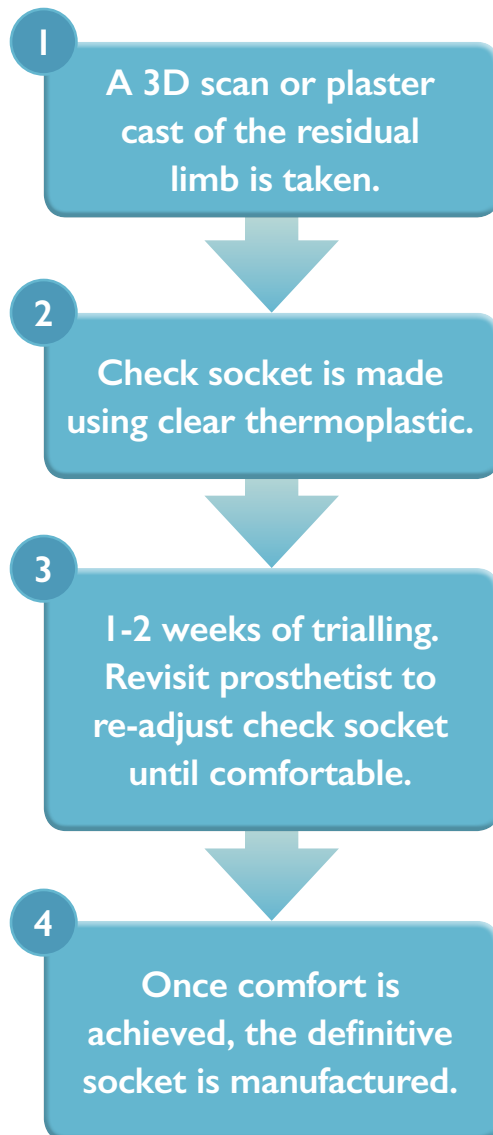
This award honours the recipient by recognising their life's achievements, and the influence they have made on others by sharing their story. It also celebrates the impact that IC2A is having within the board global community of amputee associations including Limbs 4 Life. Amputee associations are strengthening and having an increasing impact providing a strong voice for consumers advocating improved outcomes for all amputees around the world.

Consumers of orthotic/prosthetic services were at the core of this congress- every development, publication, presentation, professional standard, or new product release has the power to change the lives of the users of orthotic/prosthetic services. The passion for improving outcomes by all attendees created a dynamic environment, where international collaborations and links were formed, conversations between researchers were started, and updates in best practice were shared. The next ISPO International Congress is set to be held in Kobe Japan in October 2019. For more information about attending this congress, please see: www.ispoint.org

Louise Puli
Professional Standards Officer,
The Australian Orthotic Prosthetic Association

How is your socket made?

Replacement Socket Process



Making a check socket

A check socket is a clear plastic socket manufactured as the first stage of a new limb. When manufacturing any socket that uses a silicone liner or a direct skin fit the first stage should always be a check socket.

As soon as you have been fitted for your check socket, it can be affixed to the lower components for short term testing. Depending on how the socket is fitting and any issues that may arise, this testing stage can be expected to last anywhere from one to four weeks. This ensures that the socket doesn't just fit well while standing calmly in the prosthetists office but is suitable during your everyday activities. At this stage, it is critical that you have quick access to your prosthetist to make any adjustments that are required.

Once the check socket is fitting comfortably it needs to be copied to allow for the manufacture of the final laminated (definitive) socket. The use of a 3D scanner will allow for a detailed copy to be saved by your prosthetist without damaging the check socket. With the exception of an emergency repair or replacement, your old 3D model, plaster cast or an alginate copy of your existing socket should never be used to manufacture a final socket without first test fitting a check socket.

The NDIS (National Disability Insurance Scheme) is coming!

This is a new consumer focused funding system designed to give people with disability more control and improved ongoing care. Freedom Prosthetics is ready to help amputees make informed decisions concerning their pathway through this new system.



Helping inform difficult decisions about partial foot amputation using a shared decision making approach.

Michael P Dillon, PhD. Matt Quigley, MCPO(Hons). Stefania Fatone, PhD.

