

# amplified

edition 1 | 2022



Be delighted  
by Eve - facing  
challenges head on!

Little Seb is kicking  
mighty goals

Self-advocacy,  
know your rights

Reflection - an amputee  
in the park



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As restrictions finally start to ease and we begin to get back to some kind of normal a number of states and territories are finally beginning to allow face-to-face peer support. Peer support is a valuable part of a person's recovery process and we know the benefits that meeting another amputee can bring. If you or a family member would like to connect with another amputee please don't hesitate to contact us today.

Limbs 4 Life's peer support is provided by trained volunteers who have adapted to their amputation and share their personal journey of recovery. If you are interested in supporting your community by becoming a volunteer please let us know.

Finally, we are interested in your feedback about the impact that Covid-19 restrictions may have had on you. Information about our survey is in Amplified, and we'd appreciate you taking part so that we can share your insights with government.

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## OUR GOAL

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# Challenges

## Eve Lustig

Each morning I awake with the joy of being alive. Each day I face the same two key challenges, these being complete blindness and a below-the-knee amputation. They have blinked at this poker 'game of life', not me.

My sensory challenge is long-standing severe vision loss since undergoing eye surgery at age 17. Despite this impairment, I was able to study and establish a rewarding career as a speech pathologist working mainly with children. Together with my husband we raised a family, on the whole without feeling that I am handicapped.

My sight gradually deteriorated. Soon after cardiac surgery at the age of 40, I suddenly lost most of my remaining sight and was classified as legally blind.

I walk carefully. It is hard to recognise people, distinguish more than large shapes, and maintain my independence. My difficulty with facial recognition has been further exacerbated since 2020 due to the requirement to wear masks.

My physical challenge is that some years ago, my lower left leg had to be surgically removed. Learning the skills to cope as an amputee has been more challenging than dealing with my sight, given that my vision decreased over the years.

Set out below is how my amputation occurred and the way I have dealt with it.

I was approaching 70 when, due to a lack of feeling in my feet and legs and my very poor eyesight, I failed to recognise the severity of an infection that led to severe pain in my leg and spine and eventual collapse. I have no memory of the following two weeks until, in a darkened daze, I heard a voice asking, "Do you understand your leg must come off?" I must have said "yes".

The next thing I knew, the sun was shining brightly, and I was surrounded by my wonderful husband Lewis, supportive family, and incredible medical staff. Their love and concern helped me to accept the shock of my dramatically changed situation and sort out how to move forward.

Because I had no time to mentally prepare for the amputation, I faced a huge challenge. As I'd never being an athletic person, to learn physical skills at the age of 70 was hard, but I was determined to maintain my independence and avoid being in a wheelchair. Now, some 15 years later, I am proud that I coped with these frustrations.

How is it possible to make the most of every day in my 80s while coping with these physical and sensory handicaps?

- I am fitted with a prosthesis from Caulfield Rehabilitation Centre and I benefit from regular physiotherapy.
- A wheelie walker helps me maintain my balance and provides seated respite when I am tired.
- Unfortunately, I cannot go out as often as I would like. Many friends are no longer able to lift the unwieldy wheelie walker. They struggle to manoeuvre it in and out of their car.
- Phone ordered taxis are of use as back up, but my blindness means that they are difficult to spot when they come to pick me up when I am away from home.
- Vision Australia helps coping with blindness and vision loss. It provides practical advice and emotional support. It also has a centre with easy to use products such as a mobile phone and TV remote control.
- I have a carer to help me every morning.
- Planning is key. Prior to removing my prosthesis at bedtime, I ensure I am completely organised with those items I may need at arm's reach. The effect of removing the prosthesis is an immediate reduction in mobility. Imagine the frustration of forgetting to turn off the main bedroom light or feeling thirsty when no water is conveniently nearby. To refit the prosthesis takes time and effort.
- Daily exercise is a priority, even if only for short periods.
- Maintaining a positive attitude helps. I like to remember the time a hospital staff member described me as "the smiling one".
- My attitude is typified by my favourite song, it being Louis Armstrong's "It's a Wonderful World".

- I am comfortable talking about how I deal with my impairment. Most people are empathetic, occasionally asking, "Can I touch it?" or "Can you take it off so I can see it?"
- I am amused when someone says, "Pull the other leg!" to which I like to answer, "Which one?"
- I enjoy and value the support of my loving family and friends.
- I recognise that others are not as fortunate as me in having outstanding tender love and care.

A positive side-effect of my disabilities is that my grandchildren have learned to be caring, understanding and helpful. Not only to me, but also to others. This is evident from their volunteer work with the elderly, and with young people who live with disabilities.

Looking to the future, my will is strong. I can continue to make the most of living independently and enjoying all that life has to offer.

## Definitions

These definitions, adapted from the ACC Institute of Human Services, are helpful for explaining my world:

- An impairment is a malformation or malfunction with an organ or structure of the body, such as losing a limb.
- A physical disability is a functional limitation resulting from the impairment such as the inability to walk.
- A physical handicap is the experience of a disadvantage in filling a normal role due to the functional limitation caused by the impairment such as not being able to climb stairs.

***Limbs 4 Life is grateful to Eve for sharing her story.***



# Seb, the little man kicking mighty goals



**Seb is best described by his Mum as an "old man in a little boy's body." Seb is full of questions, expresses concerns for others and communicates personal worries that are generally apparent in older children or emerge later in life. But, at the same time, Seb behaves just like any other adventurous and friendly seven-year old boy does. He is a beautiful, inquisitive, caring and increasingly independent little amputee.**

Mel and Jai are Seb's hard working, caring and community-minded parents. Tay is Seb's older sister, a passionate registered nurse, and they share an affectionate deep sibling bond. Seb also has extended family across Australia who love and adore him. Mel also pointed out "it really takes a village to raise a child" and that diverse social network also plays a key role in the life of Seb and their family too.

