

amplified

edition 3 | 2022

Not everyone uses
a prosthesis

Amputee boxing,
get into it

Meet Karen, living
a balanced life

Amp-ed Up 2023
the countdown begins

Meagan's spirit
of adventure



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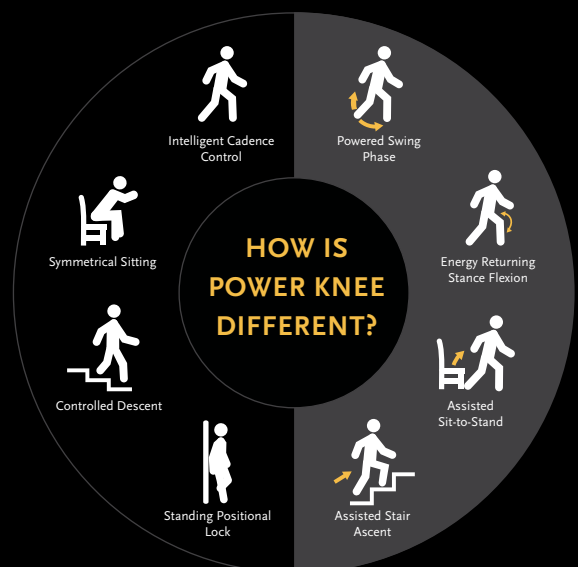
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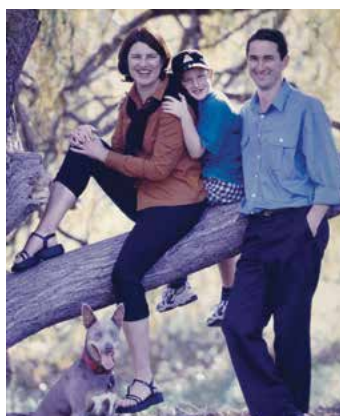
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The Amp-ed Up Conference is not far away, and we are literally counting down the days until February 24. We still have much to arrange and finalise for the conference, but here at Limbs 4 Life HQ there is a certain buzz in the air, an excited anticipation that, finally, after what feels like ages, we're finally going to see everyone together again!

The program has been finalised and we have a terrific lineup of speakers for this event. If you are interested in learning more about them, you can download a copy of the program on our website. We have more exhibitors than ever before, so the exhibitor hall is going to be a bustling hive of activity. You might even catch a once in a lifetime appearance from 'Missing Bits' the legendary amputee band! So, don't miss your chance to attend, make new friends and catch up with those you already know. There are still tickets available. For now...

We can't wait to see everyone again in 2023, but, in the meantime, from our team to yours, I want to wish you a very Merry Christmas and a happy, peaceful and healthy New Year.

Limbs 4 Life Incorporated

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A young woman with short reddish-brown hair is standing on a wooden deck outdoors. She is wearing a blue short-sleeved shirt, white shorts, white socks, and white sneakers. She has a prosthetic leg on her right side, which is gold and black. She is holding two black canes, one in each hand, to assist with her balance. The background features green foliage and a brick wall.

Living a balanced life
- meet Karen

'It's just a pulled muscle' I thought. I massaged the sore spot with menthol cream and then visited the local pool to blast it with the warm spa jets. That should do it. But it didn't, and within a few weeks the pain had worsened, a lump was now visible, and it was time to see my doctor. A mere 3 days later, after x-rays and a referral to an orthopaedic surgeon, I was in hospital undergoing scans and biopsies to confirm a diagnosis of osteosarcoma (bone cancer). It was 1987, I was 17 years old, and at the starting point of a journey that would forever change the way I moved through life. How I moved as a young person was intrinsic to my identity. As a child I was always active whether it was climbing trees, hanging upside-down and spinning from monkey-bars, sprinting in athletics, or challenging myself in gymnastics. My parents laughed that my speed was either 'one hundred or zero', nothing in between. My greatest love, however, was dancing. I did ballet as a child but as a teenager I loved to disappear into my room, turn up the volume on my music and allow my body to express the feelings that arose in response to music. Dancing was the language of my soul.

In hospital I endured three months of gut-purging chemotherapy, which successfully stopped the growth of the cancer, but then also had my right leg amputated above the knee as a definitive action to save my life. Thankfully the doctors and my parents allowed me to make this final decision. A new bone radium and reconstruction treatment was offered to save my leg, but this wasn't guaranteed to work as it was still experimental, and it meant that I would have spent months in hospital. Honestly by that stage I just wanted the leg gone so I could get out of hospital and get back to my life. After the amputation I spent eight months in rehabilitation to regain my weight and strength, and to learn to walk on my prosthesis. It was at least six months into rehab that the psychological impact of the loss of my leg began to dawn on me, but amidst the intense focus of regaining mobility I decided that the loss of my ability to run and dance was too overwhelming to think about. So, I unconsciously buried those thoughts for the next 20 years in order to I get on with the task of living.