About 12 months ago we reached out to members of Limbs 4 Life asking for feedback on a booklet we produced to help inform difficult decisions about partial foot and below knee amputation surgery.

Now that this phase of the project is finished, we would like to extend our sincere thanks to all those who provided feedback and helped us refine these resources. By way of thanks, we would like to share a little more about this research and what it might mean for the way we inform decisions about amputation surgery.

For the 6000 Australians who undergo some form of partial foot amputation each year, the prospect can be particularly daunting.

In a series of interviews unrelated to this work involving members of Limbs 4 Life, we talked with people about their experience of partial foot amputation. It seems that many people were not aware of the path ahead and the risk of delayed wound healing or another amputation. We also realised that helping inform decisions about amputation surgery can be challenging given the effect of pain medications, depression and anxiety.

"You're on massive amounts of pain killers...It's very foggy you know. You'd take pain killers and two hours later you realise you're still looking at the fish tank. It made communication so hard."

Fortunately many people told us how we could make things better. It seems that people found written information helpful because they could read it again and again, or share it with their family which helped promote conversation. While confronting, many people described the benefit of knowing what the path ahead might look like as it helped to prepare for the inevitable challenges.

"You get information from doctors and nurses, but I find it easier to read something off paper and let it really sink in. A brochure, something you can take to your room and read over and over."

Given this understanding we wondered whether a shared decision making approach may help people make more informed decisions about amputation surgery.

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What is shared decision making?

In its simplest form, shared decision making describes a process where patients and clinicians work together to jointly make a treatment decision, such as the decision to undergo a partial foot or a below knee amputation. At first glance, a meeting with a doctor using a share decision making approach might look like any other, however it is deliberately designed to explore all the treatment options, not just the option that the doctor thinks is best. As a result, there is opportunity for a meaningful conversation about the likely benefits and risks of each of the different treatment options. There are often exercises to help reflect on the different options or weigh the pros and cons of each, thereby helping guide decision making. In this way, discussions about quality of life after amputation, mobility, pain or the risk of the wound not healing and the need to another amputation can help inform decision making.

The information in a Decision Aid is deliberately written for a non-professional audience. It includes simple sentences and every efforts is made to limit the use of jargon. Data are presented using simple figures or infographics to help communicate important facts, such as the risk of another amputation or the percentage of people that regain full mobility one year after amputation. It is important that the information included in the Decision Aid is based on current research and presented in an unbiased way.

Given these requirements, there are international standards that help ensure Decision Aids are not leading, biased or harmful. It is also critical that people who have lived the experience can provide feedback to help ensure the right topics are included and that information is clear and easy to understand.

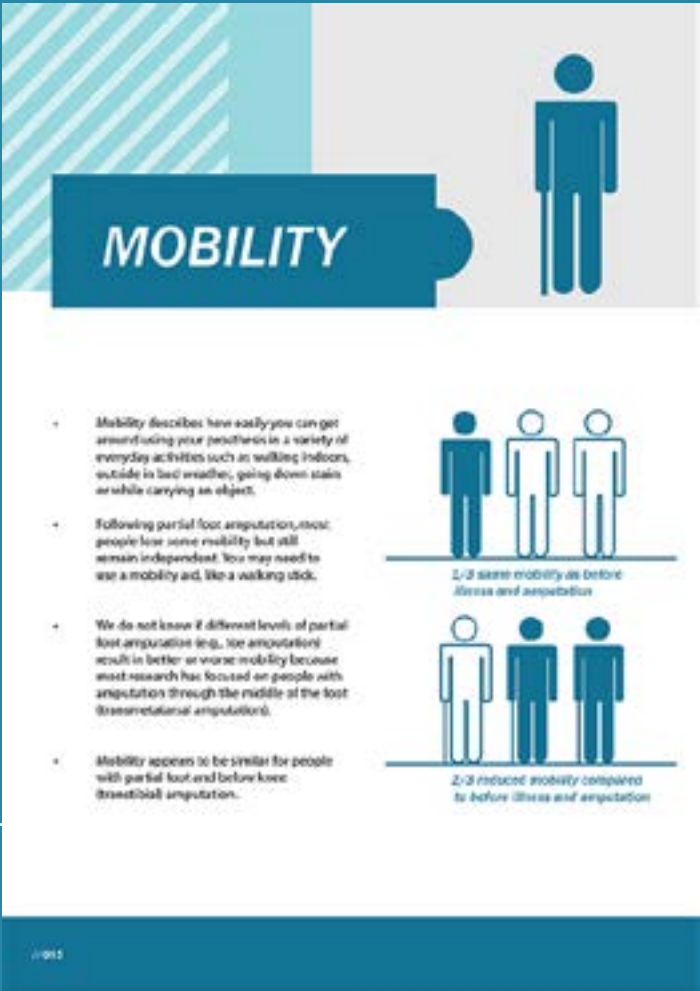
Page from the Decision Aid describing that community mobility is comparable between people living with partial foot and below knee amputation one year after surgery.

