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edition 1 | 2023

AMP-ED Up! 2023
National Conference Wrap-up
SPECIAL EDITION



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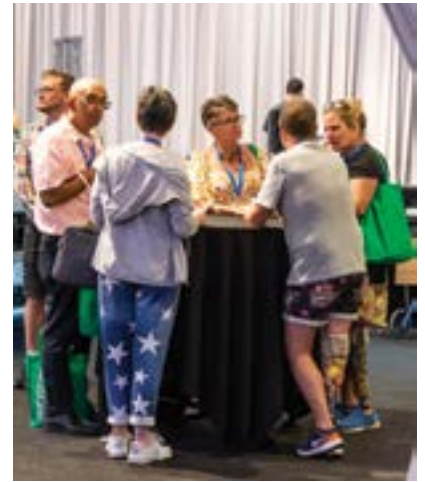
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After three long years and four attempts, Amp-ed Up finally became a reality. It was wonderful to finally see one another and bring our community together in person.

Members of the amputee community, their friends and family travelled from across the country to come together and it was equally pleasing to have our New Zealand cousins join us yet again.

Our goal for hosting an event like Amp-ed Up is to ensure that you, members of the amputee community, have the opportunity to be educated and learn something new, be empowered to ask questions and be encouraged to connect with your peers to share stories and learn from each other. The overwhelming feedback that you provided indicated that those goals were met, however one can never stop learning and it's important to continue to remain focused on what each of you want to achieve in your lives.

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A journey of firsts to Amp-ed Up!

My name's Darryl, I'm 51 and a left below-knee amputee from Perth. I'm a wheelchair user. I had my amputation in 2016 and tried to use a prosthesis in 2019. I was excited about the prospect of being able to walk again but my experiences were negative. My prosthetic leg, which I named 'George' didn't fit well and I felt that despite telling people, no one was listening. I had a few falls and hated wearing George, so I put him in a cupboard in 2020 and that's where he stayed because I couldn't wait the 6 to 8 months that it would take to see a clinician during Covid. I felt like hiding away from the world and that's what I did...

In 2021, I started to realise that I was alienated and isolated, somewhat by choice, so I decided to make some changes. I applied

for a job at Optus Stadium, in Retail Food and Beverage. My first shift was working the 2021 AFL Grand Final! I was both excited and apprehensive that I would be working in a very 'visible' role and that so many people would see that I was in a wheelchair and that I was an amputee. But after a few stares and overhearing some people talking about me, I realised that I have the right to work and be in public and I became more determined and confident right then and there!

I had met Andrew from Limbs 4 Life at Fiona Stanley and he invited me to amputee events and gatherings, but I chose not to attend any of them because, I hadn't come to terms with my amputation. In 2022, I saw an advertisement for AMP-ED Up! 2023 and I spoke with Andrew about it. He explained how I would benefit from attending. There was so much doubt in my mind and there were so many things that I had to take into consideration!

I spent a lot of time thinking about AMP-ED Up! 2023, and then in October 2022, I booked my flights to and from Melbourne, accommodation at the venue and my ticket to the conference. I was both happy and terrified! I called Andrew to tell him that I'd be there, and he was so proud of me for taking such massive steps! I couldn't believe that I'd committed to not only attending such a huge, 2-day event, but also to going on a plane for the first time since my amputation and really, going anywhere apart from the local shops! What was I thinking?

In the blink of an eye it was February 23, and I was at Perth Airport for my flight to Melbourne. The QANTAS check-in staff member asked, "Are you OK?" I said, "No, I'm petrified!" He told me that everything would be alright, and he was correct! QANTAS staff helped me board and disembark my flights and accompanied me through the terminal in Melbourne to my taxi. When I arrived at the Hyatt, the staff there were also fantastic. In the lobby, I was rapt when I saw Andrew and he was so glad that I had made it! He introduced me to Geoff, and we really hit it off. I met so many other amputees in such a short time, including people who had come from New Zealand. I found myself getting quite overwhelmed and emotional, but I felt very welcome and comfortable too.