I spent at least five years trying to use my prosthesis, but due to the high amputation which made walking difficult, and issues with skin welts and changing stump size, I decided that I'd rather be pain-free and unburdened by an appendage that made me feel more disabled. The prosthesis got thrown under the bed where it gathered dust while life moved on rapidly, as it does when you are young. By the time I was 25 I was married and raising two baby girls born a year apart. When I was pregnant with my first baby, I finally conceded that a wheelchair would be useful, and once I sat in it, I wondered why I'd waited so long. With the babies at home, I used a combination of crutches and wheelchair for mobility but used my chair if I wanted to take the girls out to a shopping centre. I would push myself in my wheelchair with my left leg stretched out and my foot tucked into the back of their side-by-

side twin pram to push them along. We drew attention of course, but it got us out and about. A wheelchair tip for parenting is not to rest a baby on your shoulder and attempt to go backwards down a hallway – it doesn't end well for anyone.

Another tumour was detected in my 40s and although it was resolved with surgery, it brought a tsunami of fears, and I wondered if this was my fate – to just keep getting cancer until it ended my life. I saw a psychologist for several months and thankfully attended to some of the unresolved fears remaining from when I was younger. Another daughter was born, and I realised that I really wanted to use my experiences to help others. My experience with cancer and the familiarity around hospitals prompted me to study at the Peter MacCallum Cancer Centre to train as a pastoral carer/chaplain. These skills led me to work in public hospitals throughout Melbourne's eastern suburbs supporting patients and families through major health crises and very often at the end of their or their loved one's lives. The work was reciprocally life-giving and meaningful. I am now training as a counsellor to continue to support people make sense of difficulties and find ways that empower them to live better lives. I marvel at the infinitely different ways we humans respond to events in our lives, and even more so, how we find meaning and hope amidst these challenges.

Over the years I've continued to participate in many physical activities on one leg such as water-skiing, hiking, synchronised swimming (like dancing, but in water!), swimming, rafting, camping, bike-riding, yoga and going to the gym. But what about the dancing? One day a friend invited me to a creative dance class, and although I couldn't believe he was asking me, he must have known something, for this began a period of exploring movement again, letting go of old expectations, and re-learning the new language of my body as it is now. I eventually joined an inclusive dance group in Melbourne and danced with them for about four years, even performing in White Night Melbourne and in the Fringe Festival. In this creative environment I was surrounded by people of all shapes, sizes and disabilities and I learned that our differences are our strengths.



Whether dancing on crutches or in my wheelchair, I reconnected with my love of music and expressive movement and through these activities began a new and more accepting relationship with my body.

As I get older, the effects of living one-legged are becoming more apparent and I am constantly balancing activity and injury management – though I'm sure I'm not alone here. To take care of myself I utilise a massage therapist, physiotherapist and chiropractor as needed, and invest in specially designed crutches that have rotating tips and shock absorbers to reduce the strain on my joints. I swim, walk my dog and now handcycle regularly both for physical fitness and because it makes me happy. I have learned to validate and value my needs and to search for the solutions that suit me. I have developed compassion, respect and endearment towards this body that has adapted marvellously and carried me through many challenges. I am grateful for balance, strength and resilience and equally thankful for peace, compassion and acceptance.



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Making the trek to Amp-ed Up!

There are a bunch of Sand-groppers from Perth making the trip to Melbourne for Amp-ed Up. Two of them share their stories and tell us why they are coming to the Conference.



Darryl Whittaker is a 50-year-old chef who lives in Gosnells, a southern suburb of Perth Western Australia. He is separated and has a 16-year-old son named Beau.

Darryl shares: In 2009 I was bitten by a White Tail spider and due to the ongoing infection, in 2013 the doctor discovered I had broken bones in my foot because of the bite and subsequent infection. On the 17 August 2016 I was admitted to Fiona Stanley Hospital and became a below knee amputee from then.

I was moved from the main hospital, known as the Tower, to the State Rehabilitation facility, where I stayed for 98 days. I have a prosthesis, but I don't like it, so I choose not to use it and I get around on "George", my wheelchair. I am a very quiet member of the WA Peer Support and Advocacy for Amputees Facebook groups and I saw the advert for Amp-ed Up 2023. I spoke with Andrew, who said to me that the conference will 'change your life'. I am always interested in learning new things, but in my head, I wasn't ready, and I had locked myself away from the amputee community. My psychologist encourages me to get involved with things, so I thought 'why not?' I had a flight credit from a cancelled trip to Bali (due to the Covid restrictions), so I added \$9 to that credit and booked my flights. I also booked my

