# amplified edition 2 | 2024





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### Inside this edition

It never ceases to amaze me how diverse our community is. We are privileged to hear people's stories and learn of their journeys post amputation. Their experiences are very different and vast. In this edition we feature stories from some of our peer support volunteers and learn of some of their incredible achievements. For others, it can be the simple joy of giving back to others and sharing their own experiences. Regardless, they all form part of the very rich tapestry that is our community.

Which reminds me, early bird tickets for AMP-ed Up! close on September 30, so don't miss the opportunity to purchase your registration ahead of time and save a few important dollars in doing so. Our AMP-ed Up! merchandise has arrived so if you're in the market for a new polo, t-shirt or cap, give as a call!

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Jason is an amputee, peer support volunteer and previous board member for Limbs 4 Life. He recently embarked on a move to the UK!

Last year, I took advantage of an amazing career opportunity and moved from Melbourne to London. My Australian employer has a UK subsidiary which won a big contract to deliver disability and health assessments for the UK government. When my manager asked me if I was interested in supporting the implementation and roll out of this contract for a few years, I didn't hesitate. Terrifying, yes, but in recent years, perhaps now that I am in my 50s, when exciting opportunities arise, I have learnt to say yes and work out the details later! I believe you are more likely to regret the things you don't do, rather than the things you do, so I jumped at the chance ... or rather hopped at it. (Well if I can't make these jokes here in a Limbs 4 Life article, where can I make them?)

#### Prosthetics and health services

Some of the "details" that I had to work out were around my prosthesis. I became a below

knee amputee when I was ten, after a muscle deficiency from birth meant my legs did not grow at the same rate as each other. In Australia, my limbs were funded through the Victorian Artificial Limb Program (VALP) and so I knew how all of that worked. (I haven't yet applied for NDIS, but I will when I get back, I promise) But I had to work out what supports and services would be available to me in the UK. I was fortunate that I had only recently received a new prosthesis not long before I left Australia, so this meant I didn't need to worry straight away about how to sort out a new one, but what would I do if I needed more socks, or sleeves, or if the prosthesis broke or was damaged? Again, I was fortunate that my working visa meant I am able to access the UK's National Health Service (NHS), but I soon learnt that this may not be all the support I needed, or when I needed it.

The NHS covers pretty much all health services in the UK, from GPs, allied health, hospitals, mental health services, and of course prosthetics. But registering with the NHS is not an easy exercise, as you need all sorts of paperwork and evidence that you are eligible. I found this out the hard way when I had bad

neck pain when I had only been in the UK for a few weeks. Trying to get in to see a GP was very difficult when I didn't yet have a permanent address, or any history on the system. Although a positive aspect of the UK health system I discovered is that codeine is available over the counter, so that made it a little easier to manage my neck pain!

Once I was registered with a local GP clinic in London, I then needed to get a referral to a prosthetic clinic. Of course I had no idea where to go, but I did get chatting with an arm amputee at the pool one day and he shared some local amputee knowledge, invaluable!! Once I managed to secure an appointment with the GP (not an easy task either, see below), I was able to ask him for the referral to my preferred clinic based on the advice I had received ... the Douglas Bader Amputee Clinic at Roehampton Hospital. For those of you who might know your World War II history, you might be aware that Douglas Bader did some pretty amazing things after losing both his legs as a fighter pilot in a training accident. He went on to fly Spitfires for the RAF in World War II, until he was shot down over occupied France. He was taken prisoner by the Germans but escaped multiple times! He survived the war and continued to attend the Roehampton Clinic for years afterwards. I read his story as a child (and saw the movie, Reach for the Sky) so to be attending a clinic in his name was pretty cool.

But getting an appointment there was not an easy task either. I decided it would be prudent to register and make an appointment just so I was known to them, even though I didn't immediately need support. I didn't want to wait until I had a prosthetic emergency before contacting them. This was a good decision, as I needed to wait 8 weeks for an appointment, in fact two appointments, one with the doctor, and then one with the prosthetist. I did ask about their stump socks, as I am quite active so go through mine guite guickly. Unfortunately, they don't supply the ones I normally use, and the ones they offered really didn't suit my stump shape (kept sliding down into my prosthesis). So. I will need to look at sourcing those from somewhere else.

I haven't yet had to access any limb technology over here, so I am not clear on how much they cover, but based on the gasps, surprise, and excitement when the clinic staff saw my Allelles leg cover (purple with scales) it was clear they had never seen that type of equipment before. So, I am guessing those things aren't generally covered.