What is a Decision Aid?

Research in other areas of healthcare has shown that the process of shared decision making can be enhanced by using a **Decision Aid**.

As its name suggests, Decision Aids are resources to you help make a specific decision, such as the choice between partial foot or below knee amputation.

A Decision Aid is very different to general information about living with limb loss. For example, at the point of having to make a decision about amputation, it may not be very helpful to know how to check the sock fit of your prosthesis or the frustration associated with airport travel with a prosthesis. As such, this information probably would not be included in a Decision Aid about amputation surgery. This does not mean the information is not important, but it may not be that important to making a decision about amputation surgery.



So how well does shared decision making work?

Research in other areas of healthcare, most commonly cancer treatment or surgery, suggests that shared decision making helps people form an accurate understanding of the potential benefits and risks of different treatment options. People report feeling more informed and better supported in their decision making. Fewer people report regret with the decision in follow up studies. The approach helps facilitate often difficult conversations, given that both healthcare professionals and patients are all working from the same information. Some studies have noted that the body language of consultations changes as patients and clinicians come together to look at and talk about the information written in the Decision Aid.

It is for these reasons that shared decision making is considered by many leading healthcare agencies to be the gold standard to inform healthcare decisions. For example, in parts of the United States, shared decision making with appropriately certified Decision Aids is being used as a basis for consenting to medical procedures.

Decision Aids can often be found online and many people access these before even seeing a health professional.

The Ottawa Health Research Institute maintains a repository of Decision Aids on all sorts of topics and independently evaluates their quality.

decisionaid.ohri.ca/

So what is next?

Before Decision Aids can be certified for use, they must be rigorously tested in the real world by people facing decisions about amputation surgery and the healthcare professionals who facilitate these difficult conversations. It is important that we find out if the Decision Aid we have created is effective and will not cause harm or unnecessary distress. We need to create training modules to help health professionals develop a better understanding of the shared decision making process and how to meaningfully engage in often difficult conversations such as the risk of dying. It is exciting work and we are grateful for the support of Limbs 4 Life and its members who provided us with valuable feedback during the development of this Decision Aid. Thank you.

Acknowledgments: We would like to acknowledge the many people we have interviewed about their experience of partial foot amputation and the insights that at have helped shape our understanding. We gratefully acknowledge the contribution and Melissa Noonan, CEO of Limbs 4 Life, for her support in finding people living in the community who provided feedback to help us refine the Decision Aid. We are thankful for opportunity to work with a very talented graphic designer and prosthetist/orthotist, Mr. Jake Eadie, MCPO, BID. This work was funded by the American Orthotic and Prosthetic Association (RFP-04012015). Dr. Michael Dillon, PhD, is the Discipline Lead in Prosthetics and Orthotics at La Trobe University. Mr. Matt Quigley is a research assistant in the Discipline of Prosthetics and Orthotics at La Trobe University. Dr. Stefania Fatone, PhD, is an Associate Professor at the Northwestern University Prosthetics-Orthotics Centre in Chicago IL.

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How to choose the right Prosthetist for you

The right Prosthetist will do all they can to help you reach your goals, keep you informed as things change and build a relationship with you that is life-long.

Making sure your prosthesis works well can be a time-consuming process. For this reason, you will need the right Prosthetist to work with you to achieve the best outcomes, for you.

What should I consider?

What are the most important things for you in relation to where you get your prosthesis and the Prosthetist you work with?

