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edition 1 | 2019

AMP-ED Up! Conference Wrap Up

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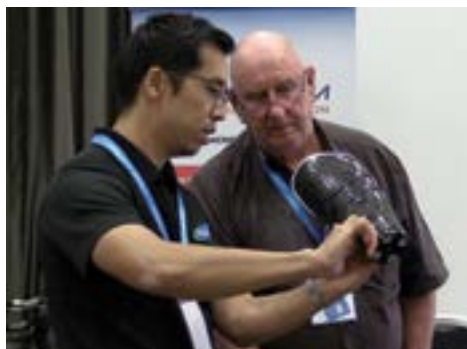
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Welcome to our first edition of Amplified for 2019.

In this edition we are thrilled to share highlights from our **AMP-ED Up!** Conference. Conference delegates had the opportunity to hear from 22 presenters, visit and speak to a range of exhibitors and take part in the Össur pre-conference activities over the course of two days. There were networking opportunities, and for some it was the first time they had ever met another amputee. As one delegate said "I feel the conference made a difference in increasing my confidence and striving ahead".

We are excited to announce that, after the success of the conference, we will be holding **AMP-ED Up!** in Melbourne in 2020!

You can learn about personal stories of three amputees - Ashok (Western Australia), Mark (South Australia) and Garth (Tasmania). There is information about two projects currently being delivered in South Australia and Western Australia, upcoming initiatives, as well as ways of supporting the siblings of children with limb differences.

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1. Miller, William C., Mark Speechley, and Barry Deathe. "The prevalence and risk factors of falling and fear of falling among lower extremity amputees." Archives of physical medicine and rehabilitation 82.8 (2001): 1031-1037. 2. Kaufman, K. Risk factors and costs associated with accidental falls among adults with above-knee amputations: a population-based study. American Orthotic and Prosthetic Association 2016. (Mayo Clinic). <http://www.aopanet.org/resources/research/> 3. Ludviksdottir A, Gruben K, Gunnsteinsson K, Ingvarsson Th, Nicholls M. Effects on user mobility and safety when changing from a carbon fiber prosthetic foot to a bionic prosthetic foot. Presented at Orthopädie&Reha-Technik Congress, Leipzig, May 2012.



AMPED-Up! 2019

More than 192 delegates from around Australia gathered at Limbs 4 Life's inaugural two-day **AMP-ED Up!** Conference in Canberra. Our conference theme of **Educate, Empower and Encourage** was a meaningful experience for delegates, presenters and exhibitors alike. **AMP-ED Up!** encompassed an array of pre-conference events, dynamic keynote speakers, informative presenters and insightful concurrent breakout sessions. In the words of one delegate "I couldn't fault the conference and program - it ticked all the boxes for me".

Day One saw amputee delegates take part in the Össur pre-conference events such as golf, a

walk around Lake Burley Griffin, physiotherapy and yoga/pilates sessions. Mike Rolls opened the event and shared his experience of septicaemia-induced amputations, how he overcame the life-changing effects of this, and shared practical strategies to 'Ditch the Dead Weight' in order to let go of anything that is holding you back.





Delegates were 'wowed' in the exhibition hall, a place where they could find out about new prosthetic technologies and services to support informed decision making. Other sessions covering the NDIS, disability employment pathways, diabetes management, financial budgeting, supporting partners/carers and allied healthcare management were educative and illuminating. Our welcome event at the first day was a chance for everyone to catch up with old friends and make new ones, while enjoying the live music provided by our very own 'One-Legged Sax Player' Andrew Fairbairn.

Day Two began with the opportunity for people to again participate in the recreational activities. Presentations commenced with keynote speaker Jamie Manning sharing his story of overcoming the adversity he faced after surviving a car accident which resulted in burns to 80% of his body and the loss of two limbs.



KEYNOTE SPEAKER Jamie Manning

Jamie is a loved husband and father, retired rodeo champion, Limbs 4 Life Peer Support Volunteer, and member of our National Amputee Advisory Council. Since surviving an horrific car accident, Jamie has also raised funds for Limbs 4 Life, local charities and is an advocate for road safety.

To find out more about Jamie visit www.youtube.com/user/TransportForNSW and search for 'Jamie's Story'.



KEYNOTE SPEAKER Mike Rolls

Mike is a Limbs 4 Life Peer Support Volunteer, Interplast Ambassador, mentor to young people after illness or injury and inspirational speaker. More recently Mike has also become an author, releasing his book 'Ditch the Dead Weight' in 2018.

To find out more about Mike or order a copy of his book visit <http://mikerolls.com.au/>

"It was a superb event and I am grateful for the experience."

Disability Advocate Andrew Fairbairn shared his tips for building self-advocacy skills; invaluable when seeking products and services to live an ordinary life.

Ottobock, demonstrated how advanced technology in upper and lower limb prosthetics are helping prosthetic users to live healthy and productive lives. Össur supported two amputees to share their personal stories of how upper and lower limb prosthetics have enabled them to pursue personal goals. Delegates also learned about Glenn Bedwell's osseointegration experience and how Jason Diederich re-identified with his disability.

Towards the end of the second day delegates were introduced to our National Amputee Advisory Council members who shared their tips for working with prosthetic providers to achieve prosthetic goals. Delegates also learned about Limbs 4 Life's strategic plans for the coming three years, and the floor was opened for attendees to ask questions and share their ideas for future organisational activity.

"I really enjoyed the guest speakers - it's great to hear and meet passionate people who have done the hard yards and are willing to share their stories."



"I attended to help Limbs 4 Life make a difference to those in need of support, hear from other amputees regarding their situation and how they have dealt with becoming an amputee."



"I do feel the conference made a difference in increasing my confidence and striving ahead."