Seb entered into the world in very challenging way at the Heidelberg Mercy Hospital for Women in 2014. Seb was growing inside Mel alongside his twin brother Zac. However, at 18 weeks into her pregnancy Mel was rushed into

hospital due to complications related to the very rare 'twin-to-twin transfusion syndrome' (TTTS) and again at 20 weeks after her waters had broken. Sadly, after TTTS complications, Mel and Jai lost their much-wanted baby Zac at 23 weeks. Mel then remained in hospital and, alongside baby Zac, their beautiful son Seb was born prematurely by caesarean at 27 weeks weighing just 890gm.

"I was quite sedated during the caesarean, but once Seb was born I could hear the team say 'there is something wrong with his leg,'" Mel explained.

**So, Mel and Jai had only the briefest of moments to kiss Seb before he was rushed to the ICU after which they tried to "absorb the shock, fear and concern" that followed his birth.**

A doctor explained to Mel and Jai that they moved Seb to ICU to provide him with all the supports that a premature baby needs. "The doctor said there was something wrong with his leg and, although early to confirm how, it was a catastrophic injury that was necrotic - in

other words his leg was dying,” Mel recalled. The doctor advised that other paediatric specialists were best placed to determine this and investigate if there were any other internal issues affecting tiny Seb. So, the best course of action was to safely transfer Seb to the Royal Children’s Hospital.

Jai and Mel were frightened and distressed. But they agreed with the medical team and knew that Seb needed to be transferred to the Royal Children’s Hospital immediately, even though it meant Mel would be separated from him. “I told Jai to go with Seb and that I would come as soon as possible,” Mel recounted.

While Mel was getting regular updates from Jai and the doctors, she felt enormous relief when she was finally discharged and could actually see and touch Seb every day. It was quickly determined his leg was necrotic and constant infections from the injury site were threatening his life, so he had a high amputation of his left leg a few weeks after birth to prevent that from happening. Seb endured countless procedures, intubations, lumbar punctures, blood tests and infusions during his recovery in the Pediatric ICU. He also had heart surgery and two hernia operations before he was discharged home.



**“Seb went through so much, but he was a real warrior and despite all of it he left hospital and came home 88 days later - amazingly on his official due date,” Mel marvelled.**

For Mel, bringing Seb home was the greatest gift of all. It meant that she could finally start to bond with him after having to leave him each night in the Neonatal ICU. Seb managed to meet all of his milestones despite being so much smaller than his peers. He received his first prosthesis at the age of one, and with lots of support and practice he was unstoppable in weeks. His first “leggy” was designed and made by the Royal Children’s Hospital prosthetics team. The team had never cared for a patient as small as Seb nor had they designed a prosthesis for a child with such a high amputation. It was a constant challenge - changing many times to suit Seb’s desire to be consistently active.

By the time Seb started 3-year-old Kindergarten he’d already outgrown multiple legs but was then wearing one with an actual socket, rather than the ‘bucket seat’ he used previously. At Kindergarten Seb and his friends played on the climbing equipment, ran around, dug in the sandpit and climbed the cubby





house ladder to be a superhero. On days where Seb didn't want wear his "leggy", he would get around on a little trike. As he grew, the small trike was replaced with a larger trike until he was big enough to use a wheelchair.

**Seb continually rose to every challenge which Mel believes was "purely because he is a determined little human supported by a wonderful family and great community".**

Seb is now in Grade 2, which he loves. Although 2022 has been a little more challenging because Seb is finding that children, whether at school or out in the community, are asking even more questions about his limb loss than in previous years. Although Seb is not always afraid to respond to questions, it's the frequency of them and the more extended looks that are causing him some concerns. Mel wonders if this is because of the impact of COVID-19 lockdowns and resulting lack of regular sight of Seb's prosthesis, or if children are generally becoming more confident to ask questions. "We've spent a lot of time discussing various situations with

Seb and helped him to take ownership of his preferred responses. I also make sure that Seb knows that he doesn't have to share his story either. Provided he is polite, it's okay for him to just say he would rather not talk about it," Mel explained.

Seb prefers to say "The doctors had to take my leg off or I would get very sick and die", "I get to wear a different leg but can still do things you do" and/or "I have a little leg". He's also comfortable with younger children saying that he has a 'robot leg', as he knows that's something which makes sense to them. So, Mel is glad and proud that Seb knows discussing his amputation and prosthesis is something which requires terms or language that needs to be age appropriate. Again, this demonstrates a degree of empathy, understanding and maturity at a level higher than his actual age.

In the same way that others are asking Seb questions about his limb loss, he too is directing new ones to his own parents. More recently he asked his Mum "does it feel







different to sleep when you have two legs than it does to have one?”. As a seven-year-old this is quite an advanced, yet very natural, enquiry. Mel, and the family, believes that openness when talking is paramount. So, when asked this very question Mel honestly said “I don’t know any different as I’ve only ever had two legs, so I don’t really know what it’s like to only have one leg sweetheart”. Seb then thought about this, and realised if the question was re-directed he could only respond in a similar manner. For he only knows what it’s like to live life with only one leg with no knowledge of the alternative.

Seb generally wears his prosthesis most of the day, each day. But as his amputation was at a very high level, he is sometimes tired and chooses to use a wheelchair or go without his prosthesis. He is also very physically active, sometimes while wearing his prosthesis and sometimes not. Seb’s favourite activities and sports are riding his scooter, playing footy, swimming lessons (which he began at 6 months old), playing cricket, playing drums and drawing. More recently he’s tried out some indoor rock climbing - something he does without wearing his prosthesis. “He absolutely loves climbing and adores looking down and waving at me. He’d love me to join him but I’m terrified of heights,” Mel laughed.