The location or type of facility. For example:

- Do you need a facility that operates outside of regular business hours?
- Do you need fast turn-around times for service and repairs?
- Do you care if the facility is old or new?
- Do you need a facility which is close to home, work or transport?
- Does it matter if it's a public or private facility?

(Often public facilities are integrated into a bigger healthcare systems. If you need access to other providers, it may help if all of your documentation is in one place.)

The type of relationship you want with a Prosthetist. For example:

- Do you want to be involved in the decision-making process about the type of prosthesis you have, or are you happy for the Prosthetist to make all the decisions?
- Do you want someone who offers you lots of information or only answers the questions you ask?
- Would you prefer to work with a male or female prosthetist, if you have the choice?

How do I find the right prosthetist for me?

A recommendation from another person with an amputation or another health professional involved in your care can be a good starting point to narrowing a list to choose from. If you speak to another amputee, remember to ask why they do, or don't prefer their Prosthetist. Everyone has different needs, experiences and expectations, so the right Prosthetist is not always the same for everyone. Limbs 4 Life do not provide recommendations about which Prosthetist will be best for you, however they can help identify facilities that might meet your needs.

A national list of providers can be found here: limbs4life.org.au/prosthetics.html#hash_facilities

Are all Prosthetist's created equal? Or do qualifications matter/differ?

Not all Prosthetist's have the same level of qualifications or knowledge. In Australia, looking for a Prosthetist that is a member of the Australian Orthotic Prosthetic Association (AOPA) is the best way to make sure a Prosthetist has up-to-date qualifications and knowledge.

You can check if a Prosthetist is an AOPA member by visiting: aopa.org.au/findapractitioner

It's important to note that some Prosthetist's specialise in certain areas such as Upper Limb Prosthetics or Osseointegration so it's good to investigate who might specialise in your areas of need.



What should I tell my Prosthetist when I meet them?

When you met with your Prosthetist for the first time, make sure you:

- Discuss your goals and expectations
- Tell them about your history and any information that you think will be relevant
- Talk about the things that you would like to do, but are having trouble doing
- Share any concerns you have
- Make sure they are listening to you and that you listen to them
- Ask questions

If you are worried that you may forget something, write your questions down on a piece of paper prior to going to your appointment.

Checklist

To help you decide if your Prosthetist is right for you, ask yourself the following questions:

- Do I feel comfortable asking questions?
- Do I feel respected and listened to when I talk about my experience, thoughts and concerns?
- Do I get answers to my questions?
- Do they give me the time that is needed or make time in the future?
- Do I feel like I am understood?
- Do they talk to me in a way I can understand them?
- Do they know what my goals are?
- Do they provide me with information to think about in a way that is easy for me to understand and remember?
- Do they understand how involved I want to be in making decisions?
- Do they make me feel comfortable both physically and emotionally?
- Can I get an appointment when I need to?
- Did they clearly outline costs or any out of pocket expenses?
- Is this someone I think can help me achieve my goals?
- Is this someone I will enjoy working with?

It may take time to find the right Prosthetist. Help your Prosthetist to understand what it is you need. Making a checklist might help you get the most out of your relationship with your Prosthetist.

Jackie O'Connor

Speaking from Experience Meet our Peer Support Volunteers

Peer Support Volunteers play an invaluable role in the lives of individuals who live with limb loss or face amputation, along with their families and primary care givers. They provide emotional and practical support to help alleviate feelings of isolation, depression and limb loss amputation related fears.

Limbs 4 Life volunteers are the core of the organisation and ensure the delivery of our Peer Support program across Australia. We're very proud of our volunteers and can't thank them enough for the work they do to help others in the community.

They use their own personal experience to accompany others in their journey. They provide a listening ear, share knowledge, advise, coping strategies and information about support and health services. They help rebuild self-esteem and sense of identity plus enable greater confidence in the future.

Here, some volunteers tell us what inspires them.



Josh - New South Wales

I have been an amputee for almost four years due to diabetes. I started volunteering because I believe that if I would have had the chance to talk to someone when I had my amputation, it would have been very helpful for me.

"By providing peer support, I can let people know that after amputation, life does go on. It's good for people to know that they are not alone and that there is someone who can support them throughout their journey about what lies ahead."



