

amplified

edition 3 | 2020



Meet Kath Tanner
Always a glass half full

Practical coping tips
for amputees

Carers and supporters
The journey



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Welcome to the final edition of Amplified for 2020. What a year it has been! The impact of the Coronavirus has tested all of us in so many ways. Like most organisations we adapted our programs and services to enable us to continue to remain connected with our community.

In this edition we meet Kath Tanner, one of our vibrant Peer Support Volunteers who shares her incredible journey of amputation and transition back to everyday living. We feature an article on 'practical coping tips for amputees' and take a look at the important role of Carers and don't miss the wonderful images from National Amputee Awareness Week.

On behalf of all of us at Limbs 4 Life we wish you a very Merry Christmas and a safe, healthy and happy New Year. Let's hope that 2021 is filled with happiness and joy for everyone.

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Kath Tanner A glass half full

Kath is a Limbs 4 Life Peer Support Volunteer, keen member of the amputee golfing community and a person who is not afraid to try new things.

How did you become an amputee?

Ten years ago, I was travelling overseas with Steve (my husband) attending academic conferences. We had just arrived in the UK from Portugal on our way, via London, to Ireland where I was presenting the findings of my PhD. I research and teach in Inclusive/special education, and my PhD thesis was on the lived experiences of adults with dyslexia. We were heading into London and trying to decide whether to take the bus or train. We decided to take the bus. As we travelled along the M25

(commonly known as the 'highway to hell') the driver behind us lost control of her vehicle, came across the lanes behind us, and wedged underneath the back of our bus, which caused it to flip. My seatbelt became disconnected and all I can remember was being tossed around and feeling like I was in a concrete mixer. Finally, the bus came to a stop on its side. I was hanging out the window and apparently my left foot was scattered all over the M25. I had also lost part of my right hand, in addition to a range of other injuries.

How did your amputation impact your life?

At the time our kids were back home in NSW and we were in a hospital a long way away from home. I was told I would be there (in London)

for a minimum of 3 months, but I set myself a big goal early on to get back home for my son's ninth birthday – I wasn't going to miss that. I think our brains do a lot more than we give them credit for and my whole philosophy while I was there was 'laugh lots because laughing heals' and 'our brain can help us to heal' – as a result I was told I was healing 'too fast', but I still made it home, 5 weeks later, for his birthday. Over the past 10 years I think my amputation has impacted my life in many positive ways that I never have imagined – the most important being re-evaluating the priorities in my life and appreciating how fragile life can be.

When did you truly accept what happened to you?

I was angry that the accident happened and that I couldn't get to where I was going. I was angry with the driver of the car because I was the one that got the most injuries including my hands and my leg. But at the same time, I knew that there are some things that are in our control and some things that are out of our control; it's a basic philosophy of life. The accident was out of my control, but I made the choice early



on not to sit there in the doldrums thinking 'why me?' Negative thoughts lead to a negative life – who wants a mum/partner/friend like that? I remember the doctors bringing in some consent forms for additional operations and asking my husband to sign them on my behalf. I responded (in my drugged-out stupor), 'no, I'll sign the forms, give me a pen and put it in my mouth.' So, I signed the papers to take control and be part of the process. I had the cognitive capacity to do so, and I wanted to make decisions for myself. I knew the importance of self-advocacy and its impact on mental health. I also wanted to protect Steve from any guilt or repercussions if surgeries etc did not go to plan. I think from the outset I accepted what had happened and simply needed to get on with it – this was just another chapter in my life.

What strategies did you use for self-care (physically and emotionally)?

Emotionally – humour and laughter. I never take myself too seriously and I always try to see the positive in everything. I'm always a glass half full kind of person. So, if something comes along that isn't great, I'll always try to turn it around. There are a lot of studies about the benefits of laughter. Surround yourself with people who also enjoy life and have positive influences on you. I hope this attitude, in some way, helped my family and friends to work through the trauma they experienced as a result of the accident.