In recent years Seb started going to Bounce, an indoor trampoline park, where he safely jumps into the air without wearing his prosthesis. It all started after he was invited to a children’s birthday party. Kindly, the parents of the child whose birthday it was checked whether it would be suitable for Seb. This encouraged Mel and Jai to take Seb to the venue prior to the party to test suitability and check for potential risks. It’s now an approach they take when Seb requests to do something new or he’s invited to a party that will involve activities he hasn’t participated in before.

**“We can’t be unrealistic, but we also don’t want to discourage Seb from being adventurous, so we test things out, try and find solutions to possible challenges and take every opportunity to educate staff if they’re unfamiliar supporting children with a limb difference,” Mel explained.**

Seb’s sister Tay has played a pivotal role in his life and, in equal measure, he’s enriched her life. Tay was 15 when Seb was born, so she felt a great many fears and worries following his birth. She was thrilled to have a new brother but, like Seb’s parents, grieved for Zac and constantly worried whether Seb would survive. She was concerned about what Seb’s future held. But over the years of growing up together they developed a sibling bond full of creativity, physical activity, babysitting and love. After seeing her brother spend considerable time in the healthcare system, Tay decided in her final years of secondary schooling that she would like to pursue a career in that very industry so that she could help others.

So, Tay completed University studies and now works as a registered nurse in the neurology department in Victoria’s largest public hospital. “I am so proud of what Tay has achieved personally and professionally, and we are thrilled to tell everyone that our daughter is a nurse serving the community,” Mel beamed.

**Tay is honoured when she has the chance to care for patients who are adult amputees and build rapport by letting them know that she has a little brother who is also an amputee. It’s another way of paying forward the kindness that the whole family have received since Seb arrived.**



Others, such as organisations and role models have been part of Seb and the family's 'village'. Mel has drawn particular strength from the Limbs 4 Kids community over the years, building friendships and networks with fellow parents. Seb has been mentored by Liam Twomey, a START Foundation Ambassador and Para-Athlete. He also had a lot of support from Mike Rolls, a bilateral amputee who plays golf and is a mentor. Mel and Limbs 4 Life built an ongoing relationship after connecting soon after Seb's birth, and we're both grateful to have maintained this strong bond ever since.

**Increasingly, Mel sees the adult amputee community approach Seb directly, something that makes her happy about his future life. "We were recently at St Kilda Music Festival when an older amputee came up to Seb and said 'hello mate, you're part of my community too' and they then engaged in a chat about both being amputees. It's so important for Seb to realise he is not alone in his challenges and triumphs," Mel shared.**



Mel, Jai and Tay have developed an array of skills and tips since Seb came into their life. Some have been formal ones offered by professionals, whereas others have been those shared by families. Even more have been skills the family have developed personally. Mel wanted to share just some of the tips and learnings important to their family and might assist others just starting on the limb difference journey:

- While your child may be different, try to remember that **all** children are different - whether that's distinct identity, personality, ability, or interests. Your child is not defined by their difference.
- The saying 'where there's a will there's a way' is valuable, as until a child tries something they can never be doubted. If it doesn't work the first time, don't be afraid to step outside the box and be creative to help your child get it done.
- When you think something might be difficult or challenging, be creative and imagine yourself in your child's situation to try and find an innovative safe solution.
- Learn to plan ahead, because children who use a wheelchair or wear prosthetics do need some pre-planning in relation to items they need prior to going out or travelling (e.g. pack enough liners, spare parts, medical supplies).

Mel is passionate about making the world an inclusive one where anyone, regardless of age, identity, health condition or difference are accepted and can access their community without difficulty or stigma. "My hope is that everyone works together, connects and realises that while we might differ, we should all want to live in a world where people are treated fairly, equally and able to get the support they need."

*Limbs 4 Life is honoured to have been part of Seb and his family's life for many years. We are so grateful to Mel for all the support she has provided to the organisation, and our amputee community, and look forward to this bond continuing for many more years to come.*



# Self-advocacy: understanding your rights

Self-advocacy means understanding your rights, speaking up about the things that are important to you, and having your voice heard. It means feeling able to ask for what you need and want, ensuring you are listened to, and making sure you have the same choices as everyone else. You can self-advocate on your own or with the support of an advocate or another person. Many people say that the more they exercise self-advocacy the more comfortable and confident they become along the way.

## How can I self-advocate?

Understanding when and where you might need to self-advocate, the benefits and some tips can assist in ensuring your needs and concerns are heard and responded to. It's important to also know yourself, your needs, your goals and how to get help.

When you might need to self-advocate  
You might need to self-advocate in a range of situations, including when you are:

- a patient in hospital or rehabilitation
- visiting healthcare providers (e.g. prosthetists, doctors, allied health providers)
- making changes to a service provider
- looking for employment and/or in the workplace
- applying for or attending education and training
- looking for housing or supported accommodation
- in the community, travelling on public transport or shopping.

## Benefits of self-advocacy

- Being able to make your own decisions.
- Gaining self-confidence and self-respect.
- Learning new ways to properly express your needs to achieve goals.
- Learning to work with others who can assist you (teamwork).
- Developing problem-solving skills.



## Tips for effective self-advocacy

- Be an active and assertive participant in the process, but avoid being aggressive.
- Directly state (say) what your needs are in a clear, firm and polite manner.
- If you don't understand something, be sure to ask questions.
- Take time to listen to others, and respect their point of view.
- Get enough information to make informed choices.
- If necessary, have an advocate, family member or friend assist you (such as during meetings).
- If you feel you are not being heard, consider putting your request in writing.
- Take notes when you attend meetings and during phone calls, so you can refer to these in the future.
- Make sure that anything you agree to is put in writing and you understand it (e.g. NDIS plan).