The conference concluded with our final keynote speaker Kath Koschel who shared the physical and emotional experiences she endured after breaking her back twice and losing her partner to suicide. Kath spoke about how these experiences led her to connect with Limbs 4 Life and become the founder, and now CEO, of the global movement and not-for-profit organisation Kindness Factory.

Limbs 4 Life would like to thank all the conference sponsors, in particular Ottobock and Össur, who generously contributed to **AMP-ED Up!** and made it an inclusive reality. We are also grateful to the Department of Social Services for assisting us to help amputees (and their partners) from around the country to attend. Limbs 4 Life is grateful to all presenters and exhibitors for sharing their skills, lived experience and professional expertise to assist all amputees and their partners to feel *Educated, Empowered and Encouraged*.



KEYNOTE SPEAKER
Kath Koschel

After breaking her back on two separate occasions, learning to walk for a third time in her life and losing the love of her life to suicide Kath has been able to create joy out of sorrow to become the founder of the global movement and not-for-profit organisation Kindness Factory.

To learn more about Kath and why she believes that anyone is capable of kind acts visit <http://kindnessfactory.com/>

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Conference videos are coming!

Limbs 4 Life is grateful to Ben, our long-standing and talented film producer, for capturing presentations, exhibitor profiles and delegate interviews during AMP-ED UP!

The videos, which will be available on our website and YouTube channel in the coming month, will be a great memento for those who attended as well as educative and empowering resources for anyone who couldn't make it this year.

AMP-ED Up! EDUCATE • EMPOWER • ENCOURAGE

NATIONAL AMPUTEE CONFERENCE 2020

The success of AMP-ED UP! assured Limbs 4 Life that there was a genuine desire from the amputee community to connect, learn and engage in a conference style event. We are thrilled to announce that our second **AMP-ED UP!** Conference will be held in Melbourne in 2020.

As a couple of delegates said "the trade show was awesome" and "my favourite part was learning from manufacturers about what is coming in the future" while another noted that at the next conference they "would like more exhibitors that deal with other items required by amputees for living independently". So, we are encouraging even more manufacturers, prosthetic providers, mobility device suppliers, physiotherapists, podiatrists and footwear manufacturers, home-based support agencies, disability employment services, and assistive technology providers to join us in the exhibitor hall in 2020.

Limbs 4 Life welcomed delegate's feedback and based on this we are exploring ways of providing more information specific to people aged over 65 or ineligible for the NDIS, running a youth forum, and offering another welcome event.

Watch this space for more information about the **AMP-ED UP! 2020** conference and ways that you can take part, either as an amputee, family member, carer, parent or exhibitor. And, don't hesitate to get in touch if you have any ideas for how we can make AMP-ED UP! even bigger and better next year.

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'Bling your Limb' competition

AMP-ED Up! didn't only enable people to feel empowered and engaged, but it also gave delegates a chance to show their creative and artistic sides through the 'Bling your Limb' competition. People decorated their limbs before arriving or were assisted by Priscilla, Spare Parts curator and Australian Capital Territory National Amputee Advisory Council member, to 'bling' their prosthesis. Participants had the chance to win a Rush Foot donated by OPC Healthcare or a foot of their choice from Oapl's Freedom range. We were astounded by the imagination and originality that went into people's 'blinging'!

The judges were in awe of everyone's efforts. But, after much deliberation, the prizes went to Ashok (Western Australia) for his lego and feathered inspired limb and Mark (South Australia) for his pirate themed limb. In this edition of Amplified we took the opportunity to ask the two very worthy winners to tell us about their creations and themselves – so read further to hear what they had to say!

Limbs 4 Life is grateful to OPC, Oapl, Priscilla and, most importantly, everyone who took the time to 'Bling their Limb'.



Mark Sicolo and his 'Pirate Leg'

Can you share some information about yourself?

I live in Adelaide with my wife Pippa, our two girls Jasmin 16 and Lily 9, and our two dogs Shaggy and Bobbie. My professional background started in the electrical industry with me commencing my apprenticeship after high school and then 25 years working in the industry. I then gained my Diploma in Project Management which led to management of large-scale solar projects. I now work

as a Maintenance Manager for a student accommodation company where I look after nearly 1,000 apartments across the city. My hobbies and interests revolve around renovating our home and sport. I currently play social wheelchair basketball and attend the gym three times a week. I recently have taken a break from kayaking, which I've participated in for 6 months, after winning a bronze medal at the Australian National Championships.

Can you tell us what led to your amputation?

I am a left above knee amputee and had my amputation on the 1st of May 2018. However, my story really goes back to 1996 when I was just 22 and knocked off my motorbike by an inattentive driver. While I received relatively minor initial injuries my situation quickly became worse and in just under two weeks I was fighting for my life with a necrotising fasciitis infection (the flesh eating bug). After twice refusing amputation the bacteria was eventually stopped through the surgical removal of a lot of tissue in my lower leg. I then had reconstructive surgery which involved muscle being transferred from my stomach and then grafted onto my leg. What followed was years of healing, rehabilitation and mental health issues. I eventually came to terms with this and realised I had to get on with my life.

Fast forward to 2018 and I was now living a 'normal' life. Family, full-time work and house renovations kept me busy. However, my knee pain was constant and I was diagnosed with end stage osteoarthritis – in other words I had no cartilage in my knee, it was bone-on-bone. In April 2018 I was admitted to hospital for a full knee replacement. The surgery went well, and I was up and walking. However, on the third day the pain started and I was unable to walk. I had an infection. Again. Eventually the infection was diagnosed as the dreaded flesh-eating bug. After 11 operations in 22 days I was told I would need an amputation or I would not survive. The first three days after my amputation were very emotional, for me and my family. From that point on I made the decision that this is how it is and started to educate myself, through asking questions and reading Limbs 4 Life material, about what life would be like once I went home. I accepted my situation and really tried to 'own' being an amputee.