AMP-ED Up! '23 was exciting and eye-opening. Just being in the same room as 100s of fellow amputees was an experience in itself. We heard from Melissa first... wow, what a woman! Then Jason talked about self-advocacy, and it made me realise that maybe I hadn't been great at that in the past. I got so much out of Andrew's presentation on exercising choice and control. Sara's story about trying things even when you feel anxious, made me think that I'd like to try to use a prosthesis again, despite my fears of pain and failure.

I enjoyed the panel sessions and heard questions and answers that I'd never even contemplated. I learnt so much about my rights as a person with a disability, that I have control over my choice of clinicians and prosthetics and that I'm protected by the law as a consumer.

To sum up my AMP-ED Up! 2023 experience, I can tell you that I've made new, life-long friends. I now believe that we all need to love ourselves and put ourselves first more often in life. There is so much mind-blowing assistive



technology that can help us to live better lives. There is support available from professionals and our peers who can help us participate in society after amputation.

On a personal note, I'm happy to share with everyone, that I have started making enquiries because I plan to try a prosthesis again; I want to get out of my wheelchair and walk! I believe that the world is my oyster and that I can do anything as a strong, happy, below knee amputee! Thank you so much, Mel and the Limbs 4 Life Team, especially my buddy Andrew for encouraging me to attend AMP-ED Up! 2023. I can't wait for the next one!



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The Hon Bill Shorten MP

Minister for the National Disability Insurance Scheme

Minister for Government Services

Member for Maribyrnong



We were thrilled to welcome Bill Shorten to Amp-ed Up! and delighted that he was able to join us. Bill acknowledged the importance of the work that Limbs 4 Life provides to the Australia amputee community and the significance of bringing peers together for the purpose of sharing experiences and knowledge.

Bill noted that he was proud to acknowledge and launch the Limbs 4 Life - KPMG report 'The socio-economic burden of limb loss Australia' a study which is the first of its kind and outlines data on the number of Australian amputees and associated costs.

He also acknowledged and launched the 'Impact of Limbs 4 Life's Peer Support program' report which encompasses the costs and benefits for delivering peer support nationally.

Bill has been a long-term champion for the National Disability Insurance Scheme (NDIS) and the benefit that it has for people with a disability in Australia. He noted that there was still a lot of work to be done on the NDIS to make it a fairer system.

Limbs 4 Life is grateful that Minister Shorten took time out of his busy schedule to join us. As an organisation we will continue to work to build partnerships with key Minister to ensure more support is provided for people not eligible for the NDIS.



Presenter Snapshot

The Amp-ed Up program featured a wide range of speakers aimed at educating and empowering the delegates. Here we give you an overview of some of the speakers who contributed to our event over the course of two days.



Jason Diederich - 'How can a question help me to take control?'

Being assertive can be a challenge for many of us. But when it comes to our health and mobility, it is imperative that we question health care providers, especially when something's not working for us. Jason's presentation provided some very helpful tips on how to ask the right questions, in the right way. The ability to ask 'better' questions can ensure that people with disabilities are supported to gain the greatest level of independence that they can. Jason is an amputee and a member of the Limbs 4 Life Board of Management. He is also co-author of 'I'm Disabled not Stupid.' Copies of this book can be purchased through Limbs 4 Life.



Dr Sally Cockburn - 'Navigating the healthcare system.'

Dr Sally launched into her presentation with the infectious enthusiasm and passion that she has for health and healthcare services. Her patient advocacy skills are a credit to her, both as a GP and a health advocate. Sally shared stories about her life and experiences as a person living with Type 2 diabetes and reminded us all that we must stay on top of, and monitor our health on an on-going basis. Dr Sally's presentation covered topics including women's health, the risks of vitamins and supplements and the importance of cancer screening. Sally also gave us a valuable insight to navigating the health care system.



Dr Bernie Crimmins - 'Blokes' Health.'

Never one to shy away from the issue of mens' health, Dr Bernie's presentation enlightened us on the differences between men and women when it comes to health. He stressed that men are more susceptible to serious health issues due to lifestyle and physiological differences.

Dr Bernie outlined the risk factors for men such as smoking, drinking and missing out on exercise. He also suggested that males don't visit their GP's often enough. Dr Bernie shared a lot of statistics with the group, some of which were alarming, but well worth being aware of especially as a male living with amputation. But there is hope! Dr Bernie has authored 2 books on the topic, 'Blokes Health 1 and 2.' You can purchase copies online.