One of the things I have discovered with the NHS is once you are in front of a health professional, the service is pretty good. They are friendly and look after you, and make sure you have what you need. Not just prosthetics, but GPs and health clinics too. The problem is getting in to see them. It's pretty hard to get a traditional appointment like we are used to in Australia. If you call up for an appointment with the GP they will insist on a phone appointment first, which can be at any time within the next few days, i.e. your phone can ring at any time at all, and you need to respond or potentially miss it. Having said that, once you do speak to them, they are pretty good. If you need a prescription, they send it automatically within minutes to the pharmacy of your choice and you can usually pick it up within an hour. There is no cost at all for the GP and the prescriptions are around \$15.

### **Getting around**

At a practical level, getting around the UK is difficult for many people with disabilities. London is a very old city with many beautiful and historic buildings. The flipside is that many of them are not accessible. I am fortunate that stairs do not pose a barrier for me, but I can imagine for many others this is a real issue. Similarly, there are some issues with train stations being accessible by stairs only, particularly the London Underground. Some stations promote accessibility to the platform, but then the train door and the platform are not at the same height!





An unexpected challenge for me occurs on some Underground trains. I regularly use the Northern Line which runs close to my flat in South Wimbledon. The Northern Line is quite old, and the trains that run on it are quite small compared to some other Underground lines. The seats run longitudinally, meaning your legs stick out into the aisle. I cannot sit for long (or even short) periods with my knee bent at 90 degrees as it is quite uncomfortable. This means that I need to stick my prosthetic leg out into the aisle, and so people need to step over me to get through. At peak hour, the train is crowded (jam packed) and I am wearing a suit, so my prosthetic leg is not visible. I am constantly trying to move my leg to let people past, and often they glare at me for sticking my leg out. On a typical journey I need to mention I have a prosthetic leg once or twice so that they don't just think I am a selfish bastard! If I am wearing shorts, it's not as much of an issue. In fact, when my leg is visible, I regularly get offered a seat by other passengers when I board the train or the bus.

Having said that, travel across the country by train (and into Europe on Eurostar) is pretty good for someone who needs a little extra leg room compared to what you might get on a plane. Compared to Australia, the trains are frequent, fast, comfortable and can get you pretty much anywhere within the UK. The Eurostar train across to France, Belgium and The Netherlands is fantastic, and in my opinion much more comfortable than the plane, although sometimes more expensive.

### **Disability inclusion**

I work in the disability sector over here, so it has been interesting to hear the narrative around disability inclusion, and exploring how that is different to what we know in Australia. In general, what I see in Australia is a conversation and an approach that seeks to empower people with disability to live independently and to participate in the community socially and economically. Over here it seems that the conversation and approach is about "rescuing" people rather than empowerment. It feels more like people are given what they need to stay out of the way, rather than to encourage them to connect with their community. Gradually I think that will change, but for now there is still so much to do.



Australia is much further advanced in this respect, and I have come to realise just how amazing the level of support provided by the NDIS is. The funding for core supports, assistive technologies and in particular capacity building, along with the practical supports to connect with the community providers, is far above what could be currently conceived in the UK. While the NDIS cops a bad wrap in the media back home, the folks here only dream of that level of support.

I haven't faced any overt discrimination anywhere in the UK, and indeed I think there is a positive perception of disability overall following the impact of London hosting the 2012 Paralympics. However, it has reinforced the idea that people with disability are either dependant and worthy of pity or are superhuman and there to inspire.

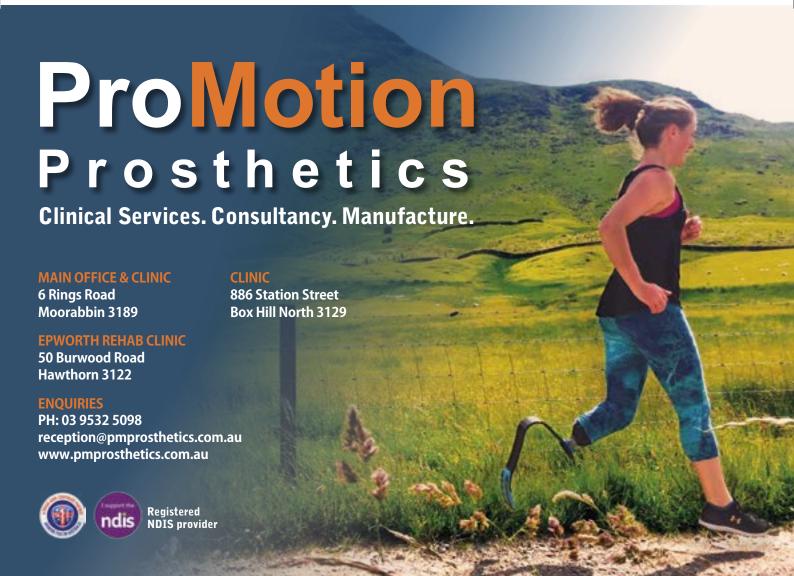
Although there are some shining lights (Channel Four for example, an amazingly inclusive employer), the ordinary bit in between is still largely being overlooked. So, I have been shouting that message to anyone who will listen (and some who won't) about #makingdisabilityordinary. Helping people with

disability to be able to shop, to work, to get around on public transport, to go to the theatre, to have relationships and so much more. I believe that's where we can make a difference over here.