Andrew - Western Australia

I became a volunteer because I believe in the values and ethics of Limbs 4 Life as an organisation, and what they stand for. I believe that what Limbs 4 Life do in the areas of advocacy and support for amputees is valuable and necessary. Without an organisation like Limbs 4 Life I think many amputees would be lost and not have access to any support.

Peer volunteers share freely of their time, and experience. Peer support is about giving knowledge in a timely manner in a way that the individual can understand. I think peer support assists the individual by giving them access to other amputees.



Kevin - Victoria

In 1982, I had elective surgery to amputate my left leg (below the knee) due to having one leg shorter than the other. In my case, it was a very positive step as it allowed me to be involved in recreational activities and lead a normal lifestyle.

I decided to become a volunteer to help support people who live in rural and remote areas. Living kilometres away from the city can make it difficult for people to get the help and support they need when they need it most. Over the years, I have supported quite a few amputees via phone. I gave them information on how they can be resilient, as well as tips to overcome barriers that may be hindering their health and wellbeing.



Terri - Canberra

I believe information is power. Having someone to ask a question that you know comes from a similar experience is invaluable. I am passionate about being an advocate for others so that they can achieve self-determination in their own health and choices.



Graham - Victoria

For me, it's great to be able to give back to the community. When I help others to face fears, it gives me a sense of purpose and gratitude. Becoming an amputee can be a pretty scary prospect and people don't know what their future will hold.

I once spoke to a lady in hospital pre-amputation, she was unsure how the amputation was going to affect her work and family life. With peer support, and support from her family, she is moving forward with her life. I have a saying that life does not end with amputation, in most cases it is just starting.



Marilynne - Tasmania

I believe peer support is crucial to assist in the confidence of someone's recovery and outlook on life. It's healthy to talk to others and share fears and concerns. It could be to check if what you are feeling is normal, or just to ask questions about the process moving forward. Talking to others about aids, equipment or experiences that I found helped me, can help others.



Alan Hare - Victoria

As an amputee I found initially that there wasn't enough information or support. This made things extremely difficult for me. I don't wish to see anyone else go through this journey unsupported. I am passionate about supporting upper limb amputees to get the information that they need so that they can get the most out of their life.

"Peer support is vital for amputees because while occupational therapists, doctors, physios and other medical professionals may have the technical knowledge - amputees have the genuine understanding."

Become a Peer Support Volunteer?

Our volunteers are a passionate bunch of people who form a network that we are keen to grow. So if you, or someone you know would like to become a Peer Support Volunteer contact Limbs 4 Life today or email: peersupport@limbs4life.org.au



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Have you ever wanted to sail the high seas?



The Jubilee Sailing Trust (JST) is an international, United Nations accredited disability charity, promoting integration through the challenge and adventure of tall ship sailing.

JST provide life-changing adventures to people of all ages, backgrounds and levels of physical ability. The voyages change lives by improving self-esteem, building confidence, and providing fantastic leadership and life skills.

The custom designed tall ship 'Tenacious' include features not seen on other vessels - the entire ship is wheelchair accessible including the platforms up the mast; there are aids for the visually impaired like a speaking compasses and braille signage; people with limited dexterity can even helm the ship with a joystick - so people with disabilities and able-bodied crew members can work together side-by-side.

A JST voyage provides a unique environment where disability is not a factor and those with disabilities can operate as equals alongside the able-bodied, where everyone comes together to work as a single team.

The voyage is about joining in and getting involved in all aspects of sailing the ship, regardless of your ability. Whether you are a tall ship enthusiast, fair-weather sailor or complete beginner, everyone is welcome. Don't worry if you haven't sailed before. Most people step on board 'Tenacious' with no experience of sailing a tall ship, so you won't be alone. Tenacious' permanent crew will support you through all the tasks involved with sailing the ship.