Jamie Grant - 'How buying a car is similar to getting a new prosthesis - your rights explained.'

Jamie is a barrister, with experience and interest in Consumer Law. Prior to Jamie's presentation, many of us weren't aware that our prosthetics

are in fact consumer goods covered by warranties and Australian Consumer Law. Jamie outlined the fact that as consumers we have rights when it comes to lack of safety and that prosthetics must be 'fit for purpose,' just like any other consumer goods.

Jamie shared some key takeouts: Knowledge is key. Know what you want before you meet with your provider. Know what outcomes you are looking to achieve and have a clear picture of what you expect. Do your homework, research the process as much as you can and know your rights.

Jamie suggested that as amputees, we shouldn't 'second guess' ourselves and that we should trust our gut. If something is wrong or causing pain, then speak up.



Dr. Maxwell Limakatso - 'Phantom Limb Pain and Treatments.'

It was fascinating to learn from Dr Max Limakatso about the physiological reasons why people experience Phantom Limb Pain, including how the brain functions after amputation(s). The treatments currently available have had limited success so it was exciting to find out that research is currently being conducted on possible treatments and, hopefully, a cure for Phantom Limb Pain in the future.

Dr Maxwell is currently working with the team at Neura investigating Phantom Limb Pain. The researchers are looking for people currently experiencing Phantom Limb Pain to take part. If you are interested in participating, please see the advertisement on page 13.



Sara Shams - 'Embracing my Quirks at 30!'

Sara shared her fascinating and inspiring life story with us. She asked us all to think about what's stopping us from trying the things that we really want to do and experience, because... why not?

Sara spoke of her lifelong disability and the impact that it's had on her body image and feelings of self-consciousness, and how she's managed to turn her life experience into a positive and create a space where people (especially women) should and can feel confident in themselves. She shared how growing up in the 90's, Sara never saw anybody like herself on TV, in the media or advertising.

Today, the situation has improved slightly but there's still a lot of work to be done. Disabled individuals go to the gym, wear active gear, enjoy wearing fashionable clothes, but are never seen to be doing any of these activities and not portrayed in such scenarios in the media. Sara told us how she wants to be a part of a world where having someone like herself on mainstream TV and in marketing campaigns is no longer a ground-breaking story. Every body deserves representation!



Dr Natasha Brusco - 'The Impact of Peer Support'

Many of us have either received or provided Peer Support through our association with Limbs 4 Life. Dr Brusco's study, 'The Impact of Limbs 4 Life's Peer Support Program' investigated the affect that peer support had on program recipients - people requesting peer support, Limbs 4 Life's Peer Support Volunteers, and the healthcare providers who refer clients to the program. Dr Brusco presented her findings on the year-long study at Amp-ed Up 2023. Dr Brusco explained how valuable Peer Support is and that this service should be available as standard care for amputees nationally.



Dr Natasha Layton - 'Understanding Your Human Rights'

Dr Natasha Layton's presentation educated us on our rights under the Convention on the Rights of Persons with Disabilities (CRPD). Dr Layton's passion for people to exercise their rights shone throughout her presentation. She explained how referring to these rights when engaging with healthcare providers and government departments can potentially improve the level of care and support that we can receive.

Natasha also outlined the importance of people with disability knowing and exercising their human rights and to think about using the language and the terms in the Convention when speaking to others, especially when advocating for your human rights to be recognised.

Panel sessions



There were a number of speaker Q and A panel sessions delivered over the course of the two-day event. Panel sessions were featured as part of the Mens' and Womens' health presentations in a 'You can't ask that' format.

We also asked the panel to tell us their thoughts about the importance of connecting with community, and the value that locally based support groups can bring to amputees, their partners and family members.

Over the coming months Limbs 4 Life will be bring you a special webinar series featuring a number of presenters from Amp-ed Up!

Sarah Mulroy-Lang Ossur will present a demonstration about direct socket casting and achieving a comfortable socket fit in a single visit!

Adam Gill - Ottobock will share insights about how technology can help you to meet your goals.

Andrew Fairbairn will share his conference presentation - Exercising your choice and control.