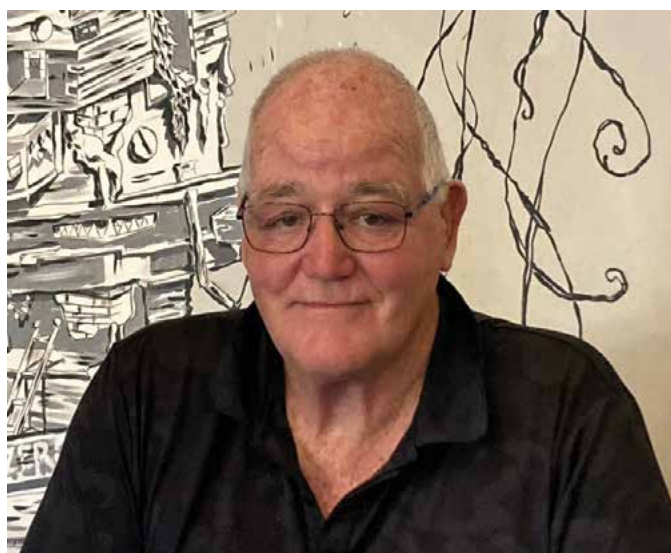
accommodation and used my NDIS funding to pay for my conference ticket.

Why do you want to go to Amp-ed Up 2023 in Melbourne, and what do you hope to see?

This whole trip is going to be a massive adventure for me. I haven't been on an aeroplane since my amputation, nor have I travelled alone. It is both exciting and scary. I feel that it's time for me to meet members of the amputee community and to get involved with people who are 'just like me'.

I am looking forward to seeing all the Assistive Technology for amputees that will be on display and to meet people from all over Australia and build relationships/connections with everyone. This trip, I feel, is going to assist me to accept myself, help to build my confidence and to finally feel included.

Darryl is really looking forward to being a part of the amputee community.



Gary Thompson is 65 and a left above knee amputee from a small suburb east of Perth. Due to ongoing infections that couldn't be controlled, Gary had his amputation done on 30 October 2017 and his amputation is high above his knee.

Gary shares: I completed my rehabilitation at Sir Charles Gardiner Hospital and that is where I first met Andrew. Initially I was fitted for a socket at TLCU in Belmont and then went over to OPS in Osborne Park, but because of the ongoing skin issues, I was having, I went to see Professor Richard Carey-Smith to explore the possibility of Osseo Integration (OI). I had the surgery for OI in October 2019.

I have trialled both the C-Leg and the Genium because initially I was fitted with a Rheo Knee, which I couldn't get to work for me. I had 8 falls and a broken hip on that knee.

Why do you want to attend Amp-ed Up 2023? What do you expect to get out of attending?

I saw the advert for Amp-ed Up on the WA Peer Support and Advocacy Facebook group and spoke with Andrew, about attending the two-day event.

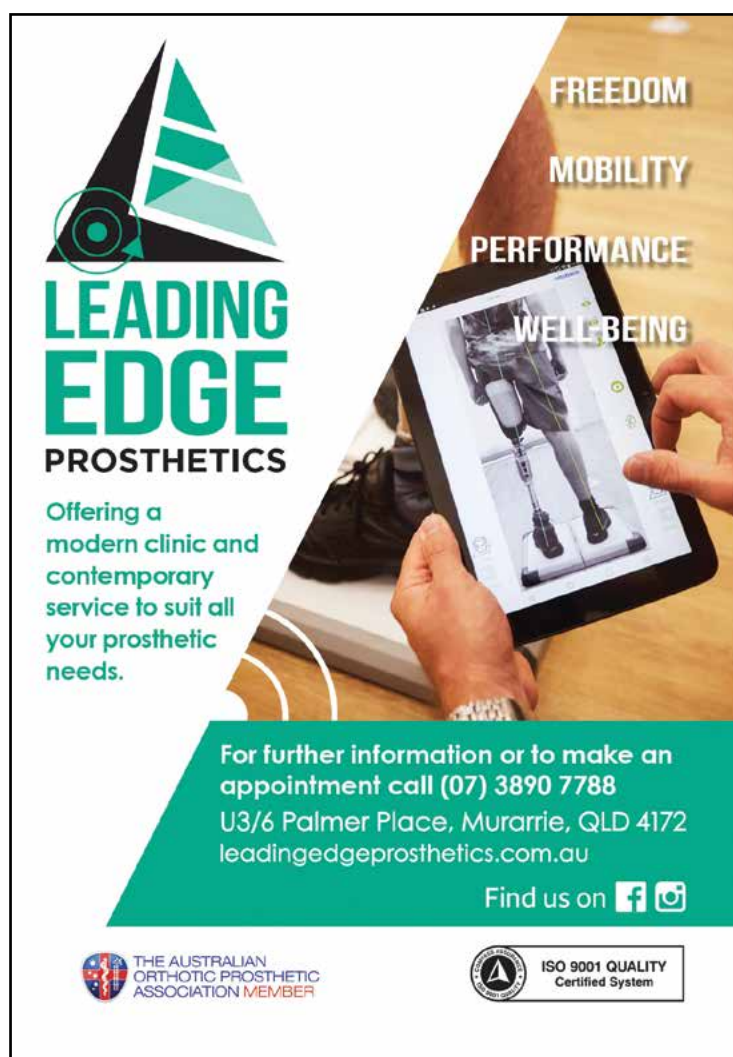
I am really excited about meeting other amputees and getting to hear their stories.