# Self-advocacy steps



## 1. Problem analysis:

- What is the problem or issue (e.g. need a new prosthesis, need an updated NDIS Plan, need new working arrangements)?
- What do you need to do to fix this problem or issue (e.g. trial a new prosthesis, request more funding)?
- What facts do you have (e.g. information about new prosthetics, disability rights)?

supplied it. Depending on the situation you may be entitled to repair, replacement or refund. This law protects you when you use your own money, or buy goods and services using your NDIS or other government funding supports.

To find out more, learn about your rights and options, or get assistance when making a complaint:

- The consumer protection agency (sometimes called 'consumer affairs') in your state or territory
- NDIS 'Quality and Safeguards Commission' (1800 035 544)



## 2. Information gathering:

- What additional information or facts do you need (e.g. laws, rules, policies, reports)?
- Where can you get this information (e.g. personal notes, internet, organisations)?
- Who is the decision-maker (person) that can help solve this problem (e.g. doctor, prosthetist, teacher, NDIS staff)?
- Are there other people who can help (e.g. Limbs 4 Life, family, disability advocacy organisation)?

## Where can I get advocacy support?

Your rights, such as human and disability rights, are very important. You are entitled to have your voice heard when expressing your views, concerns and important decisions being made about your life. If you need support to speak up about your rights or make a complaint, you may benefit from a disability advocate. An advocate can help by speaking on your behalf to services, organisations and employers, making complaints about discrimination and more.

The National Disability Advocacy Program lists a range of advocacy services. Some agencies are general, and available to assist people with any type of disability or cultural background. Whereas other specialist ones provide assistance to people with a specific type of disability, regarding specific issues (e.g. housing, employment), or those from diverse, cultural or Aboriginal and Torres Strait Island backgrounds.



## 3. Solution analysis:

- What are some possible, specific and realistic solutions to this problem or issue?
- What are some barriers that might get in the way of these solutions?
- What should the other side (people or organisation) do to help?

**To find a Disability Advocate to support you visit [www.disabilityadvocacyfinder.dss.gov.au](http://www.disabilityadvocacyfinder.dss.gov.au)**

## What are my consumer rights?

As a consumer all people have the right to complain if they buy a faulty product or receive a product or service that is not suitable. So, if you've received a product or service (e.g. mobility aid, prosthesis, home repairs) that is not 'fit for purpose' or not working properly you should complain to the business or person who

**Limbs 4 Life is available to assist amputees to learn self-advocacy approaches, act as an advocate and point you in the right direction if you are making a formal complaint. While we may not be able to assist in all cases, we are always here to listen and support you to the best of our abilities.**





## An amputee in the park

Jane Nicholls

**During Covid lockdown, I spent a lot of time in the park. Everybody in my suburb was in Fleming Park, near my place. People- and dog-watching were one of my major pastimes.**

The rules were broken. Friends met for picnics on the footy oval and under the surrounding trees. They bought takeaway and coffee from the surrounding cafes. There's a McDonald's not far away, and a place called, alarmingly, "Fat & Tasty." There are trendy joints, where the young would normally meet for Sunday brunch. It's a great park for that, with lots of choice.

It's a dog park. Suddenly, everyone had a dog. Every breed, from chihuahuas to great danes. They walked them. They let them off the leash. They played with them. Dogs chased each other, sniffed each other's bums and eyed one another off. The dogs had a wonderful time.

As the title of this story suggests, I'm an amputee. My leg was amputated above the knee rather than below. What might appear as a small detail actually changes someone's life profoundly. There are many things I simply

can't do – climb a stepladder to change a light globe; carry anything weighing more than about a kilo; change my sheets. (My doona's too heavy for me to lift.) Just staying upright – let alone walking – requires close attention to the surface I'm on; the direction and force of the wind. Softer surfaces, even carpet and definitely grass, mean I have to balance differently. And I wouldn't even attempt to walk on sand!

Walking across the oval on the grass is a major challenge. It feels as though I'm on stilts, walking across an old inner-spring mattress that seems to stretch forever. When I reach the other side, I'm flooded with relief. I look for somewhere to sit down.

One day I set out, shaking with trepidation. As usual, I kept my eyes glued to my feet. But, from the corner of my eye, I could see a young man with a large half-grown dog. It was bounding about like a puppy. I gave them a wide berth. In vain. The dog ran towards me, curious. It jumped up. It licked my face. Of course I fell backwards: there was nothing I could do. A small crowd of concerned onlookers gathered. Landing on the



soft grass, I wasn't hurt but I was shaken up. Its owner came over. He was angry. "People like you shouldn't be allowed in this park!" he shouted. "It's a dog park."

A couple of people – not the man responsible – helped me up. They were incensed. I was in a public park, after all, where dogs off the leash are expected to be under someone's control at all times. I was fine – not even a bruise. I didn't waste time being concerned. What would be the point?

If I'm not feeling very confident about venturing onto the grass, or if it's windy, I enlist a passer-by to walk beside me. We make conversation. I feel the need to explain my request. "I'm an amputee, with very poor balance," I begin.

Nine times out of ten, the automatic response is, "Oh, that's all right." In ten per cent of cases, they respond with, "Aw.....aw aw aw" as though they're talking to a baby.

Think about it: no, it's not all right. It's inconvenient, often scary, and very unfortunate. It's also time-consuming. And I don't want to be pitied or treated as though I'm a child.

I don't say this aloud, of course. I engage in appeasement. A series of questions follows.

"How far away do you live?"

"Oh, just down the road."

"Do you live alone?" They sound anxious.

"Yes. I prefer it that way", I respond calmly. They nod. "Do you have family nearby?"

"Not really. My son comes to see me every couple of weeks." This causes alarm "But if I need something urgently, I have neighbours who help."

Often, for some reason, the next question is this: "Do you have any pets?"