If you or your friends are interested in sailing on-board Tenacious contact Peter.Mitchell@jst.org.au or visit jst.org.uk/australia/about-us/. Find out about the **Inclusive Sailing Adventures** and special offers for Limbs 4 Life members using the promotional code: **LIMBS4LIFE2017**

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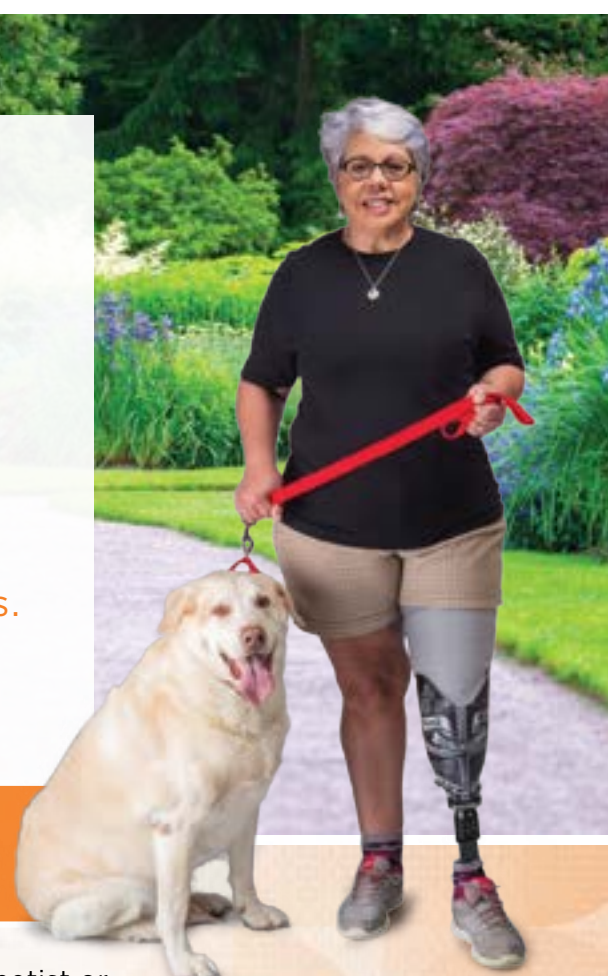
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—Sheila, transtibial amputee since 2002

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www.massonshealthcare.com.au





Connect with us today.

 Join the conversation at Amputees - Limbs 4 Life Facebook

 Follow us on Twitter@Limbs4LifeInc.

 Connect with us on our Limbs 4 Life You Tube channel



National Amputee Awareness Week 4-11 October

Don't forget to contact Limbs 4 Life to order your Amputee Awareness Week ribbons.

What do you have planned for National Amputee Awareness Week? Let us know so that we can promote your event and help to encourage new amputees.

Take part in our awareness campaign by posting a photo of you, your family and friends on our social media sites.

Order your free ribbons today!

INCORPORATING THRIVE
limbs 4 kids



Walking the Walk with William

In April 2017, Össur Australia held a Mobility Clinic at St Bernard's College in Melbourne. The 2017 event saw over 140 amputees, physiotherapists, prosthetists, family and friends from across the country to take part in this positive, educational and fun filled event.

Sally and David White, mum and dad to William, who attended his very first Mobility Clinic, share their story with us below.

In 2014 when our son William was 2 and a half years old we visited our local park for William to ride his scooter. As active children do he rode off, munching on his lunch, not a care in the world, then disaster struck. Time stood still and the noise was deafening. I could not see my child, what I could see was a massive fallen gum tree covering the pathway ridden by William many times before. The tree had landed directly on him.

His scooter obliterated and our precious son losing consciousness and out of reach. When eventually able to find him it was evident his life was to change forever. His whole life flashed before my eyes. I tried to stabilise what I could of his injured leg and body and prepare myself to give him CPR. It was the moments following this when I realised what an incredible young man we have and he has proven this right to this day.

Following many surgeries, overcoming infections and an emergency retrieval to the Women's and Children's Hospital in Adelaide our son exemplifies the true meaning of a hero. As his parents we made a hugely agonising decision to have his right lower leg amputated below the knee in order to provide him with a greater quality of life.

William was cast for his first prosthetic leg whilst laying in an induced coma in the Critical Care Ward in hospital. We are very grateful for the dedicated team that surrounded William and our family during this time.