### Life is an adventure - if you want it to be

This journey to the UK was always going to be an adventure for me. There have been highs and lows, and I have certainly learnt a lot about myself since last year. Overall, I am actually really proud of myself for taking the leap in to the unknown and relocating halfway around the world at my age. It is also the first time in my life I have lived alone, so that brought with it some adjustments too.

The bottom line is, even for those without disabilities, there will always be some barriers and challenges when you move outside your comfort zone. When you have limb loss, you just experience some different ones. In my opinion, if the opportunity presents itself, take it... and work out those details later.





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# Jeff, the community contributor!

Jeff is a valued member of the Limbs 4 Life community, peer support volunteer and all-round advocate for Australian amputees.

The year 2020 will remain memorable as I became a right below knee amputee just as Covid was stealing all the attention. After damaging my feet in a new employment role, I succumbed to ongoing diabetic foot ulcers. Eventually, I developed Charcot Marie Tooth disease and after extensive treatment, it came to be that the most logical and beneficial process would be amputation. Welcome to a whole new world.

At the time, I had to change hospitals and surgeons, but I had, and continue to have, some of the best people on my healthcare team. The difference this makes post-surgery is not fully recognised, and sometimes they need to be reminded how appreciated and important their input is. Thanks, Pauline, Lauren, Craig and Tim.

Whilst in hospital, an innocent trainee asked me if even though I had a prosthetic leg, did I still have my own, real foot? At the encouragement of an experienced nurse I explained how I lost my leg and after giving them the basics, I alluded to the fact that my dog loved the bone. Their reaction was priceless, especially after suggesting that I could do it because it was my own leg! You have to maintain a sense of humour in hard times!

In my daily life I try to remain active, and I keep in regular contact with all the 'iatrists' and 'ologists.' For me, they consist of my physio, podiatrist, prosthetist, endocrinologist and my GP. I also pay close attention to my mental health. I'm my 88-year-old mother's carer and a Justice of The Peace, amongst other things. For me, a great day can be simply tinkering in the shed or just a drive in the bush. Life doesn't



have to stop if you become an amputee. My 'normal' days can include a visit to the gym, a trip to my prosthetist to trial a new hydraulic foot or to cast a new socket, or to have a BROKEN check socket attended to! I also regularly attend Justice of The Peace meetings, amputee group meetings, inductions/registrations where my local amputee group are registered volunteers, the list goes on.

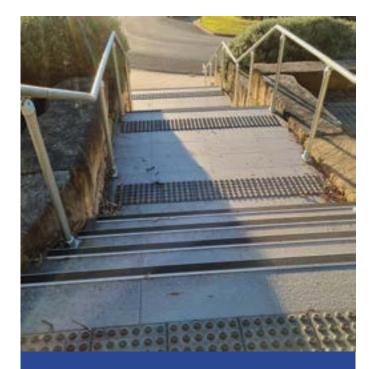
Now to Peer Support, and why I volunteer. In my initial rehab hospital stay, I was fortunate to share the ward with an above knee amputee, who is a great communicator and his energy no doubt made me more active and focused at the time. He remains a good friend to this day. Being known as 'The Lord of the Ward' he unknowingly encouraged engagement and interaction with many patients including myself in my new 'amputee world.' Thanks, John!

Myself, and other amputees in the hospital had no access to formal peer support, but luckily, I'd received some great resources from an excellent staff member, so we at least had those to share. Thanks, Mia! This sparked my interest in being there for others and I found Limbs 4 Life. I trained and came on board as a Peer Support Volunteer. I have since spoken with many clients, both pre, and post amputation, who I learn so much from, which in turn helps me.

Due to only being an amputee for a short while, I often feel like a fraud, simply because I feel that I have had so little trauma compared to many others. Whilst I experience mostly the same challenges as other amputees, I think it's all about perspective. I'm lucky that I am only a below knee amputee rather than above knee, or bilateral or quad. And even with my dodgy, diabetic, arthritic, neuropathic hands I feel privileged to have them.

Even though I've only been a Peer Support Volunteer for a short time, 3 clients that I visited have since become Limbs 4 Life Peer Support Volunteers themselves. Hi, Clay, Lee and 'Saint' George! A huge benefit is also being able to correct misleading comments, which can cause distress to individuals and families. Whilst we do not provide medical or prosthetic advice, the lived experience we have and can share is something that only actual amputees can.

On several occasions I have had to disagree with information provided by well-intended professionals that caused unnecessary concern and stress. Instead of saying 'can't,' when speaking with new amputees, I prefer to use words such as 'maybe', 'possibly' and/or 'I don't know.'