I want to learn about new prosthetics, see exhibitors and learn about what is going to be available to the community. It will be amazing to be able to touch and feel products in real life.

To me, educating yourself is a big thing and I am hoping to learn so much more from the wider amputee community and see a bigger picture.

I don't know exactly what to expect, but I know it will be a good, eye-opening experience. I expect that I will build some good relationships and meet a whole bunch of new friends. I think that I will be like a kid in a lolly shop!

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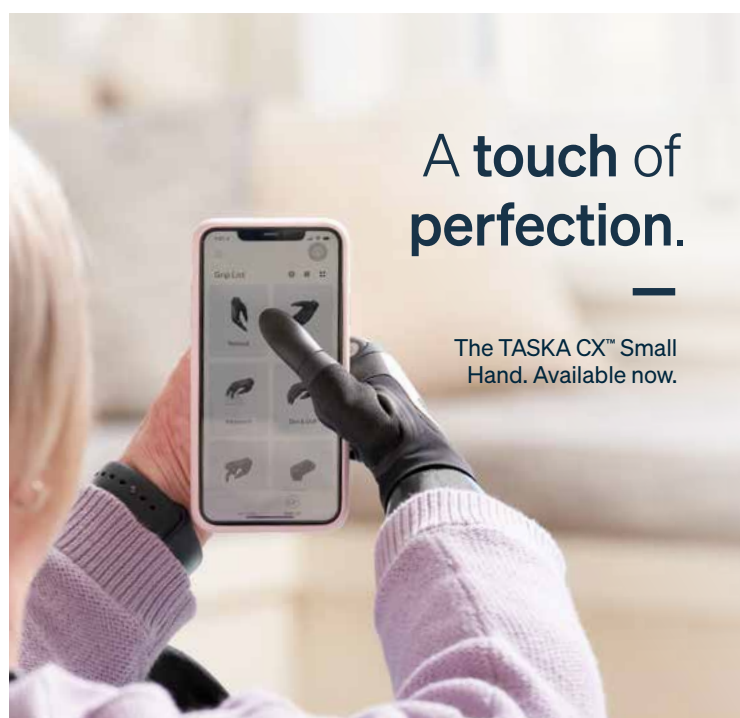
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Getting the gloves on! Ben's passion

I started Ampubox/Chairbox two years ago in January 2020. Boxing is a passion of mine, and I wanted to improve the participation rates of people with disabilities in the sport of boxing. With this in mind, I developed an exclusive service that tailored individualised boxing programs for people of all abilities.

The sport of boxing offers many benefits, both physically and mentally. It encourages people to push themselves to be better than they were yesterday. The clients I work with enjoy overcoming mental barriers that may have stopped them from learning new skills - skills that ultimately improve the physical functioning of their body. My service offers all people a safe outlet to learn the art of boxing no matter what their physical capabilities are.

I have been an amputee most of my life. My right leg was amputated below my knee when I was 14 months old as I did not have a tibia bone or heel/ankle bone (calcaneus). I am a twin and thankfully my parents never treated me differently from my brother. I learnt from a young age that when I put my mind to something, and with the encouragement of family and friends, I was capable of more than I truly believed. I was always physically active and loved individual and team sports. I competed in little athletics, basketball, and football from the age of five.

My father and uncle started a boxing gym in 1968 and I learned the sport of boxing as soon as I could walk. The Brizzi Brothers boxing gym has trained World Australian and Victorian title holders, both male and female. The gym is still family run and owned, after 54 years. The gym has always encouraged participation from youths and adults and has received countless community service awards.

I have been training amputees, wheelchair users, children with autism, ADHD, multiple sclerosis, and other physical and mental disabilities. My sessions always start with the basic principles of boxing. Balance, core stability and basic hand-eye combinations. Each session builds on from the session before. The sessions are fluid and skills are developed as fast or slow as each individual requires. There is no set method to learning boxing.



Some clients enjoy developing specific skills, other clients enjoy the physical exertion and some just enjoy the chat and laugh. Every single person has left their sessions better than when I first met them.

When I start working with clients, I start with basics that anyone can do. I focus on slow basic movements - punches or combinations, always dependant on each person's ability. I teach core stability, upper or lower body strength, basic steps, balance, and focus. Fitness and strength are a natural progression that people gain from boxing. I love building connections and friendships with people I train, and giving them the enjoyment factor, whilst sharing my passion.

NDIS has given more people the opportunity to try new things, without major costs. For those that access NDIS, I can create a service agreement. Initially, when I first make contact with new clients, I offer the chance to come down to see what I do, to chat over the phone or to jump on my social media pages (Ampubox & Chairbox). Each new client always begins with a free trial. I run my sessions from

the boxing gym, and for those who are unable to travel or who are interstate, I organise online zoom sessions.