I turn it into a joke. "No. I'd trip over them!"

Then I change the subject, asking them about themselves. We usually part the best of friends.

I've met all kinds. Many have been working from home. They come to the park during their lunch break. There was the Iranian academic from Sydney University, stuck in Melbourne; business executives; a cyber security expert, tradies. Lots of people, it seems, work in "media", requiring copious knowledge of how computers work. When I told others I was a writer, some confessed to being in the arts: a circus performer, other (would be-) writers, designers, painters, musicians. A snapshot of my suburb's population these days.

Nowadays not many are from the wave of migrants who moved here in the fifties and sixties. But there are exceptions. Spanish Teresa, who lives in my street, walks round the park too, and we exchange greetings. Her son Oscar is also a neighbour. He helped me when my kitchen was flooded after a huge downpour. Teresa's husband died in the West Gate Bridge collapse of 1970. She supported young Oscar by working in factories.

Koula lives on the corner. She's Greek. She's very old and blind now: she no longer walks in the park with other Greek women, all older, all dressed in black. Her sons Bill and George run the fish shop at a nearby shopping centre.



Because I can't run around the oval, I've spent a fair bit of time just sitting on one of the benches. It's a great place for people- and dog watching.

Dogs arrive at the park on a leash. Their owner frees them and then often they do their daily poo. The owner always collects this in a plastic bag – conveniently tied to the leash – and finds



a rubbish bin. The dog rolls happily (and no doubt relieved) on the grass, shakes and runs around in circles, wagging its tail. Then it sniffs the air, looking for other dogs to play with. Labradoodles, Australian terriers, scary looking, huge dogs – they all behave the same way.

In the middle of the oval the owners gather to chat while the dogs enjoy their freedom. I'm not a dog person, but I'm told that there is a whole dimension of social interaction where people refer to others as, "You know – Kenny's Mum", "Prince's owner", "the woman with Susie, that poodle".

Balls, occasional frisbees and sticks play a central role here. Most dogs seem well-trained. They sit, glance up at their human overlords, trembling with anticipation, until the object is launched. Then they dash off, sometimes making a deft catch mid-air. They trot back, place the ball on the ground, sit and wait. They don't seem to tire of this game. They race each other. But they're intent on pleasing their master or mistress. It's not fun for me, the viewer: it's poignant and a little sad.

Passing dogs sniff my prosthesis in puzzlement. "Sorry," their owners say. "He's just friendly!" But it's not that: they don't know what to make of me. If I'm walking they bark and stare in fear. What is this strange creature?

If my prosthesis is visible, few people notice it. They focus instead on where they're going. Occasionally, as they glance in my direction, you see them do a startled double-take. Amputees are rare in Australia now – unlike, say, after the First World War. Most people don't remember ever seeing an amputee.

Thus people remember me. As I walk, someone proffers a greeting. If I stop, they'll explain that they've seen me before. I've long given up feeling guilty that the recognition isn't reciprocated. Someone told me that his son, who was born without a forearm, has the same experience.

Small children have an interesting reaction to my unusual, swaying gait.

"Mummy, what's that lady doing?" The mother looks appalled. The child has drawn attention to the fact that I'm different.

"Let me show you my leg," I say. I pull up the bottom of my pants to reveal the steel shaft, the computer-driven knee, and the blue socket above it. "Do you want to touch it?"

Usually they back off, startled. "It's not an ordinary leg," I continue. "But it works fine. It's a special leg, just for me. Mummy or Daddy will explain it to you."

Often they ask questions: "Does it hurt?" "Can you jump?" Or, once: "What did the doctor do with your old leg after it was cut off?"

The park is far less peopled since the lockdown finished. My former workmate, Jenny, has vanished; and Virginia, a young woman with an apparent eating disorder. Her sticks of legs carried her round the oval several times a day.

But the park stalwarts remain: Mick and Jim among them. They come here every day – rain, heat, whatever the weather. They arrive around five. They do circuits of the oval like I do. Jim always says g'day. Mick, a retired computer programmer, is always up for a walk across the grass with me. I know a lot about his life and have met most of his family. He got a barbecue last Christmas and his daughter is a police officer. Take an interest in people and they repay you in spades.

But, for me, there are always the few who spoil my day for a moment. Some people – all ages and genders – smile in a patronizing way when they see me. "You're doing very well!" they say.

I'm afraid I respond. "What do you mean? I'm just walking."

They're non plussed. "I mean... you've had a stroke, haven't you?"

"No. I walk funny because I'm an amputee. I've been doing this for over ten years. It's just how I walk."

They hurry off, embarrassed.





I overhear snatches of people's conversations. Two older blokes sitting at a table: "...So she bought a hovercraft..."

"What?"

"Oh sorry, I mean one of those drones..."

One day I bumped into someone I knew. He was having lunch on the grass with his family. He introduced me to his son-in-law, who is a lecturer in Prosthetics at La Trobe University. Now a story I wrote about my prosthesis is used as a teaching tool in the La Trobe University Prosthetics course.

I got chatting to Dave in the park. We talked about what it's like to be an amputee. He works for The Guardian. I emailed him the piece of writing that will be used at La Trobe. In a briefer form it appeared in The Guardian. That's quite something for a writer like me.

Recently I sat down on a seat next to Alex, an Open Space Planner with my local council. We talked about my difficulties walking in the park. We discussed the camber of footpaths; the problems presented by bluestone, tree roots and the height of the kerb. He was particularly interested to see this story you're reading now. Fleming Park for me has an added dimension. My leg - or the lack of it - adds to my experience. In some ways it's richer now. I've learnt how to communicate with people in a new way. I've met people I'd never have met. Every day the people I meet bring something unexpected and, in its own way, interesting.