Advocacy at work - stairs at a local family park now have railings and anti-slip pavers after Jeff made a submission to council.



Jeff and his local amputee group have donated 7 wheelchairs to local hospitals, where there were previously no manual wheelchairs on site.



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The most vivid memory my neighbour has of THAT NIGHT isn't mine. She remembers it as the jubilant shout of "He's conscious!", uttered by an emergency worker. Since arriving back from an overseas holiday, I had been feeling unwell, which I had put down to the flu or maybe COVID. More seriously, as a result of a cut foot, an infection was taking over my body, eventually resulting in a lower right leg amputation. Another contributing factor was undiagnosed diabetes. Upon entering the hospital, I had a blood glucose level of 78, meaning there was a high risk of death or brain damage. Each year over 8,000 people in Australia have some kind of amputation, with varying causes including accidents, cancer, and the combination of infections and diabetes.

My own experience was similar to that of Clayton, a Peer Support Volunteer with Limbs 4 Life, who called me to provide Peer Support during those early days in hospital. He described his own life-changing experiences following his amputation, including changes to his personal life and career.

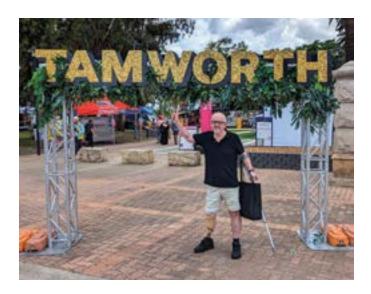
Fuelled by powerful pain medication during the early weeks of my hospitalisation, I found it hard to think clearly. Simple emails and messages of support required multiple readings before I could even attempt a response. I also had to put modesty concerns aside as nurses helped me with the most basic of human functions.

"How are you REALLY?" was a frequent early question from concerned family, friends, and medical staff. At first, their responses to my "I've had a couple of tough days, but mostly I feel pretty good," seemed laced with disbelief. I noticed that there were two main ways in which people responded. First, there are those who take my positivity at face value, offering enthusiastic support like, "You've got this!". And secondly, there were others who approached the situation with a different perspective, perhaps wondering if the full weight of what happened might hit me later, once the hospital's comfort and support system faded. And maybe that's a possibility, even now, a year later.

In the weeks leading up to my illness, I visited Vietnam and Cambodia. Among the people I met were some who had lost limbs to landmines. In the grand scheme of things, millions around the world have lost limbs, some even more than me. And they've faced this without the privileges I've had, living in an affluent country with a top-notch health system. "I feel lucky to be alive," I told my friends, "like I've been given a second chance."

The period at Sydney's Sacred Heart Rehabilitation wasn't merely about physical therapy. Mindfulness techniques helped me manage the mental toll, while mirror therapy aimed to retrain my brain to accept the new reality of a missing lower leg. In total, I spent close to four months in hospital. Preparing for discharge was always at the forefront of my mind, including whether I could navigate in and out of my apartment independently? Would I be able to shower independently? What modifications, if any, might be necessary for me to live on my own? A good friend stayed with me on the first night back home. Although I went to bed feeling good about things, I quickly found myself in tears, comforted by her. "I don't want everyone to worry about the tears on the first night," I told her the next day. "I don't want them to think I've fallen into a deep depression now that I'm home after the safety of hospital life." My friend responded, "The tears are perfectly normal," and "maybe there will be more tears in the future, it's likely there will be difficult days."





Early on, I realised it wouldn't be a simple linear progression from amputation, to wheelchair, to prosthesis. As I've read in online amputee forums, many people find their prosthetics don't fit well, or they cause irritation to their stumps. Recently, after heavy rain, the lift in my apartment block stopped working, which meant it was harder for me to get in and out of my apartment. It was a reminder that I could easily find myself housebound, despite my apparent mobility.

The NDIS has also provided me with a transportation allowance, allowing me to catch taxis and ride shares. Mostly though, I use public transport where the interactions have been both good and bad. Sometimes people don't notice I still have mobility requirements, especially now that I'm walking independently, without crutches. Even though my prosthetic remains fairly obvious, many people never look down (especially when they're using their mobile phones).

After my amputation, I had four months away on sick leave (as a long-time public servant I'm lucky to have plenty of reserves), I returned to work part-time in November 2023. At first, it was really hard balancing work, managing my diabetes and the additional demands surrounding amputation. It often felt like twice the effort compared to someone without an amputation. For example, walking 5,000 steps for me is akin to 10,000 for others.

Having a dedicated Wednesday off work for medical appointments and rehabilitation activities like swimming and physiotherapy has been a welcome relief. However, fatigue persists, sometimes forcing me to spend most weekends resting in bed. My workplace (the ABC) has been wonderful, both at a personal level (lots of colleagues reaching out, visiting, and sending gifts) and at a more institutional level by allowing me to work part-time. Progress is evident, and I'm optimistic about returning to full-time work later this year.