Limbs 4 Life has given me another avenue to connect with amputees. It provides me with the opportunity to talk to others, to share experiences and to encourage new amputees with different ways to move forward. I am also a member of the Northern Amputee Empowerment group here in Melbourne.



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Jason Diederich, Mike Rolls and Sara Shams

Spare Parts is joining us again to help you to Bling your Limb!

Great prizes to be won!

Pick up your official conference T-shirt and visit the Limbs 4 Life stand for our latest merchandise.

AMP-ED Up!

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Get ready to Bling your limb!



At the AMP'ED Up! conference we are bringing back the Bling Your Limb competition for attendees to show off their prosthetics and go in the draw to win a very special prize.

Having a bright and colourful prosthesis is a popular choice of many amputees these days, with personalised fabric choices on sockets and removable covers. We encourage attendees to decorate their prosthetics in new, temporary, and creative ways.

So, between now and February pop your creative hat on and check out the craft shops (or the craft aisle of the \$2 shop!) and see what you can come up with! During the conference we will also have a craft station to help out with any last minute ideas or entries.



This competition is supported by Spare Parts, which started as an exhibition over 12 years ago when a diverse range of artists used donated prosthetics as a canvas to create new works. The founder of Spare Parts is Priscilla Sutton - who is also our ACT representative on the National Amputee Advisory Council. Through Spare Parts, Priscilla has helped to create an open and honest conversation about amputee life and loves to encourage prosthetic pride and body positivity.

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A photograph showing the lower half of a person sitting in a silver wheelchair. The person is wearing a light blue t-shirt and blue jeans. They are on a cobblestone path next to a red car. The text 'Not everyone uses a prosthesis' is overlaid in white on the left side of the image.

Not everyone uses a prosthesis

When it comes to adjusting to living with an amputation there are many decisions to make based on the unique skills of each person. These unique physical, psychological and environmental skills will help to inform the different choices each person will make to live a comfortable and meaningful life. One of these factors is whether they will wear a prosthesis. Not all amputees will wear a prosthesis. In a 2011 national survey of Australian amputees, Limbs 4 Life found that 7 percent of amputees don't wear a prosthesis, and in another Australian hospital study this number was closer to 20 percent

There are many reasons why some people don't wear a prosthesis.

For people living with a lower limb amputation (or difference) these reasons can include:

- issues with residual stump and limb
- prosthetic issues – limb feels too heavy
- other medical conditions
- issues with the 'good' limb
- pain issues e.g., uncomfortable/ill-fitting socket
- falls or fear of falling
- the high energy needs required
- unmotivated
- unable to put on or 'don' the prosthesis
- balance issues
- personal choice
- the prosthesis restricts, rather than supports

For people living with an upper limb amputation (or difference) these reasons can include:

- prosthesis inhibits, rather than supports function
- the harness is uncomfortable
- socket is painful or heavy
- perspiration affects use
- prosthesis is too complicated to set up
- mental or physical workload is too great
- reliability - prosthesis doesn't do what the user wants it to do
- funding restrictions in the public system prevents the development of, and access to, new technology
- wearing prosthesis during rigorous activities can increase the chance of injury



Things to consider when not wearing a lower limb prosthesis

Mobility

People living with lower limb loss use a wide variety of mobility devices to get around at home and in the community. These can

include (but are not limited to) skateboards, crutches, wheelchairs, motorised scooters, saddle-chairs with wheels, handcycles – pretty much anything that suits their needs and their level of activity. The most common though, are wheelchairs and crutches.

Wheelchairs are constructed from a variety of materials, and with the help of occupational therapists and manufacturers can be measured and customised for your specific needs. You will require a certain style of wheelchair that can manoeuvre around your home and can get you out into the community. Some people have a chair for home, and a separate one to get them out and about. Your wheelchair may be a manual chair that can easily fit into a car, or it may be a motorised wheelchair that enables you to visit friends, go to the shops or travel on a train for example. Long-term wheelchair use reduces physical activity levels, but the benefits include providing basic mobility that supports independence.

Crutches are another way to support your mobility. They are easily accessible from a chemist or mobility supply shop and can be improved by a vast array of accessories that enhance their comfort. There are specially engineered and lightweight options from around the world that might be worth investing in, if you are a long-term user. When using crutches, the risks include falling on slippery surfaces and the possible development of joint problems. The benefits of crutches are that they increase a person's physical activity which supports muscle and cardiovascular health, and they provide a freedom of access to many environments. Crutches require a level of strength, balance, and fitness to use, and while some people can use them daily, others prefer to use them only for specific activities or for added support. It is important to be aware of any muscular or joint pain and to seek support from a healthcare professional.