Dr Maxwell Limakatso will discuss Phantom Pain and Treatments.

Stay tuned for the dates of this exciting webinar series.



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Phantom Pain Insights

Researchers at Neuroscience Research Australia and The University of New South Wales are investigating two new, non-drug treatments to reduce pain intensity and disability for phantom limb pain.

The problem: Phantom limb pain is a common and debilitating complication of limb amputation. There are more than 8,000 lower limb amputations performed each year in Australia alone. It occurs in up to 80% of people who undergo the procedure. A majority (~92%) of amputees experience phantom limb pain at some stage in their lifetime, and 39% experience severe pain. Both traumatic and non-traumatic limb amputation have increased in recent years as a result of war-injuries and chronic diseases such as diabetes. Phantom limb pain is a major cause of morbidity and leads to limitations in daily activities, employment, and a reduction in quality of life. The current standard treatment for phantom limb pain is inadequate, often involving high-dose pain medication.



The solution: A major step towards solving this problem would be to develop low-cost, evidence-based interventions that can be easily translated to clinical practice. An efficient way of achieving this is to establish a coordinated, multi-national collaboration of highly experienced clinical researchers, clinicians, and consumers to develop and test the most promising interventions in high quality randomised controlled trials.



Do you have phantom limb pain?

Researchers are looking for people with phantom limb pain to take part in exciting new research that compares two new drug-free treatments for your phantom limb pain.

The trial will start mid 2023.

Scan the QR code or visit the website to register your interest!



titan.neura.edu.au





My Amp-ed Up experience

John Keighran South Australia

My wife and I attended the AMP-ED Up! '23 Conference and we thoroughly enjoyed the experience. It was extremely beneficial to listen to the speakers who had undergone amputations and had not let any disability stand in the way of their success in the corporate and business world.

We were made to feel very welcome and our accommodation at Hyatt Place was more than suitable. As a Limbs 4 Life mentor, I was pleased to meet the Melbourne staff with whom I had shared many telephone conversations.

We were able to speak to several amputees from other States, and the main thing that we came away with, was the inequity of assistance given to amputees in each State. In South Australia I elected to go with the public health

system and have had no problem at all in obtaining, as required, new legs, a wet leg, new "sleeves" and I have regular follow-ups at the Queen Elizabeth Hospital Podiatry and Prosthetics Section. I could also have decided to work with a private provider if that had been my choice.

It was obvious from meeting people at the Conference, who came from Western Australia, Tasmania, and Queensland in particular, because they have not been cared for in the same manner as I have. Generally, it appears that they have not been given a wet leg, are not provided with more than one rubber sleeve, and in Tasmania it seems that there are no funds available for any aids. It was quite distressing to learn of the difficulty which has been experienced by several of those with whom we spoke.



Last week I heard from an amputee in New South Wales, whom I had previously mentored. He had finally been provided with a wet leg, and on delivery was told that he had to pay \$1500. I was not charged for my wet leg.

I believe that as a priority our organisation should be lobbying the Minister for Health and Aged Care, Mr Mark Butler MP, to address the inconsistency across Australian States, particularly with the amputees over 65 years of age who are not eligible for NDIS. I know that Limbs 4 Life has tried to address this issue with the Federal Government, but it seems that only the squeaky wheel gets oiled.

Some of the speakers at the Conference were inspirational and it was excellent to hear from people who had overcome adversity. In particular, I'll mention Sara Shams and Mike Rolls, who both incorporated humour in their presentations. Dr Bernie Crimmins was forthright, and his message was very clear and Dr Natasha Brusco, who spoke on the Impact of Peer Support, also had an important message for the community.

It was extremely interesting to see the prosthetic legs on display in the Exhibitor Hall; the intense colours, designs and electronic aids on turbo-charged prosthetics! My very plain prosthetic leg serves me well but, if I were younger, I would have enjoyed making a selection from the modern and colourful aids like the ones we saw at the Conference!

Melissa and her team were all energetic and maintained timely order of the programme. They are to be congratulated for organising and bringing to fruition (after several Covid delays) such a wonderful event. Thank you very much and I look forward to the next Conference.