The next couple of weeks went by slowly. During this time I contracted pneumonia and was close to being put on dialysis due to kidney failure. As awesome as the ICU nurses were I just 'wanted out'. All I wanted to do was get my body right so I could start rehab and begin my recovery. After eventually convincing doctors to reduce my medications, I regained my appetite and my body began to repair itself.

Once I was finally transferred to rehab the hard work began. As tough as it was, because I was so tired all the time, I started going to the gym twice a day. My rehab team were amazing. Once I was fitted with my prosthesis I pushed myself hard. I would walk between those parallel bars for hours, every day. On one occasion my smart watch recorded over 1.2 km of walking. Then on the 28th of May I heard the words I had been waiting for - "You can go home tomorrow". This is where the real challenges started. But with amazing support from my entire family these challenges were made somewhat easier.

Can you tell us why you chose to attend our AMP-ED Up! Conference?

I attended Amped-ED Up! in Canberra with my wife for a few reasons. I wanted to support Limbs 4 Life who are an amazing organisation who have supported me from the beginning. I also wanted to meet people in similar situations who are facing the same kind of challenges as me. Then there are the issues I have had with my prosthesis and socket, and I wanted to look for ideas and solutions that would best suit me. Being able to see and feel different feet and knees, along with seeing examples of socket solutions, was far more beneficial than using Google or purely relying on explanations from my prosthetist.

You were the successful winner of a Rush Foot provided by OPC Healthcare in the 'Bling your Limb' competition. Can you describe your winning creation, design process and tips for anyone considering entering the competition next year?

I chose to enter the 'Bling your Limb' competition for a bit of a laugh. There were pretty epic prizes up for grabs. The idea came about while throwing ideas around with my



family where we had three pretty solid ideas. The final decision was made when my wife came home from the shops with a 'dogs' pirate costume. As soon as I saw it I could picture the final outcome clearly. And let's not ignore the irony of the pirate being a 'peg leg.' From there I went to Spotlight to get a few accessories and went to work on creating the final look.

Is there anything else about your experiences that you would like to share?

I would recommend attending the AMP-ED UP! conference to anyone who feels like they are going through limb loss alone, or if they feel overwhelmed by what seems like a different language regarding prosthetic options and NDIS assistance. You will find many helpful and friendly people that are happy to share their story, ideas and knowledge.

To anyone who feels like they are struggling through amputation with doubt and anxiety, know you are not alone. We all feel like that at some point, if not all the time. I believe the key to overcoming these feelings, or at least not let them control your life, is acceptance. You really do need to mentally accept what has happened so that you can face the physical challenges with a positive mindset. Only that way can we show to others that people living through adversity and with disability are strong, capable and productive members of the community.

Limbs 4 Life would like to thank Mark for sharing his personal story and for taking part in the 'Bling your Limb' competition.

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Ashok and his 'Feathered Lego Leg'

Can you share some information about yourself?

I'm 26 years old and have lived in Perth (Western Australia) since immigrating from India with my family when I was a toddler. I am privileged to have a supportive and fun-loving family, girlfriend and range of friends, something which came to the fore after the accident which resulted in a below-knee amputation.

Since completing secondary school I have followed a diverse higher education pathway. Initially I completed a Bachelor of Engineering, majoring in mechanical engineering. But since my accident I decided to pursue a career in social work and at the end of this year, all going well, I will graduate with a Master of Social Worker qualification. It's often said that some things in life happen for a reason, and I do feel that becoming an amputee made me re-evaluate what I career I wanted to pursue in the future. So, I decided to study social work to enter a sector where I can collaboratively work with individuals, families and communities to maximise their potential and feel empowered. While it seems like a 180-degree shift from engineering there are actually some similarities between these two disciplines, as both are focused on problem solving and finding solutions. I'm really looking forward to commencing work as a qualified social worker next year!

Can you tell us about the accident which led to your amputation?

In 2016 I had an accident while riding my motorcycle to attend my final engineering degree exam. My accident resulted in a number of injuries, and I spent 55 days in hospital and then many more months participating in physical and neurological out-patient rehabilitation afterwards. The most significant injuries resulting from the accident were a left below-knee amputation, an acquired brain injury which left me with post-traumatic amnesia, facial trauma, and loss of hearing in one ear. In some respects the amputation was my least concern. Instead I was more troubled that the brain injury, which largely affected my memory, retention of information and speech would impact on my ability to finish my studies and pursue a career.



I was blessed to have support from an incredible network of family, my girlfriend and friends. As I wasn't conscious in the early stages it was my Mum who had to consent to the many risky surgeries I had, so the emotions of my support network were really tested during that time. Returning home from hospital was difficult. Suddenly I went from a routine hospital environment, which I actually enjoyed, to an unstructured home setting. But through the love of my support network, I felt ready to tackle this next stage in my recovery.

A year after my accident, and a lot of rehab to regain memory skills, I took the final engineering exam that I was meant to take on that fateful day.

Can you tell us why you chose to attend our AMP-ED Up! Conference?

I saw the conference as an opportunity to attend an event that was specifically for the community that I now belong to; the community of amputees. I felt the conference would be a chance to connect with a diverse range of amputees from across Australia, consolidate the learnings I acquired during Peer Support Volunteer training, as well as learn about the latest in prosthetic technology. I also discovered more about the NDIS system, the difficulties which some amputees living in rural communities face, and the funding challenges those aged over 65 are experiencing - all of

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which will help me not only as a Peer Support Volunteer but also as a future social worker. I was also exposed to the Revo adjustable socket and, as I was due for a socket change, I asked my prosthetist to find out if this would be suitable for me. Overall I came away from the conference feeling more empowered, and had a greater sense of community belonging and being part of a big movement. I can't wait for AMP-ED Up! in 2020.