Foot care

Looking after the health of your remaining foot/leg is important. If you use a wheelchair, it is helpful to be aware of the circulation through your leg and remaining foot. Check regularly for the shape and colour of your foot

and notice if there is any pain. Your health care provider will be able to give you simple exercises and stretches to keep the circulation flowing to keep your remaining leg and foot healthy. If you are a below knee amputee your wheelchair should be fitted with a stump rest to avoid hanging your stump over the edge of the wheelchair. Stump rests also provide an amount of protection to your residual limb.

If you are using crutches, you will be placing extra weight on your remaining foot. To maintain the strength of your bones and muscles, a podiatrist can create supportive innersoles to evenly redistribute the weight as you walk, reducing any pain and ensuring the longevity of your foot. Footwear that provides protection and stability are vital with some amputees using their funding streams to enable them to use a specific non-slip or orthopaedic shoe. Persistence or luck might connect you with an amputee foot buddy to share unused shoes with!

Clothing

Skirts and dresses are an obvious choice for some lower limb amputees, but for all of us who wear pants – what do we do with the leftover leg? Again, this is a personal choice with many choosing to knot, tuck or sew up the loose pant-leg of their trousers. Depending on the length of stump, others have their trousers or shorts professionally trimmed.



Things to consider when not wearing an upper limb prosthesis

Adaptive equipment

There is a vast array of adaptive equipment available for personal hygiene, dressing and eating, home, work, and social activities and for leisure and sports, and these can be accessed through healthcare providers and online companies from around the world. It is important to ensure that any equipment is functional to you and if it is not, to find something that is. If you are living with an upper limb loss you will find unique ways to do activities that support your independence and your lifestyle.

Physicality

People living with an upper limb loss naturally use their dominant arm and hand more and depending on the level of loss, find their body naturally shifts towards a new centre of gravity with the muscles adjusting accordingly. These issues can, over time, impact the shoulders and back from bracing and twisting, and the dominant arm and hand from general

increased use. In addition to feeling tension on the over-used shoulder, arm or hand, being one-handed means it is impossible to self-massage or rub any minor aches or pains oneself, so finding ways to bring relief is a necessity. Some people with upper arm loss utilise support funding for regular massages to release the tension from their upper body and their dominant side. Some attend yoga, go to the gym or see a physiotherapist to learn adaptable stretches to give relief.

Clothing

Clothing can provide options to show as little or as much of the remaining arm as is preferred, and people with upper limb loss vary in their sensitivity to the hang of the loose arm in a shirt, jumper, or jacket. Some amputees are comfortable in sleeveless tops, some prefer the loose arm to always hang for aesthetic symmetry, while others prefer to pin or tuck the sleeve into a pocket and out of the way. The fact that gloves come in pairs will remain a frustrating reality!

Visual difference

People with an amputation who don't wear a prosthesis will have a more obvious visual difference in public and will attract stares and comments. Particularly in the early stage after an amputation this can be a very sensitive and difficult time, and each person will navigate this in ways that suit them. The only way to strengthen your ability to manage this and

continue to live your life is to keep going out and literally practice being seen. Over time it will become easier, and as you integrate your new body shape into your life your sensitivities will lessen, and your capacity to be in public will increase.