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Exhibitors

Amp-ed Up 2023 attracted our biggest range of exhibitors yet. There were 19 different companies which supported this year's conference. We couldn't run this event without their dedicated support. Special thanks to Ossur and Ottobock for being our major conference partners.











The Welcome Event

The official 'Welcome Event' at the end of day one was a fabulous opportunity for delegates, speakers and exhibitors to get together in a relaxed environment. We were all entertained by the wonderful duo 'Missing Bits' featuring Andrew and Bruce. 'Missing Bits' had everyone entertained with their incredible music and got everyone into the spirit of this event.





Your feedback

Here at Limbs 4 Life, we're constantly striving to deliver support that is meaningful to and has a positive impact on our community. We asked AMP-ED Up! 2023 conference delegates to complete a survey regarding their experiences and opinions of the event. The feedback we received will help us to make the next Amp-ed Up bigger and even better again. Thank you to everyone who contributed.



I thought the conference was amazing! The speakers you provided for us had experience and it was great to see and talk to a lot of different amputees and hear about what they get up to from day to day .

Delegate Western Australia

I loved the conference but would have liked to see more exhibitors. It would have been good to have representatives from accessible clothing companies, mobility aids like scooters and wheelchairs and something tailored to younger amputees.

Delegate South Australia





I FOUND THE PANEL SESSIONS TO BE INFORMATIVE - 88% AGREE (survey respondents)

When can we do that again? AMP-ED Up! '23 was beyond how good I thought it would be. My highlight was seeing so many amputees together in the same place. Everyone was so friendly and positive. It gave me a great sense of community. It was an overwhelming experience. Just the best!

Delegate - Victoria



HOW WELL WAS THE EVENT ORGANISED? - 86% VERY WELL ORGANISED (survey respondents)



Whatever the highest score is, I give AMP-ED Up! '23 even more. It was absolutely fantastic! I cannot explain how much I got out of it. I can't believe what I've gained from being there. To be able to speak with people who are in a similar situation to myself was so rewarding. After AMP-ED Up '23, I have a completely different outlook regarding what to expect as a new amputee. Now I ask questions because I've realised that I don't have to stay with a clinician that I'm not happy with; I can go somewhere else. Thanks to AMP-ED Up! '23, I know which questions to ask. Every person of the 300 people at AMP-ED Up! '23 was approachable. Melissa and Andrew were clearly very busy, but they took the time to sit and talk with me.

Delegate - Victoria



AMP-ED UP PROMOTED CONNECTIONS WITH PEERS - 97% AGREE (survey respondents)

I talked with Mike Rolls who was inspiring. I took a lot away from his presentation. Everything at AMP-ED Up! '23 was fantastic. Ossur's Direct Socket Solution and Bernie Crimmins presentations were highlights.

I got to meet and talk with new people, and they were all excellent. Meeting so many other people who are amputees like me made me feel like I'm part of a community. I rarely see other amputees where I live.

Delegate - Victoria



The Amp-Ed Up! 2023 conference was the absolute highlight for me since becoming an amputee 4 years ago! I left the conference feeling so empowered, wanting to get involved with Peer Support and looking forward to the next conference. Thanks so much Limbs 4 Life team for organising this incredible event!