You were the successful winner of an Oapl Freedom range prosthetic foot in the 'Bling your Limb' competition. Can you describe your winning creation and design process?

My design was a mix of Lego parts and colourful feathers, and a lot of glue to hold it all together! I wanted my creation to show my limb to be something beautiful and visible. It reaffirmed that, even when it's not decorated, I wear my prosthetic leg with pride every day! The use of feathers also had another meaning for me. Feathers are something that allow birds to fly and reach incredible heights. And for me, wearing feathers on my prosthesis was an extension of how I feel about being an amputee – while I am now missing my leg I can still reach for personal heights in life.

Of course, the opportunity to potentially win a foot also fed into my desire to participate in the competition too. I must thank my girlfriend and brother for assisting me with gluing all the parts. I think I went into engineer mode project managing the activity and revising the design to make it stronger and more outrageous as we created it!

Funnily enough my 'blinged limb' was completed a few days before I left for Canberra and during the final days of my social work placement at the Charles Gairdner Hospital in Perth. So, I spent the last few days at the hospital wearing this fabulous, colourful and strange looking prosthesis. It was the subject of much laughter and questions from staff and patients. Even if people couldn't see it visually, when I was wearing pants the glued Lego parts made it look like I had a square leg!

I was in awe of the creative legs on display during the conference, and really everyone

deserved to win. So, it came as quite a shock when my name was called out. It is an amazing foot which is going to suit my active life, and I'll never forget how privileged I feel to have received it. Thanks to Oapl for this amazing gift!

Is there anything else that you would like to share?

I would to acknowledge the important role that Limbs 4 Life plays in role of Australian amputees. As an organisation it works to create a community of amputees, a tribe, as sometimes being an amputee can be lonely. But through Limbs 4 Life activities it really assists a unique group of people who share the same language to discuss experiences, find happiness and meaning, foster friendships and reduce social isolation. The advocacy and research work that Limbs 4 Life does on behalf of all amputees is really helping to ensure that our community's voice is heard by policy makers and service providers alike. I also value the nuggets of information I receive through Limbs 4 Life's resources, on Facebook, and through the tips that fellow amputees share online.

It was great to learn about Limbs 4 Life's strategic plans at AMP-ED Up! I'm so pleased to hear that Limbs 4 Life will be advocating for amputees over 65 years during the Australian Government's Aged Care Quality Reform 2019, as it worries me greatly that many older amputees can be at such a disadvantage. I'm also looking forward to playing an active role as a Peer Support Volunteer in Western Australia and contributing to the Ramping Up 4 Work project here once it gets off the ground.

Limbs 4 Life would like to thank Ashok for sharing his personal story and for taking part in our very first 'Bling your Limb' competition.



Engaging with my new community

Garth Johnston has lived a life dedicated to supporting the community, at professional and personal levels. Since becoming an amputee in 2018 Garth has found another community to both support and be supported by - the community of Australian amputees. Garth attended his first Limbs 4 Life event, the AMP-ED UP! Conference, and chatted with us about his experience and what fuels his passion for community engagement.

Garth spent 30 years in law enforcement, which included roles as a police member, corrections officer, security operative and federal investigator. Garth relished the public support opportunity that these roles offered. "I worked in law enforcement in South Australia, Victoria, Northern Territory and Tasmania and enjoyed the challenges that came with roles in different jurisdictions, not to mention the opportunity to serve and protect the public," Garth said.

Towards the end of his career Garth gained qualification as a Level 3 Justice of the Peace - a Bench Justice - a casual role he has held in his hometown of Penguin (Tasmania) over the last nine years, although he's not in the current rotation at present. Coupled with his volunteering at Burnie's Men's Shed and Vinnies, as well as appearing in amateur theatre productions, Garth is a well-known face around town.