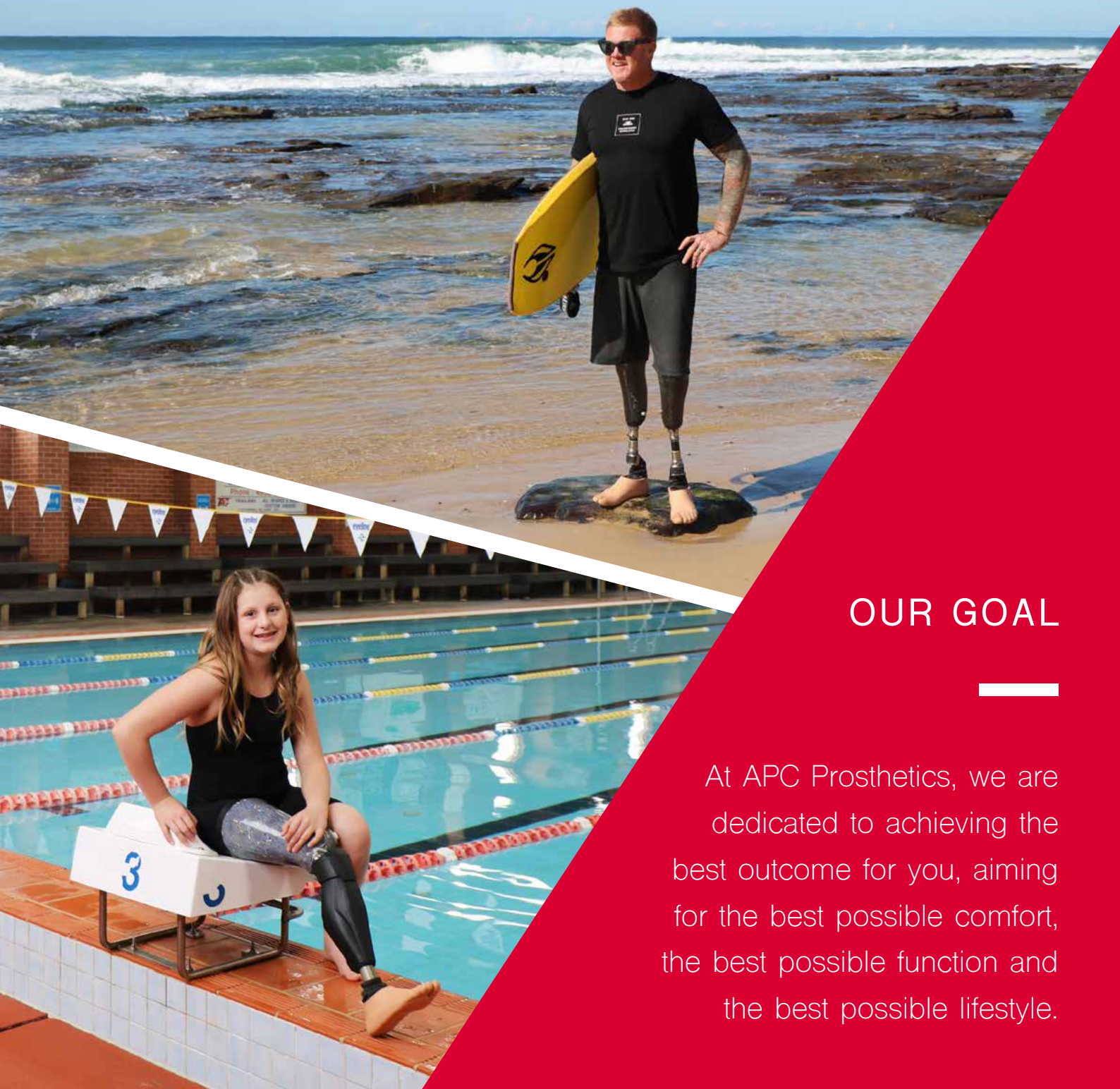
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Meagan's spirit
of adventure

My name is Meagan Shand, it's been almost a quarter of century since I became an amputee, and looking back, it's been a wild ride. I often describe my journey as 'adventurous and abundant', there have been highs and lows, twists and turns, chaos and calm, and many challenges along the way.

I was adventurous before I lost my leg, it was my spirit for adventure that led me to this disabled life. I lost my leg in southern India, in a motor vehicle crash and the ordeal of getting to a decent hospital and medivacked back to Australia was terrifying.

The accident is not something I dwell on, it never has been. For me, it was a matter of 'wrong place, wrong time'. It was simply my 'bad luck.' What did matter to me, was where I travelled next. It spurred me to action. Motivated by the lack of peer support and unimpressed by the 'shit leg' I was given back in Australia, I started Amputees In Action with the aim to build a better future for the amputee community.



The memory of being fitted with 'Mr. Roberts' old discarded yellow foot in a Perth rehab clinic, still makes me feel sick. Yes, they didn't even bother to remove his name or the manky brown slipper that was still attached to it. It seems like a small thing, but when you are a 33-year-old woman whose body has been traumatically altered - these little things make a BIG difference to your recovery.

Losing my leg was traumatic - there was nothing insignificant about it. Although my heartless Physio seemed to think differently, once in rehab, when I was crying from my pain and loss, she exclaimed - "it is only a leg you've lost". I witnessed other people struggling through the rehab process, and I wanted to help make things better.

It is this ambition to 'make a difference' that has led me on some extraordinary adventures across Australia and across the world. One of the biggest adventures was taking eight artists with disability to Germany, for the first Aus-Berlin Arts Exchange in 2017.

I love the power of the arts to transform lives, Australia has some incredibly talented artists

with disability, and it was a great honour to serve them in the role of CEO of Arts Access Australia. In this role, I led three national arts and disability forums in Perth, Alice Springs, Canberra, as well as the international exchange in Berlin. Standing on the stage at the Berlin Embassy was a defining moment for me, not in my wildest dreams had I thought I would go so far. That I suppose, is the GIFT I received in return for my lost leg.

This spirit to push beyond the limits, to transcend boundaries, to colour outside the lines. As a famous limbless artist once said, "who needs legs ... when you can fly", right? If only that were true, the reality is legs and limbs are very useful things to have, and it is our shared quest to find good ones that brings some of us together as a community.

So how are we doing in the amputee community, have things changed for the better over the last 25 years? Yes, in many ways they have, we now have peer support programs in place, thanks to Limbs 4 Life and we do have better prosthetic technology to choose from. But ... these are not the only measures of

success, and we have a new set of challenges to face and a new generation of leaders to nurture.

I am committed to supporting leaders and emerging leaders with disability to live and lead well and was recently invited to join the Disability Leadership Coaching Panel. The first of its kind in Australia the program offers one-to-one coaching for disability leaders at all stages of their leadership journey.