I am really conscious of my physical state and I know I have to keep strong and healthy because if I don't, I know I will lose my independence and mobility. Pain also becomes an issue if I don't keep physically fit. I installed a heated swim spa, which helps me with my fitness and pain management. With the assistance of the NDIS I also have an exercise physiologist who I see twice a week – this has dramatically improved my prosthetic movement capacity. I play golf weekly and I've also taken up wheelchair basketball, which is hard work, and just recently joined a contemporary adult dance class! Before the accident, sport was a big part of my life. I loved sport and at an earlier age played at an elite level. When I lost my leg, all I thought was that I wouldn't be able to run or play sport at the same level. I did, however, get back onto



the hockey field 4 months after getting my first prosthetic leg – I became the ‘standing’ intimidatory backline :) The first time I played wheelchair basketball, it was so incredibly exhilarating. It was really the first time, after the accident, I had physically pushed myself to the point that my heart was literally bursting out of my chest and that adrenaline rush came back. It encouraged me to get that upper body strength, which in turn has further assisted the stability of my legs.

Who were the key people in your support network?

My husband, Steve and my two kids, Hamish and Emilija. The accident really affected my kids, in particular my daughter who felt that she had to step in as a mother figure to her little brother, given initially we were on the other side of the world. Also, my amazing sister, Sue who was looking after my kids at the time. I have a couple of fabulous friends who were, and still are, fabulous for my emotional and physical health. They were always there when I needed them and they never wanted to do things for me, they wanted to do things with me. Yes, I'd lost a leg and other stuff, but I didn't want special attention, I just wanted to get back quickly to enjoying life.

What advice would you give to people that don't necessarily have a support network?

Find a community or outlet that you enjoy, or want to try, whether it's a physical activity, cooking, book club or workplace activities. No one will worry whether you have one leg, two heads or whatever. That's not the point, the point is to find something that you enjoy, people to engage with, and opportunities to be in an environment other than your own four walls. There are lots of communities of people with similar interests, for example golf. The amputee golf community is amazing. Sometimes you choose your friends, sometimes they just come along. With the amputee golf community, we have this amazing eclectic group of people at different stages in their amputee journey, with varying golfing skill levels and with a range of life experiences, which makes for a really vibrant and loving community because everyone cares for each other and respects each other's quirkiness.

What do you know now that you didn't know before your amputation?

All sorts of things! I know a lot more about the medical system and how it works. I know how it works in the UK – that's very interesting and I was pleasantly surprised. I knew a bit (about the medical system) prior to the accident, but as a patient, you discover all sorts of fascinating things. I learnt that I can bounce back from something so significant/life changing pretty quickly. I've known for a long time that I am fairly resilient. From personal experience, I just know that no one else is going to pick you up except for yourself. Shit happens in life. I've had a lot of shit happen in my life, but you can either let it compound and fester in a negative way and you can get into a real hole about it, or you can take responsibility and find strategies to increase your positivity and get on with life. No matter who's around you, you are going to get support but in the end it's up to you as to how you respond to that support and use it to your advantage.



What advice would you give to amputees in terms of coping strategies?

Three things:

1. Become aware of your body and tune in to how it moves. Over the years, as a leg amputee, I have become more in tune with the impact of my prosthesis on my body. So, I realise when something is wrong, for example: if I have lower back pain, I know my leg needs adjusting – so I visit the prosthetist before the pain becomes worse or another body part starts to hurt. Having clear communication and a good working relationship with your prosthetist is really important.
2. If you've got a good support network, make sure you appreciate them. They put up with so much and you don't know what's going on underneath and how your trauma is affecting them, especially if you've got kids as they can't often find the words to tell you how they are feeling. If you've got a supportive partner, they may internalise their pain in order to make you feel better. Remember that they need support too.
3. Someone said to me early on during my recovery phase: 'You're not at work so you may feel a loss of your sense of self-identity'. Their advice was: 'Your rehab and your recovery are now your job, it's not an added extra – you've got to look at rehab as your

job now. And once you've completed that job then you can go to the next job whether it's going back to work or doing something else. But during that period of time, that is your job.' Ten years later my advice is, if you're working full-time, part-time, retired, or just enjoying life, you still have an on-going job that is about maintaining your physical self - so eat well, make sure you're exercising, and keep healthy.