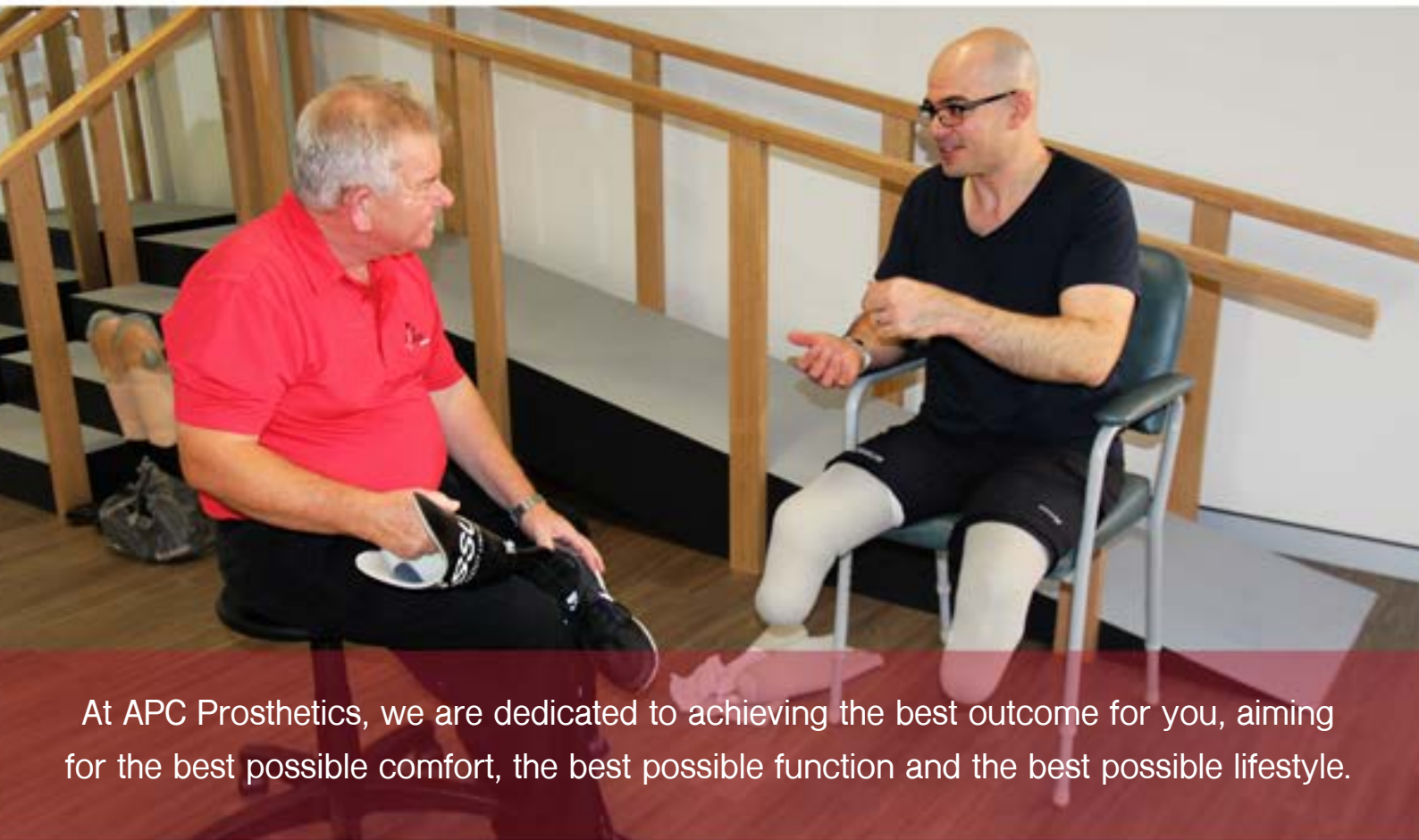
What is less known about Garth is that he became a below-knee amputee in 2018. An accident in 2015 resulted in a 400kg pallet fall on Garth's feet. "Initially I didn't realise how

bad the accident was, as it was a month before I started experiencing a fair amount of pain in some of my toes. But once it started it was the beginning of years of multiple toe amputation surgeries," Garth explained. It was August 2018, after early onset of gangrene in a left foot toe, when it was discovered that Garth had osteomyelitis and that a below-knee amputation was the only way to stop the spread of the infection. "Strangely, my amputation surgery took place exactly three years to the day of the initial accident that led to the loss of my leg," Garth said.

Garth commenced his rehabilitation as soon as possible. He is grateful to the entire team who supported him during his recovery but feels particularly indebted to his prosthetist, Anne-Marie, for two important reasons. "Not only was she a joy to work with and built my leg, but she also introduced me to Limbs 4 Life and suggested I might want to get in touch for information and support," Garth explained. "I chatted with Melissa and was blown away by her passion to support people like me. We talked about peer support and Melissa arranged for one of their Peer Support Volunteers, Ren Gallet, to give me a call," Garth reflected. Ren called Garth to see how he was adjusting, and give encouragement. "I immediately felt a connection with Ren as he was so candid, relaxed and helped me to realise I could move forward with my life. It was a really profound experience. I then knew that, life was going to be a bit different but that I could positively adjust to this physical change," Garth revealed.



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Melissa and Anne-Marie also told me that the go-to person in northern Tasmania was Lyn Johnson from the Tasmanian Amputee Society. Garth has now built a strong connection with both organisations. He is a regular contributor to discussions in the Limbs 4 Life Facebook Group and helps the Tasmanian Amputee Society activities whenever he can.

Garth was thrilled to attend Limbs 4 Life's AMP-ED UP! Conference, an event and experience he found to be "informative and empowering". Garth acknowledged that he felt "nervous" about attending his very first amputee event, but that feeling changed immediately after arriving. "Suddenly I came face-to-face with the Limbs 4 Life team and felt like I'd known them for years. I started chatting with other attendees and exhibitors and fitted in straight away".

On reflection Garth thought the conference was positive on many levels. "Having the chance to meet people in the Facebook Group was terrific as not only could I put a face to name, but I learned they were just as funny, informative and empathetic in real life as they were online," Garth emphasised. Making new

friends, other amputees with a wide range of personal histories, which have extended beyond the conference was another outcome for Garth. "I thought having a mix of personal stories, informative presentations from experts across a range of fields, and the opportunity to take part in yoga/pilates workshops kept the conference really motivating and professional," Garth commented. As a recent amputee he found the exhibitor hall extremely beneficial as he is now more aware of supports and products, which has given him some ideas for assistive technology that he might want in the future. "What I really liked about the exhibitors was that they weren't pushy or in your face. They welcomed you and could respond to any questions, and it was great to be able to touch and feel products," Garth remarked.

Garth looks forward to become a trained Peer Support Volunteer soon to "hopefully offer others the empathy that I received from Ren after my amputation as well as help Limbs 4 Life so that it can continue to play an important role in the lives of Australian amputees for decades to come".

Limbs 4 Life partners with Healthdirect Australia

Partnerships are an important way that Limbs 4 Life increases awareness of amputation and limb loss in Australia. Our partners help to ensure that all Australians affected by limb loss have access to information and resources to actively manage their own health and wellbeing.

Healthdirect Australia is a key partner assisting Limbs 4 Life to achieve this. Healthdirect Australia is a national, government-owned, not-for-profit organisation that has been helping Australians manage their health and wellbeing for over a decade through a range of different information and advice services.

Limbs 4 Life became a formal Healthdirect partner in December 2018 and has contributed to the development of content and resources on

this valuable national health information portal. To find information related to limb loss search under the terms 'amputee' or 'amputation'. You might also find the 'What not to say to an amputee' blog post interesting too.