We all have our own disability journey to make and although there is no right way or wrong way to do this, there are some things that will help along the way. The key to success is to surround yourself with the right people and the right support, people who truly care for you and are invested in your wellbeing.

As I write this article, I am reminded of all the people who have helped me and continue to support me on my journey and from the bottom of my heart I say a big wild and abundant ...
THANK YOU.

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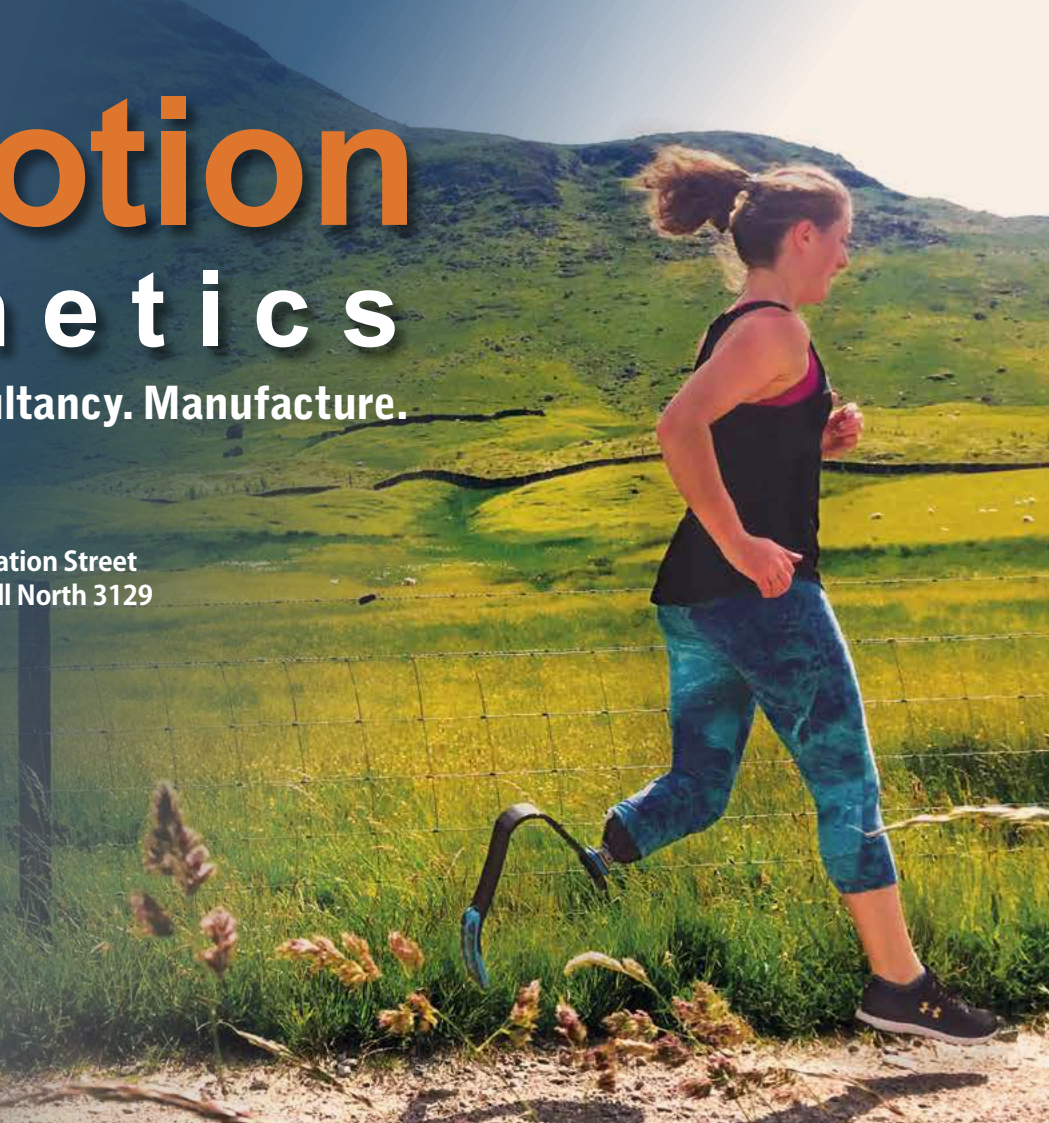
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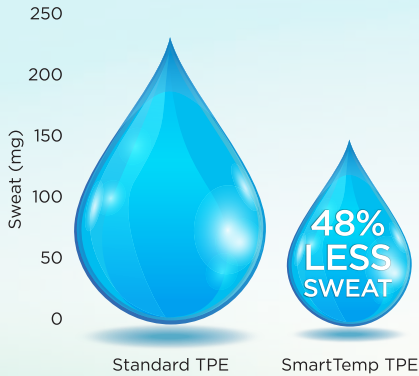
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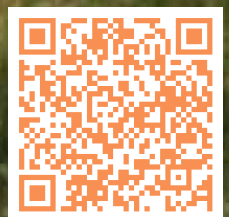


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