The amputee Facebook group I joined, Amputees - Limbs 4 Life Australia, has been invaluable as a guide. Discussions there shed light on the varied experiences of returning to work. Some, like a bank employee facing ongoing medical challenges, have struggled for years even with a part-time return. Others, like a remarkable guad amputee, transitioned from part-time to full-time office work. Challenges abound, though. One small business operator spoke on the group about a gradual return to running his business, until ultimately closing it due to compounded difficulties including pandemic-exacerbated mental health issues. However, there are also inspiring stories. A few weeks ago, the Sydney Morning Herald featured Joey, a young man from Newcastle who returned to work as a plasterer after two years. Now, he's even training for the Paralympics! Go Joey!

For many, the journey back to work is arduous, and for some, it remains unattainable. The Facebook group has truly helped me understand that everyone's experience is different. There's no single answer to the everpresent question for new amputees; "When can I return to work?"

As I approach my "stumpiversary" (as it's sometimes known in amputee circles), I'm feeling both positive and reflective. I'm consciously aware of how lucky I have been, supported both institutionally and personally. But not everyone is so lucky. Many people struggle, find themselves isolated, or are unable to navigate the associated complexities.

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# Addressing the gap in information and resources for upper-limb amputees around the world.

Upper limb amputations are less common than lower limb amputations and as a result the literature and access to information for service users is limited. The gaps in information for people with upper limb loss has also highlighted the gaps in service provision and the lack of trained personnel with specific experience in upper limb amputation rehabilitation.

The International Confederation of Amputee Associations (IC2A) participated in a European Commission funded project called the OneHand Project that aimed to create key resources for upper limb amputation rehabilitation personnel and service users. The project ran from December 2020 to March 2024 and worked collaboratively with The Simulation Crew (The Netherlands), The University of Groningen (The Netherlands) and Ottobock Austria. As part of the project, a virtual reality system was developed and tried and tested to support the rehabilitation journey for people with upper limb loss. The system hopes to be available commercially in the future and aims provides a rehabilitation tool for all stages of rehab regardless of the type of prosthesis used.

Whilst upper limb amputation rehabilitation is very individualised, rehabilitation options vary depending on the geographical location, access to services and funding. IC2A's focus was on the development of key standards for service providers, that encompassed vital elements of rehab and for all service providers globally to work towards. IC2A worked with a working group to also ensure that the voice of the user was heard. As a result, key resources were created which include:

- a service user guide to upper limb amputation rehabilitation
- list of peer support groups
- pre-prosthetic exercise list and
- FAQs for service users

IC2A's aim was also to ensure that all of these resources can be accessed globally. These are now featured on the website OneHand project - IC2A and IC2A is working towards translating these into other languages. IC2A also aims to create a service user and carer document for congenital habilitation in the future.

Article provided by the IC2A team. If you have any questions or comments about the current documentation, please contact the IC2A team at projects@ic2a.world.



In 1993 at the age of 19, I was diagnosed with aggressive bone cancer, known as osteosarcoma, in my right leg. The news really scared me, and I had no idea what this meant and how my life would be affected. I had no choice but to prepare myself for whatever was going to happen. Following many months of intensive chemotherapy and the removal of my knee joint, I was left with a stiff leg, which was held together with a long metal pin and screws. Doctors advised me that I would only be able to do an office job, and that I needed to be careful as my leg was fragile. They told me that the metal rod and screws could fail at any time. Up until then, I'd been a very active 19-year-old, so this turned my world upside down. My life had changed so drastically because I had to learn to walk with a stiff leg and I had to find a suitable job. With limited education and a physical disability, I really struggled to comprehend what I'd do.

During my long rehabilitation at Shenton Park Hospital, I felt the need to educate myself as prior to my surgery, I had just passed high school and was doing odd labouring jobs as a fit and healthy young man. So, I started by learning to write again with a hand that was damaged during the 10-hour-plus surgery, and needed physiotherapy, as did the rest of me! Writing short letters and a diary helped to improve my literacy, and I also found it therapeutic to write down my feelings.

Years and many medical appointments later, I decided to pursue my interest in the environment by enrolling in a farm forestry course in the southwest of Western Australia. Hoved this course and learnt to use farm machinery, write assignments, and work outdoors. Following this, I completed a few more TAFE courses to strengthen my interest in the environment, but I was still finding it difficult to get work, despite now having qualifications. I put this down to my physical disability. I thought that the only way to solve this problem was to enrol in a degree in Environmental Management at university. So, at the age of 24, I was a student again. I was terrified of the university system and found the complexities of the course daunting, so after about a year, I had no choice but to put my studies on hold. I was diagnosed with posttraumatic stress disorder and depression and needed urgent medical help again.