Healthdirect is a great way of finding out about a wide range of health matters and is a gateway to a range of partner organisation's websites. So, if you are looking for trusted information across a range of areas visit www.healthdirect.gov.au





Thanks to our dedicated volunteers!

National Volunteer Week (20 – 26 May 2019) is the annual celebration of the almost 6 million volunteers who make a world of difference in communities and organisations across Australia.

Limbs 4 Life is supported by hundreds of volunteers who, in the last year, donated thousands of hours to assist us in working towards our goal that no one experience the journey of limb loss alone. The power of volunteers within Limbs 4 Life is remarkable, and it doesn't go unnoticed because we know it changes lives and fosters a positive community spirit.

Our Peer Support Volunteers give an extraordinary amount of time and effort supporting others commencing their limb loss journey. Their support ensures that people who have just lost a limb or parents of children with limb differences receive support from someone who understands them. Our Peer Support Volunteers really are the backbone of the organisation. Our wonderful volunteers take time out of their busy lives to make hospital visits or pick up the phone to have a chat with someone, regardless of whether that's during the day, night or on the weekend.

Our National Amputee Advisory Council members, located across Australia, provide invaluable feedback to ensure we are meeting the needs of Australia's limb loss community. They identify gaps in services, review our information materials, and identify ways we can do things better. These volunteers play a key role in ensuring Limbs 4 Life remains true to its mission and advocating for the rights of all Australians affected by amputation.

Our Board Members are also integral volunteers sharing their professional skills and expertise to govern the organisation and ensure it meets its financial, legal and ethical responsibilities. Meeting regularly and contributing to community and strategic activities, our Board plays a vital role in the advancement of Limbs 4 Life.

We extend a huge thank you to all our wonderful volunteers, both past and present!





'Get Your Ribbon On' for National Amputee Awareness Week - #NAAW19

October 4 -11 is **National Amputee Awareness Week**. This annual '**Awareness Week**' aims to increase community knowledge of limb loss, educate people about the causes of amputation to influence better healthcare management, and minimise the stigma that some amputees still face. It is also an opportunity to celebrate all Australians living with limb loss.

Get on board with this year's campaign and show your support. Taking part is easy. Order your free ribbons and posters, and upload a photo of you, your family, friends and work colleagues wearing your ribbons. Send your photos to us or share on social media. Don't forget to use the hashtags **#GetYourRibbonOn**, **#NAAW19**, **#Amputees**.

For more information or to order your **FREE** ribbons call Limbs 4 Life or email info@limbs4life.org.au

Connect with us today.



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Get on board for Geoff's Big Walk

Limbs 4 Life is thrilled that Geoff will be walking to increase awareness of amputation and raise funds during this year's National Amputee Awareness Week. Geoff is an enthusiastic walker who, since becoming a below-knee amputee nine years ago, has participated in numerous fun runs, walked the Kokoda Trail twice and even climbed Mount Kilimanjaro

Geoff now has his sights set on a new adventure – to walk for 50 kms a day in eight Victorian locations. "I can't wait to begin my new challenge of raising awareness of amputation across Victoria. It means a lot to me to help raise funds for Limbs 4 Life so that it can continue to do the fantastic this organisation does to support people across Australia. Please donate to my 'Big Walk' or even come along, say hello, walk a couple of laps or just say hi!" enthused Geoff.

If you want to catch up with Geoff he'll be 'walking laps' at the following locations:

- 4 October 2019: Wodonga Sports Ground
- 5 October 2019: Wangaratta Showgrounds
- 6 October 2019: Benalla Showgrounds
- 7 October 2019: Bendigo Lake Weeroona
- 8 October 2019: Ballarat Lake Wendouree Foreshore
- 9 October 2019: Colac Botanic Gardens
- 10 October 2019: Geelong John Landy Field Track
- 11 October 2019: Melbourne (location to be confirmed)

Come and meet up with Geoff and walk a mile in his shoes! Or consider donating to his Everyday Hero fundraising page - give.everydayhero.com/au/geoff-s-big-walk

We hope to see you there!

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Western Australia Ramping Up 4 Work Project

Ramping Up 4 Work aims to encourage, empower and motivate people experiencing limb loss to gain and/or maintain employment, through the provision of information, advice and one-on-one peer mentoring. This will be delivered through face-to-face and telephone support provided by Peer Mentors.

What will the project do?

Ramping Up 4 Work will be offered in Western Australia and provide four streams of employment assistance.

1. Realise employment - designed to assist those living with limb loss and entering the workforce for the first time.
2. Retaining employment - support for those in employment at the time of their amputation surgery.
3. Returning to employment - support and assistance for those who have been out of the workforce for some time.
4. Re-adjusting and retraining for employment - advice and assistance for people who need to change career fields as a result of limb loss.

Who can benefit from the project?

Ramping Up 4 Work will benefit employers, peer mentors and people living with limb loss.

- Employers will gain greater knowledge about limb loss, the capabilities of those who live with this, and information about workplace adjustment and funding.
- Peer Mentors, who also live with limb loss, will receive training so that they can support peers to develop resumes, prepare for job interviews and engage in career planning.
- People living with limb loss (mentees) will gain greater job seeking and workplace confidence and be supported to achieve career goals.

How will the project be delivered?

Limbs 4 Life has developed a range of Ramping Up 4 Work resources including manuals, templates, planning materials and fact sheets to assist mentors and mentees. People wishing to become mentors will be provided with opportunities to take part in training, which will be delivered in various parts of Western Australia over the coming year. People seeking employment support will be matched to a mentor so that they can build a relationship aimed at enhancing workplace participation outcomes.

How to get involved?