I see how most-able bodied people, unless they're with friends or family, experience the park in their own bubble. They run; they walk the circuit of the oval, they walk a dog. I go there to exercise by walking, ever-careful and tentative about my steps. Otherwise I'm open to whatever the place brings me.

Something sudden and entirely unexpected led to my amputation. My immediate thought, on hearing what was about to happen, was this: fate has shifted the goal posts on me; life will be different now. In some ways it will be more interesting. And it is.

I'd have my leg back in an instant: who wouldn't? But perhaps - perhaps - I wouldn't change things.

***Jane [Nicholls] has worked in the union movement; as an adviser to a Labor front-bench politician; and as a consultant in education policy. These days, she's a writer. She lives in Melbourne.***

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# Accredited Exercise Physiologists:

## How can we help?

### Who are AEPs?

Accredited Exercise Physiologists (AEPs) are allied health professionals that undertake four years of university study and over 500 hours of practical experience to become accredited. We are experts in the design, delivery, and evaluation of safe exercise interventions that are tailored towards your individual goals. These are constructed with input from you and your wider support network including other health professionals. AEPs specialise in prescribing exercise both as a preventative measure and a treatment for a large range of injuries, conditions and disabilities. These can range from sports injuries, cardiovascular, metabolic, neurological, cancers and mental health.

### Taking charge of your health

An amputation is a significant life changing moment. Post amputation you are faced with a huge amount of new information and will face unique challenges. It is important to have a personal and professional support network around you that can assist you to absorb and implement this information when you are ready to move forward.

For amputees, it is common for multiple health factors to be involved both in the short term and many years down the track. Studies have shown that lower limb amputees use 40-100% more energy to walk than a non-amputee. This places higher demands on the cardiovascular system and other parts of the body such as the sound limb and lower back, not to mention of course the residual limb. An AEP can help improve your strength and range of motion as well as work with you on improving your gait to make it as efficient as possible.

Improving your cardiovascular fitness will improve your ability to walk further and faster. Increased cardiovascular fitness has benefits such as helping manage existing chronic conditions and can reduce the risk of



developing health conditions such as diabetes, heart disease and some cancers. Balance difficulties and fear of falls are commonly reported issues amputees face, however with targeted training to build strength and confidence it can be improved.

Progressing along the path of regaining your mobility or getting back to an activity you love can have huge impacts on your self-esteem and sense of control in your life. Alongside this, undertaking regular physical activity is well researched to have positive effects on stress, anxiety and other mental health conditions.

### Goal setting

Your goals are unique to you, some people want to navigate around their home safely and others may want to get back to or start recreational and sporting activities. These goals can change over time, what you hoped to achieve coming out of hospital may be very different to your goals now. Equally, some people may have been travelling along comfortably for many years but have

picked up an injury or a new health condition that is now holding them back. Wherever you are in your health journey AEPs can provide guidance and support.



Your AEP will work with you to identify your goals and the level of function you aspire to. We will help create targeted goals with short, medium and long term milestones. A management plan will be created detailing how we are going to support you to achieve your goals and evaluate your progress along the way. You will be provided an individualised program that will improve your mobility, confidence and ability to navigate daily tasks and participate in the activities you care about. Importantly you will be educated and empowered to integrate exercise into your life and create lifelong habits so you can self-manage and take ownership over your goals.

Australian physical activity guidelines for adults recommend a minimum of 150 minutes of moderate intensity activity or 75 minutes of vigorous activity a week. This can be a combination of both and can include sports, walking, gardening or anything that makes you breathe faster. In conjunction with completing two strength-based sessions, these are the

activity levels recommended to improve your physical and mental health and wellbeing. Most Australians are not achieving these minimum recommendations and the statistics for people with disabilities are even lower. However, it is important to know that doing even a little bit is better than nothing and sets you on the right path to create a habit and build a positive relationship with physical activity. AEPs are here to support and guide you through this process.

## How to access AEPs

AEPs often see clients referred through the NDIS, GP referrals in Medicare chronic disease or diabetes programs, Department of Veterans' Affairs, or privately with health fund rebates. Use the find an AEP function on the Exercise and Sports Science Australia website to find your local AEP.

[www.essa.org.au/Public/find-aep.aspx](http://www.essa.org.au/Public/find-aep.aspx)



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## HANDY TIPS FOR WHEELCHAIR USERS

Not everyone is able to wear a prosthesis after amputation and this can depend on a range of different factors. Some people simply make the choice not to use a prosthesis, while for others, wearing a prosthesis and/or getting a comfortable fit might prove difficult and for others it may just be too challenging.

In Australia the majority of amputations are the result of circulation problems. Poor circulation not only affects the legs but other parts of the body. You might be dealing with other health problems such as kidney disease, memory issues, loss of sensation in your hands and in the remaining foot. These problems may have affected your activity level for some time. If that is the case, it is common to become weak, lose fitness and possibly need more help with doing everyday things. For others, skin sensitivities or on-going stump pain can make it difficult to tolerate prosthetic socks and liners.

For older amputees, particularly if the amputation is above the knee, this can make rehabilitation a lot more challenging. Building up strength, balance standing endurance and stamina to use an above knee prosthesis can be difficult. Simply, some people just find it easier and safer to use a wheelchair or crutches.



**TIP - When speaking to wheelchair suppliers make sure you ask to trial a chair before you buy!**

### What should you consider when choosing a wheelchair?

- What are your goals?
- Do you have shoulder or upper body problems?
- How will you be getting in/out of the wheelchair?
- Where do you live?
- What is the access like at home or your discharge destination?
- Will you use your wheelchair to get to the shops or to work?
- Can you go back to driving, if so, how will you get your chair in and out of the car?
- What is the best option for you – self propelling manual chair or a power chair/scooter?
- You should discuss your goals with your Occupational Therapist and think about any barriers you face.