A decade later following treatment and, with a few qualifications under my belt I needed to find work, so I applied for many positions and was lucky enough to find work as an Environmental Officer in 2008. I continued to work but realised that I wanted to return to my undergraduate studies, so at the age of 33, I went back to university to complete my degree in Environmental Management. I loved this course, applied myself, and as a result, was invited to do an honours program. I found it hard to juggle work and my studies, so I chose to do a Masters's degree in Environmental Management part-time, so that I could also keep working full time. I graduated with a degree in Environmental Management in 2012, a postgraduate degree in Environmental Management in 2014, and a Master's in Environmental Management in 2016. I loved the academic world and became involved in writing articles, presenting my research at international mining conferences, and I've been writing and attending mining conferences ever since.

About 30 years after my surgery, I was used to having a stiff right leg, but in late 2019, the metalwork holding my right leg together catastrophically failed. As it happened it was the first day of some annual leave and I was out enjoying a meal and drinks with friends when this occurred. I called my wife Charlene, who rushed me to the emergency department at Sir Charles Gairdner Hospital and we waited for hours to see a doctor. Little did I know, but this was the start of another life-changing experience as I was thrown back into the medical system in 2020 at the start of the COVID-19 global pandemic! After months of tests and scans, I was referred to an orthopaedic surgeon who gave me three choices: salvage my leg returning to a stiff leg, amputate above my right knee and have osseointegration surgery, or amputate and use a socket and prosthesis. After many discussions with my wife and doctors, I opted for the latter. In May 2020, my leg was amputated, and my journey as an amputee began. Not only did I find it difficult, my wife did too, but she has been a great support throughout this and continues to be today. I will forever thank her for being there for me.

Following my above knee amputation, I felt freedom and got involved in rowing, swimming and joined the Limbs for Life community. I also trialled many knees and feet, but finally settled on a Genium X3 microprocessor knee, which allows me to swim, ride a bike and run, all of the activities that I'd been missing out on for 30 years! In November 2023, I began running training at the gym, which included drills, weights, strength training and endless one-on-one sessions with running coaches, exercise physiologists and the trialling of running feet. This evolved into running sessions at the gym which I have been doing biweekly for the last 3-4 months. I can now run outdoors independently for short distances, and I aim to increase my endurance and cardio health so that I will be able to run kilometres rather than 100s of metres.

Losing my leg is not a loss per se, but a new beginning. It's given me my life back, and allows me to do much more, like being involved in community events, meeting other like-minded people, visiting new places and setting new goals. I love testing myself and working on my physical training. I wonder what my next challenge will be... My advice to other amputees is to stay focused and get support as early as possible. There is plenty of help out there and you're not alone with this journey.



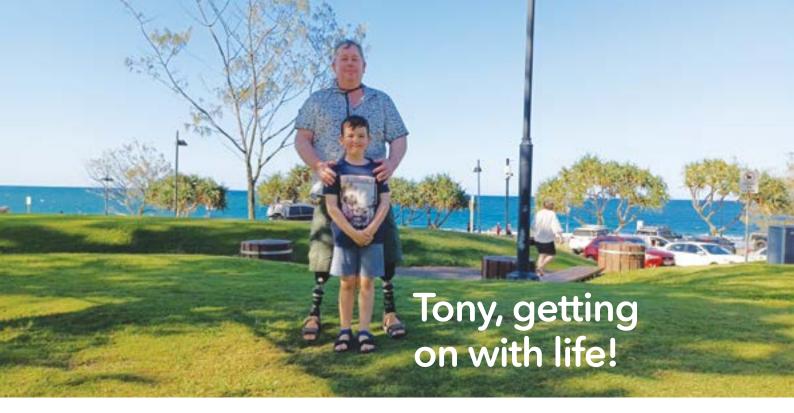
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My name's Tony Mockett, and I'm a bilateral, below knee amputee. In fact, 2024 is my 30th anniversary of being an amputee. What a ride! In December 1994 at age 24, I unfortunately contracted a rather nasty bug known as Meningococcal Septicaemia. Perfectly healthy one day, ICU the next! I spent nearly two weeks in ICU, followed by three months in a high dependency ward at Monash Medical Centre. I then spent another three months in rehab at Caulfield Hospital.

Rehab was gruelling but also very rewarding. After a lot of blood, sweat and tears I vividly remember the day I stood up and walked for the first time. The best advice I received when learning to walk again - swing those arms! So, with my pre-NDIS, government issued prosthetics, and no 'home mods' to speak of, I finally got out of hospital in June 1995. A new life began!

A while after rehab, I went for my driver's license again. I was successful in this and was issued a restricted license, being that I could only drive an automatic car and I had to drive with my prosthetics on! Slowly returning to the workforce over the next 3 years, I eventually returned to full time work in January 2000, and I've been working full time ever since.