If you are interested in getting involved, either as a mentor or as a person keen to be matched, contact Limbs 4 Life on **1300 78 2231** or email info@limbs4life.org.au



Government of Western Australia
Department of Communities

This project is an NDIS Information, Linkages and Capacity Building (ILC) initiative.



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Airline Security Survey

Limbs 4 Life is currently conducting a national survey to help us to learn about the experiences of amputees and children living with limb loss when passing through airport security in Australia. This survey only applies to travel within Australia (domestic travel), and NOT international travel, in the last 12 months. The reason for conducting this survey is because we have recently been contacted by several amputees who have experienced issues when passing through security checks at Australian airports. In some cases these encounters have potentially breached human,

disability and/or discrimination rights. This is of great concern to Limbs 4 Life and we would like to advocate for better practices with the businesses that manage airport security and any relevant government agencies.

In order to do this, we are keen to capture airport security experience/s – whether negative, positive or both. This survey will be treated with utmost of confidentiality and your details will not be shared with any other person or organisation. This survey will take 5 minutes or less to complete. To access the survey visit – www.surveymonkey.com/r/AIPORTSURVEY2

If you have any questions about this survey please call Limbs 4 Life on **1300 78 2231** or email info@limbs4life.org.au

Joint Standing Committee on the Assistive Technology NDIS Inquiry

On the 19th October 2018 our CEO Melissa Noonan and National Amputee Advisory Council member/ Peer Support Volunteer Ren Gallet gave evidence at the Joint Standing Committee on the National Disability Insurance Scheme Standing Committee (Provision of assistive technology under the NDIS) held in Sydney.

The Joint Standing Committee is comprised of 10 elected Members of Parliament tasked with inquiring into:

- the transition to the NDIS and how this has impacted on speed of equipment provision
- whether the estimated demand for equipment to be sourced through the assistive technology process in each roll out area was accurate
- whether market-based issues impact the accessibility, timeliness, diversity and availability of assistive technology
- the role of the NDIA in approving equipment requests
- the role of current state and territory programs in the assistive technology process
- whether the regulatory frameworks governing assistive technology are fit-for-purpose
- any other related matters.

The purpose of taking part in the hearing was to provide further information regarding Limbs 4 Life's Inquiry submission and answer any additional questions the Joint Standing Committee had regarding the provision of assistive technology to people living with limb loss.

To read Limbs 4 Life's submission visit – www.limbs4life.org.au/about-us/research-and-submissions

To read the Joint Standing Committee's Final Report and Recommendations visit - www.aph.gov.au/Parliamentary_Business/Committees/Joint/National_Disability_Insurance_Scheme/AssistiveTechnology





Understanding the roles of healthcare providers

Amputees and people of all age with limb loss may find they need support from a range of healthcare providers during their life. Knowing who the various healthcare providers are, and the roles they play, is important in maintaining good health and wellbeing. Whether you are an amputee or the parent/carer of a child with limb difference we hope this brief introduction to healthcare providers will assist in meeting your needs and goals.

Doctor:

- This could be your GP or rehabilitation specialist
- Provides information and conducts medical and health checks
- Makes referrals to other healthcare services or specialists where required.

Prosthetist:

- Discusses your prosthetic options
- Manufactures, fits and supplies you with a prosthesis (if you are a suitable candidate)
- Can assist with gait/functional training
- Provides ongoing repairs and maintenance to your prosthesis.

Physiotherapist:

- Assists you to regain balance and strength
- Teaches you how to use assistive technology aids
- Helps with your gait training program
- Develops an exercise program that suits your needs.

Occupational Therapist:

- Works to help you adjust to daily living activities
- Assists with the fitting of assistive technology (such as a wheelchair)
- Teaches upper-limb technology tasks
- Assists with home and vehicle modification planning and assessment.

Social Worker:

- Advocates for you
- Assists you with financial problems and concerns
- Helps with accessing community resources and services, such as legal aid and accommodation.

Podiatrist:

- Treats your feet
- Helps you to manage and maintain good foot healthcare and hygiene.

Exercise Physiologist:

- Develops an exercise plan for your rehabilitation, general fitness and overall physical maintenance.
- Conducts fitness assessments.

Psychologist:

- Supports you with any emotional and mental health issues, which may relate to your amputation or other matters in your life.

Dietician:

- Works with you to develop healthy meal planning options.

Diabetes Educator:


- Provides information and education to best manage living with diabetes.



Limbs 4 Kids families have once again been selected to participate in the 2019 'Special Children's Christmas Party' events held across Australia. These events are sponsored by a wide range of donors and businesses, and it is wonderful that children with limb differences and their families can participate again this year.

Children and siblings will have a great time at these events which feature stage shows, rides, face painting, dancing, gift bags and presents from Santa! Limbs 4 Life and the event organisers hope your family can make it to this free event and join in the fun. Parties will be held in capital cities and regional centres around the country. For more information including event locations and dates, email kids@limbs4life.org.au

Numbers are strictly limited







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The Össur Mobility Clinic is a unique experience for amputees to improve overall mobility and have a great time with other amputees!

- This year the Mobility Clinic attracted our largest number of attendees yet, with a total of 50 athletes (amputees) of all ages and abilities, and over 40 buddies (healthcare professionals) travelling from across Australia.
- The Amputee Surf Day was a great day for athletes who were keen to hit the surf after the Mobility Clinic.
- Athletes chose their preferred sport or activity to conquer, including golf, soccer, a running reprise, or a session on how to use your micro-processor knee for above knee amputees.
- A total of \$4,500 was raised from the Mobility Clinic and was donated to the Limb Difference Clinic at the Queensland Children's Hospital.