Delegate - Victoria

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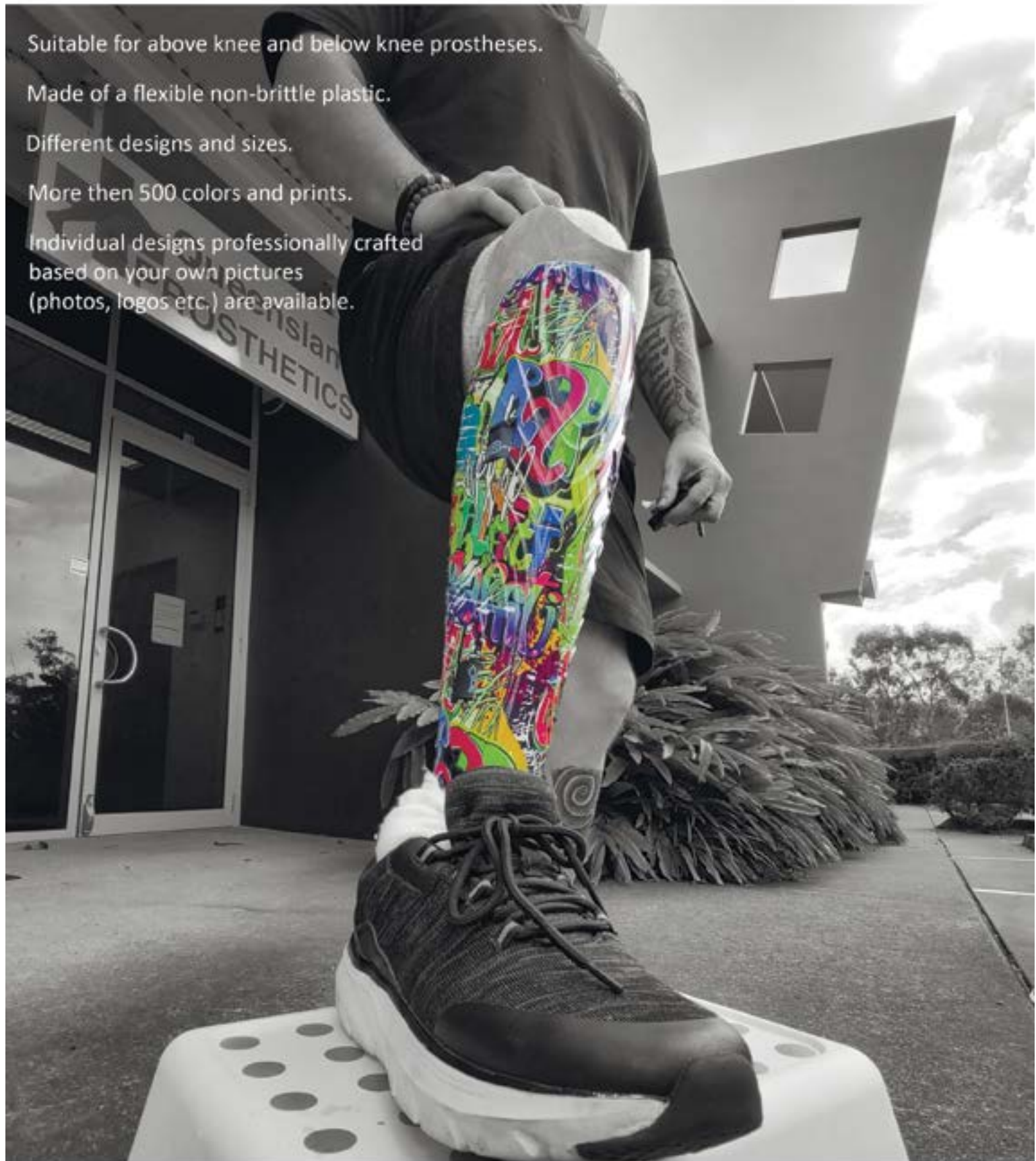
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Connecting with community

Meeting other amputees can help new amputees to adjust to limb loss. Support groups can also provide a space for long term amputees to share their knowledge and experience with those who are just beginning their journey.

Local support groups can be a wonderful way to share information with others, learn new things, find out what is possible, grow your network and connect with people who understand.

Limbs 4 Life have just launched a support group community connect page on our website. If you are interested to know if there is a Limbs 4 Life support group in your area, you can visit the site or contact us directly for meeting times and locations.

Currently there are support groups operating in:

- Adelaide South Australia
- Perth Western Australia
- Penrith New South Wales
- Various locations around metropolitan and regional Victoria

SUPPORT GROUP DATES

Location	Date	Venue
NSW		
Penrith	8 May 12 June 10 July	Blind Chef Cafe
SA		
Hilton	23 July	Hilton Hotel
VIC		
Preston	5 July	Cramer's Hotel
Brighton	5 July	Brighton Hotel
Fyansford	5 July	Fyansford Hotel
Sale	5 July	Lakeside Bowling Club
Wodonga	5 July	Eddie's Tavern
Blackburn	23 July	The Blackburn Hotel
WA		
Perth	23 July	TBC

***Expressions of interest**

We will be establishing groups in Goolwa South Australia and Mornington Peninsula Victoria. Please register your interest if you would like to attend either of these locations.



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