I've had no problems flying and travelling as a bilateral below knee amputee and a prosthetic user. In 2005 I travelled with my partner to Hong Kong which was fun and very humid. I've also been to the US three times and done several domestic trips including Western Australia and Queensland. A big shout out to my partner, who has pushed me around in a wheelchair at times, when we've been out and about sightseeing.



2015 saw my greatest life achievement - having a son, Ted, who is now 8 years old and getting bigger by the day. We went to the Gold Coast in 2022, did all the theme parks and had a fantastic time. We regularly play basketball, go swimming or to local parks for a bit of bike riding and we love going to the footy to see our beloved Richmond Tigers!

What else can I say about being an amputee? Get involved! Through Limbs 4 Life I became a Peer Support Volunteer in 2022. Unfortunately, when I was in hospital back in the mid-nineties, Peer Support was frowned upon, so this service was not available to me. One day when I was in rehab, an elderly gentleman saw me exercising and came over and spoke with me. He was also a bilateral below knee amputee, and he proceeded to tell me about his life and experiences - it was the greatest motivation I received whist in rehab.

I've attended many Limbs 4 Life events including the AMPed Up! Conference. I got so much out of the last one held in Melbourne, and I cannot wait for Adelaide next year. I'm a Group Leader, attending lunches where I get to meet other amputees. During these social get-togethers you get to give and receive some great advice, have a chat and a laugh about all things, not just amputee related topics!

I won't lie, being an amputee is tough, and you have to adjust your life accordingly, and get to know your limitations. You have your ups and downs, but who doesn't? I have been laid up at



times, confined to a wheelchair, but for the most part I'm mobile and I live a 'normal' life. Afterall, I'm just lucky to be here!!!

Tony is the Group Leader of the Victorian Metro East Amputee Support Group who meet for lunch throughout the year. You can find out about Limbs 4 Life's support groups and social events on our website.

# Connect with us today @Limbs4Life

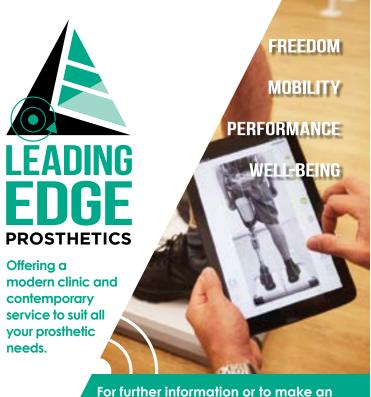












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# Security screening tips at Australian domestic airports

The Melbourne Airport Accessibility Working Group's purpose is to ensure the head of security and operations understands the needs of passengers with various kinds of disabilities. At the same time, the purpose of this working group was to provide some important suggestions for travellers.

For many people, flying brings a range of different levels of anxiety; arriving at the airport on time, accessing a carpark (if you are driving) getting luggage checked and probably one of the favourite things (especially for prosthetic / wheelchair users), the security screening process!

Those of us who travel regularly know that the screening process is a standard part of the journey, but some of the horror stories shared over the years can raise the level of fear and cause angst. For this reason, I thought it was worth spending a day behind the scenes (from the other side of the scanner) to learn some tips in the hope that I could help to ease the process and raise concerns on behalf of our community.

As some of you may have noticed, body scanners (not x-ray technology for those of you who are interested) are slowly being phased in at airports across Australia. Body scanners

should make the process for prosthetic users more streamlined as these devices detect any metal on the body. The screens that the security officers watch, clearly display a complete arm / leg or both if metal in nature, therefore it is quite easy to tell if a person is wearing a prosthetic device, which in turn, may avoid the need for any kind of physical pat down. Security operations are working to remove any form of physical contact by way of touch for travelling passengers.

One of the key messages outlined by the head of security operations is to 'communicate your position early'. For example, tell the security officer that you are wearing a prosthesis prior to approaching the security screening point, and stepping onto the body scanner.

### **Key tips**

- If you are asked to remove your prosthesis or your shoes, you can refuse to do so. Escalate your concerns if necessary.
- 2. Remain calm but be direct in your messaging and explain your situation clearly.
- 3. Request a pause in the process and ask to speak with a supervisor.

### **Interesting fact!**

One thing that I found to be quite interesting was learning that both airport security and the Australian Government send people through the scanners and through the security system carrying a range of prohibited items. They do this to ensure that staff are thorough and are picking up on items such as weapons, drugs, scissors etc. The federal government have different strategies than the local authorities and the security staff never actually know when this will happen and what the 'item of the week,' so to speak, will be. With that in mind, if you are going through security and a possible (but staged) breach had just taken place, then officers may be more alert than normal, resulting in overzealous searches and heightened attitudes!