## Wheelchair features – which features do I need?

Wheelchairs come with a range of different features. You should think about which features will help you to get the most out of your chair and what you need to live the lifestyle you choose.

- **Anti-tip bars.** These are rods at the lower back area of the chair which prevent the chair from falling over backwards and help to keep the chair upright.
- **Stump support (or stump rest).** If you are a below knee amputee you should have a stump rest fitted to your chair. The stump rest should be set at a comfortable height, similar to the same height of your cushion.
- **Arm rests.** Consider arm rests, whether you want to have them or not and if you do, ensure that the arm rest can either be removed or can swing away for the purpose of transferring.
- **Wheel positioning.** The wheels on your chair should be set-up to ensure safety and balance.
- **Wheels that easily pop off.** To enable the chair to be carried in a car.
- **A rigid or fold up chair:** This is important if you plan to take your chair with you shopping or on an outing and it needs to fit into the boot of a car.
- **Clothing guards.** Often when wearing bulky or loose clothing it can fall between the arm rests or the side of the cushion and get tangled in the wheels. You might like to consider adding removable clothing guards to the sides of your chair.
- **Chair height.** Will your chair fit under a table when you are going out to meet friends at a café or even at the dining table at home?
- **Foot-rest.** If you are a single side amputee then chances are that you will need a foot-rest for your sound side.
- **Consider size and width.** Will your chair fit through doorways at home?



### TIP - Gloves.

Often a wheelchair with new tyres can be harsh on your hands, so consider purchasing a pair of gloves which will also help to give you better traction/grip on the tyres or rims.

Most wheelchair providers will allow you to trial a chair before making your final decision.

It's important that your chair is fitted to the right width and height for you so it is not too heavy for you to push around.

## Seating needs

If you are planning to use your chair for long periods of time, it's important that you have the right cushion to support you. Wheelchair cushions need to provide seating comfort, prevent pressure and give relief to sitting bones. There is a wide range of cushions to choose from so ask your provider to let you trial a few different kinds prior to making your final decision.



**TIP - Make sure you take your wheelchair for an annual service and maintenance check!**

**We want to hear from you!**

## **Impact on amputee treatment and care due to Covid-19 restrictions - survey.**

The impact of COVID-19 and related restrictions has affected some amputees in various ways. Limbs 4 Life is interested in learning about how these restrictions may have affected your ability to access rehabilitation, prosthetic and allied healthcare services (like physiotherapy, occupational therapy etc.) and general supports.

Limbs 4 Life is currently offering an anonymous survey to amputees across Australia, which will help us to develop a report in response to the impact of Covid-19 restrictions. The survey can be completed online or as a hard-copy.



- If you would like to participate in the survey online visit [www.bit.ly/3DozQ2n](http://www.bit.ly/3DozQ2n)
- If you would like to fill out the paper-based survey just call or email Limbs 4 Life and we will send you a stamp self-addressed copy in the mail. Call 1300 782 231 or email [info@limbs4life.org.au](mailto:info@limbs4life.org.au) to request a copy.

Please remember, your voice matters and we appreciate you taking the time to participate in this important survey.



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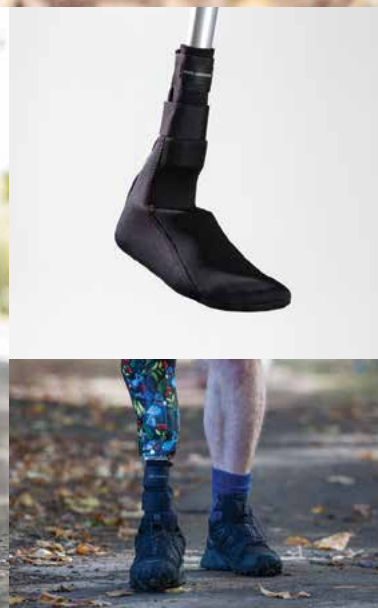
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**- Ross Powrie, Custom Prosthetics, Australia.**

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**- Naomi, BK amputee**

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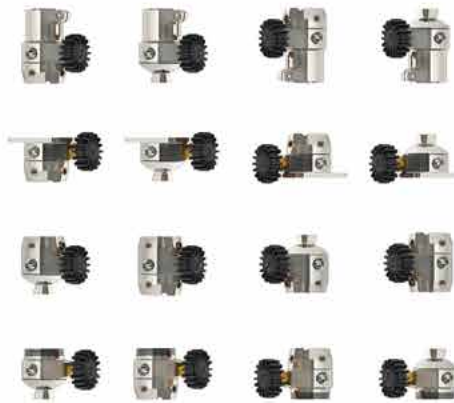
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## Why not join an amputee support group today?

A support group is a great place to:

- Connect with others who understand what life as an amputee is like
- Share valuable amputee specific information
- Increase your community connections
- Build your support network

**For more information on support groups in your area, contact Limbs 4 Life today!**

## Are you an amputee? Are you nearing 65 years of age?

If you answered yes to both questions and are not yet registered with the National Disability Insurance Scheme (NDIS), then now is the time to do so.

To be eligible for NDIS support you need to be under the age of 65, have a permanent and significant disability and be an Australian citizen. The NDIS may provide funding for prosthetics, assistive devices like wheelchairs, home and vehicle modifications, and access to support services such as cleaning and gardening (for example) if you are unable to do those tasks yourself because of your disability.

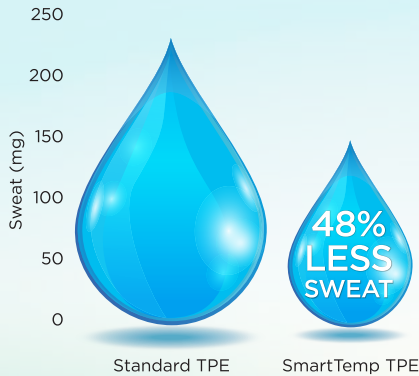
**If you would like more information you can contact Limbs 4 Life or call the NDIS directly on 1800 800 110 or visit [ndis.gov.au](http://ndis.gov.au)**



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# Have you checked out our new Prosthetic Directory?