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Peer Support Program

Limbs 4 Life's cornerstone program is its National Peer Support Program which sees 'experienced', carefully vetted and trained amputees connect with others who have had, or are facing, limb amputation. This service is also provided to parents of children born with a congenital limb difference or who experience amputation during childhood and seek parental peer support. Peer support visits occur in hospital, rehabilitation centres or community settings, as well as over the phone. Peer support is free and offered across Australia.

Why is peer support beneficial?

Our Peer Support Program is beneficial for not only the person receiving it, but also for the volunteers providing it.

Benefits of receiving peer support:

- managing fears associated with amputation and limb loss
- coping with feelings of vulnerability and depression
- understanding anxieties associated with body-image and self-esteem
- adapting to a physical disability
- managing short and long-term expectations
- re-engaging with the community.

Benefits of being a Peer Support Volunteer:

- extending personal skills and knowledge
- increased self-confidence
- learning about local communities and healthcare systems
- potential entrée into further education or employment
- feeling 'good' about donating time and lived experience with others.

How to access peer support?

Requesting a peer support visit is easy! Visit www.limbs4life.org.au/peer-support/request-a-peer-support-visit and submit a request via our website. Or, if you can't access the internet call us on **1300 78 2231** to ask for peer support.

How to become a Peer Support Volunteer?

Limbs 4 Life enjoys supporting people to achieve their volunteering goals and ambitions. We know that many people with limb loss welcome the opportunity to share their well-earned knowledge and experience with others just commencing on that journey. If becoming a volunteer interests you, feel free to get in touch so we can talk about the program and formal training sessions we run across Australia.

To find out more or submit an online application visit www.limbs4life.org.au/peer-support/become-a-peer-support-volunteer



Support siblings

Whether your child is born with a congenital limb difference or acquires one later in life, finding the words to explain this limb difference with a sibling can sometimes be difficult. Much will depend on the sibling's age, level of understanding and ability to engage in discussion. It may also be influenced by your own family structure, cultural factors and social issues.

There are many positive experiences that come from being the sibling of a child with limb difference. Children who have a brother or sister with limb difference often possess greater compassion, better understand disability, demonstrate higher levels of loyalty, and are often more open to diversity in our community.

However, some siblings can be affected by their brother or sister's limb difference making it important to initiate and maintain 'open communication' as soon as you think it appropriate to do so. Having open communication, recognising potential challenges faced by siblings, identifying how you can assist, and knowing when to seek support will greatly assist your children. But it is important to remember that, like any family, challenges and issues will occur from time to time. This is a natural feature of growing up as siblings and developing relationships within the family.

Talking to a sibling about limb difference

When speaking with siblings ensure that your information is honest and realistic. Try to be factual, use positive language and undertake discussion that is age appropriate. For very young children there may not be a need to discuss limb difference just yet, it can just be gradually brought up as they grow. If you meet or see pictures of children or adults with limb difference it can be good to highlight that the person has a limb difference – just like their sibling.

When talking to a sibling you may want to:

- explain how your child's limb difference occurred, as they may worry that it will happen to them or that they caused the limb difference
- discuss the language that your family want to use, so that the sibling starts to use those words or terms with others
- explain that everyone is different, but try to limit over-emphasising your child's limb difference or allowing it to become a key feature of their identity
- remind them that they have more in common with their brother or sister than they have differences
- reassure them that their brother or sister can be expected to do and learn the same things as them, although they may need a little more time or some assistance at times

- assist them to understand and know what to say to others (such as friends) when asked about their brother or sister's limb difference.

Challenges faced by some siblings

While there are many positive aspects to being the brother or sister of a child with limb difference, some siblings may encounter challenges or difficulties from time to time.

Not all siblings will experience challenges. Most adjust well, while others may experience difficulties at times. This is normal. Some children may appear to be coping well but may show signs that they are feeling stressed. There may also be different reactions depending on whether they are a younger or older sibling.

All siblings are unique individuals and therefore react differently. However, some challenges and concerns can include feeling:

- like their brother or sister matters more than they do
- that they are seen by others as the sibling of a child with limb difference, rather than the individual they are
- confused about any mixed emotions they have about their brother or sister (eg. love, anger, jealousy or resentment)
- responsible for looking after and protecting their brother or sister (particularly at school or during peer activities)
- embarrassed or sad about other's reactions to their sibling's physical appearance
- frustrated, sad or guilty about their brother or sister not being able to play in the same way they can
- worried about the future for themselves and/or their sibling
- the need to keep any worries or concerns to themselves and not burden parents or carers with these.

Supporting siblings

There are many ways that you can support and guide your child and encourage them to share their feelings and thoughts. Some of these include:

- calmly and honestly answering any questions your child may have
- encouraging your child to talk freely about their feelings
- letting your child know that it is OK to feel angry, sad or frustrated at times
- celebrating your child's personal achievements
- supporting your child to connect with other siblings of children with limb differences or disabilities
- seeking professional support for your child if you feel that he or she is not coping.

Sometimes your son or daughter may openly communicate their feelings with you. However, at other times they may not openly express their concerns but instead display these through certain behaviours, such as:

- withdrawing from social situations or peer activities
- excessive 'acting up' and/or attention seeking
- being overly concerned with being the 'good child' or 'people pleaser' in order to achieve recognition and approval.

Being conscious of any issues or concerns your child has is a good way of providing early intervention support, whether that through you or an external psycho-social professional.

Additional information or assistance

Should you think that your child needs some additional support there are several professionals you may want to access. You may want to consider speaking with your GP, social worker or a psychologist.

A number of organisations are available to assist siblings, including:

- Siblings Australia - www.siblingsaustralia.org.au
- Kids Helpline - www.kidshelp.com.au

Visit <http://limbs4kids.org.au/fact-sheets/> to download a Fact Sheet related to sibling support, as well as a range of other information sheets specifically related to childhood limb difference.

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