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# Practical coping strategies to help amputees and their families

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, amputation can disrupt future plans and affect how they view themselves and the world. Amputees are often required to cope with ongoing health issues (e.g. 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 (e.g. 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 negatively impact a person's recovery, rehabilitation, and their physical and mental health. There are, however, a number of things that people and their families can do to help facilitate the process of coping.

Amputees can experience various challenges and will have different reactions and needs dependent on the stage of their journey. For example, the challenges straight after surgery will be different to the challenges faced by someone who is 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 the person seeks 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 the 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 concerns, reduce uncertainty and plan for the future, 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 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 possible, 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. 'Putting things into perspective' and reminders of one's achievements (both relating to rehabilitation/ recovery and life in general) can encourage a positive 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 activities, to re-establish a sense of normality and selfworth. This can include caring for themselves, being a family member, returning to work, driving and hobbies. Having a prosthesis can assist with one's integration back into such activities. We know from mental health research that participation in pleasant, community and social activities along with having a general purpose in life, are beneficial to one's physical and emotional wellbeing.

Re-engaging in life activities can demonstrate to amputees and their families, 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 help to facilitate the process of coping, leading to positive health outcomes.

Sarah Fitzgerald, Clinical Psychologist

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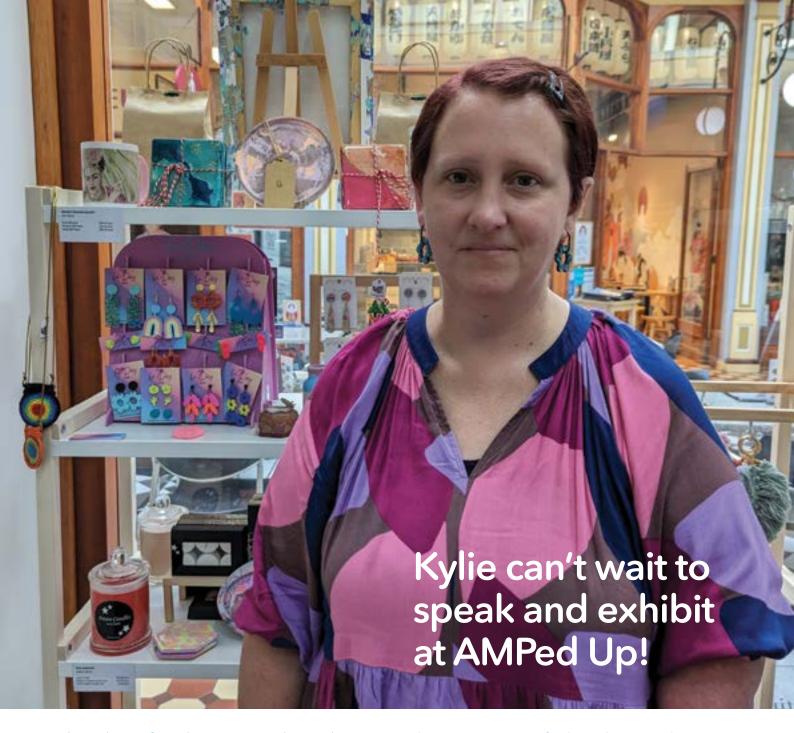
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### Kylie's always found ways to get things done.

I've been living with upper limb loss all my life. For the first five years I had no idea that I was any different because my entire family made a point of treating me like everyone else. In fact, I had no real idea that I was different, it just was what it was.

During my schooling years and growing up I managed to always find a way to get things done. What you do or don't achieve during the time that you are growing up somehow helps to determine how you tackle situations that you are confronted with throughout life. A lesson in 101 of personal resilience? I was brought up being told that there is no such

thing as can't - just find another way, there's always someone worse off than you. So with that advice, I tackled everything head on. I played cricket and volleyball, participated in shot-put and javelin and had a pretty well-rounded experience during my schooling years. I don't recall experiencing much bullying. Kids were curious, they just wanted to ask questions and know why my arm 'wasn't there' and I always just gave them the facts.

Unfortunately trying to find a job, wasn't as easy as I thought. Adults were not as accepting of my disability as classmates had been. In hindsight, I could have allowed that experience to impact my dreams, but I wasn't going to let other people and their pre-conceived ideas



discourage me. After a few decades of trying a range of different jobs in some wide and varied industries, I found my niche helping and supporting other amputees. I am an active member of the Limbs 4 Life peer support network and member of the National Amputee Advisory Council. I welcome the opportunity to highlight the fact that amputees and people with difference can do whatever we set our minds to regardless how we go about doing it. The support available to people now is very different than when I was growing up and people should take advantage of what is on offer – exploring pathways and embracing opportunities.

I can't wait to present at AMP-ed Up next year in my hometown of Adelaide. I'm also excited to share my new business concept with you - and exhibit my range of merchandise and designer concepts during the conference. Make sure you stop by and say hello.

See you in Adelaide in 2025! **Kylie** 





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