Three years on and we are in a far better place than we ever thought we'd be. With a wonderful team still supporting William and exposure to amputee organisations, namely Limbs 4 Life we are excited for his future. He has amazing tenacity and resilience, we feel it is our job to educate and expose him to the endless possibilities before him.

Earlier this year it was recommended to us that we consider participating in the 2017 Össur Mobility Clinic in Melbourne. We enrolled without hesitation as this was an opportunity for our whole family to be involved as the impact of William's trauma was widespread.

What is hard to convey in writing is the amazing impact the clinic had on us all.

It was an overwhelming sense of 'belonging', something hard to describe. I could recognise that for the first time in his young life William was surrounded by 'his own', evident by his demeanour and the way he saw that everyone was just like him. He was motivated and so excited to participate in the team games.

Our proud moment was seeing him run with his newly acquired Össur blade, he's not run this fast and with as much confidence since the accident.

As parents we listened intently to the wonderful guest speakers, namely Joany Badenhorst, Liam Malone and Don Eglin who provided much inspiration and



availed themselves to questions that as parents we needed to ask to set our son on the right path for his future. We met other parents in the same situation and that sense of belonging cropped up again. Candidly our children showed each other their residual limbs and were very proud of themselves.

William was taught to kick a football with Don Elgin, the time spent with him was invaluable. He acquired new skills and techniques in walking, balance and resistance training.

We hope to attend the next Össur Mobility Clinic for William and no doubt watch him flourish yet again amongst greatness. - Sally and David White

Össur is a global leader in non-invasive orthopaedics that help people live a life without limitations. Össur Australia hosts the Mobility Clinic annually for amputees of all ages and activity levels. For details about the 2018 Mobility Clinic, visit ossur.com.au and search for Össur Mobility Clinic Facebook Group to stay in touch with others who have attended the events in the past.



Special Children's CHRISTMAS PARTIES

CHRISTMAS PARTIES FOR SPECIAL CHILDREN

Limbs 4 Kids families have been selected to participate in the 2017 'Special Children's Christmas Party' events held across Australia. These events are sponsored by a wide range of donors and businesses, and it is wonderful that children with limb differences are being invited to attend this year.

Children and siblings will have a great time at these events with features including: stage shows, rides, face painting, dancing, gift bags and presents from Santa! Limbs 4 Life and the event organisers would love it if your family can make it to this free event and join in the fun Parties will be held in capital cities around the country.

For more information including event locations and dates, email:

kids@limbs4life.org.au

Numbers are strictly limited.

Don't forget to visit the Limbs 4 Kids website

The Limbs 4 Kids website offers a wider range of information, personal stories, news items, videos and publications that may be of interest to families, healthcare professionals and community members. The 'Learning Centre' section is a library housing information about limb difference, your child, family and friends, education and employment, funding, health and wellbeing, advocacy and inclusion.

limbs4kids.org.au



ottobock.

LIMB-iless 2017

Amputee Conference

Understand the NDIS
'Walk Better' workshops
Train with a Paralympic Triathlete
See how a prostheses is made

LIMB-iless is back, bigger and better than ever in 2017. This years event will be held on the beautiful Gold Coast and will be a weekend packed full of information, interactive exhibits, hands on workshops, demonstrations and social activities.

LIMB-iless 2017 is a great way to meet people, so make the most of this experience and join us for welcome drinks on Saturday 28th October 2017 from 5.30pm onward. Beer, wine, soft drink and nibbles are all included in the price, so come along and join in the fun.

| | |
|--------------|--|
| Where | Southern Cross University Coolangatta - Gold Coast |
| When | Saturday 28th October and Sunday 29th October 2017 |
| Time | 9.00am to 4.00pm |
| Cost | (for 2 days, incl. morning tea, lunch and afternoon tea) Adults \$50.00 Child Free (under 18) Clinician \$90.00 |

LIMB-iless Welcome drinks

| | |
|-------------|---|
| When | Saturday 28th October 2017, 5.30pm onward |
| Cost | \$25.00 per person |



To register please go to : <https://www.trybooking.com/264593>

Discounted conference accommodation packages are available with 'Mantra Twin Towns' Coolangatta. For further information on this special deal please contact:

Anita Stapleton - anita.stapleton@ottobock.com

#LIMBitless2017