Limbs 4 Life has added a wonderful new addition to our website. The prosthetic directory features a wide range of upper limb prosthetic options along with lower limb devices such as feet and knees. The lower limb technology is showcased based on activity level from K1, being a low impact user, through to K4 devices, which suit people with high activity levels.

In the future we will be adding to this directory to include the various socket options and cosmetic prosthetic covers.

Check out the Prosthetic Directory today!

[www.limbs4life.org.au/prosthetics/directory](http://www.limbs4life.org.au/prosthetics/directory)



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# Information sheets

Limbs 4 Life has developed a range of new resources to support members of our community and provide them with valuable information. You can download a copy of these information sheets under the resource section of our website or call us today and we will send them out to you.

Our information sheets include:

- Understanding the healthcare system
- How to set goals
- What to expect when trying a lower limb prosthesis
- Getting back into recreation
- Preventing falls
- Partial foot questions
- Understanding grief and loss, and your mental health
- Talking to your prosthetist.

Our information sheets are designed to educate and empower amputees and their families.



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## Join us, become a peer support volunteer today!

Limbs 4 Life's peer support program provides people facing amputation and new amputees with access to a trained volunteer. Volunteers share their journey of recovery and learned knowledge with those who are new to limb loss.

If you would like to join our team and become a volunteer then we would like to hear from you.



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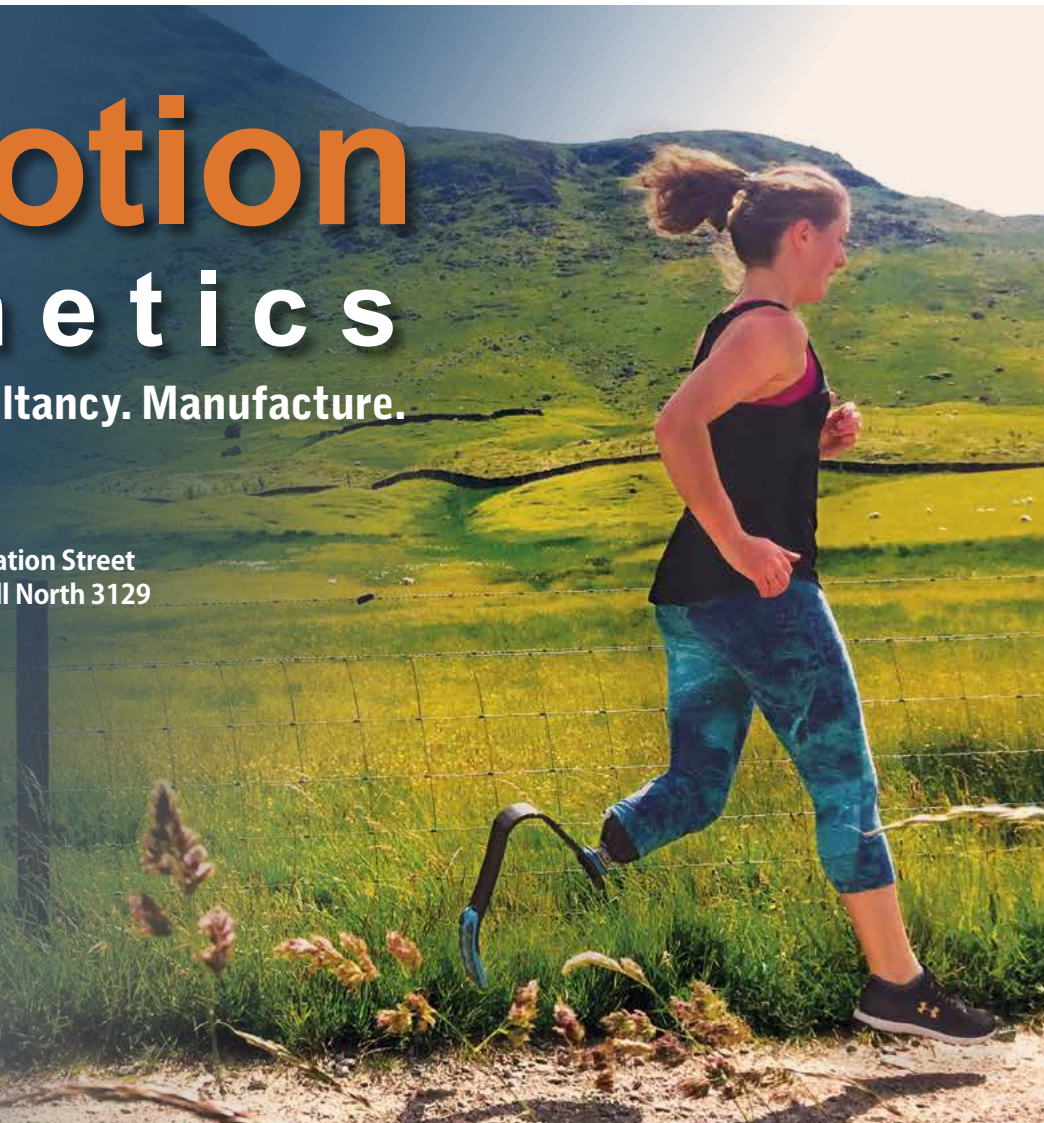
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A woman with short dark hair and a smile is using a water treadmill. She is wearing a blue and white one-piece swimsuit and a black prosthetic leg. She is holding onto the white handrails of the treadmill, which is partially submerged in a pool of water. The background shows a wooden bench and a green wall.

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