What practical tips or advice would you give to other amputees?

My leg doesn't define who I am, it's just a part of who I am. If you don't already ... Go Commando (naked prosthesis - no trousers/sleeves). I go commando all the time - not only can you show off your wonderful designs on your prosthetic, it is also a great conversation starter and increases awareness and inclusion of amputees in our communities I hear parents all the time telling their kids to be quiet when they say something about my leg, and I turn around and say it's fine.

I invite them over to have a look, have a feel and answer their inciteful questions. Educating people is one of the things that I think is really important - by being visible helps reduce people's fear and general misunderstanding regarding disability.

Do you have a story you would like to share with the amputee community?

We would love to hear from you!

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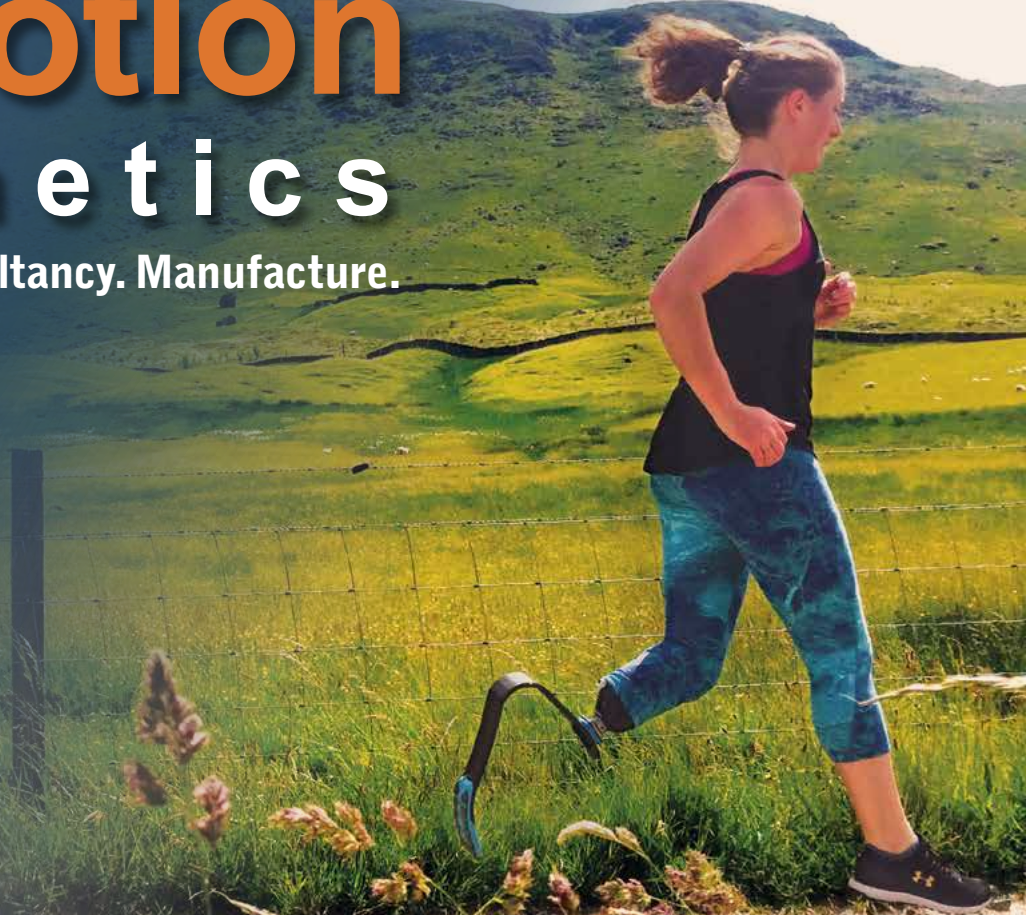
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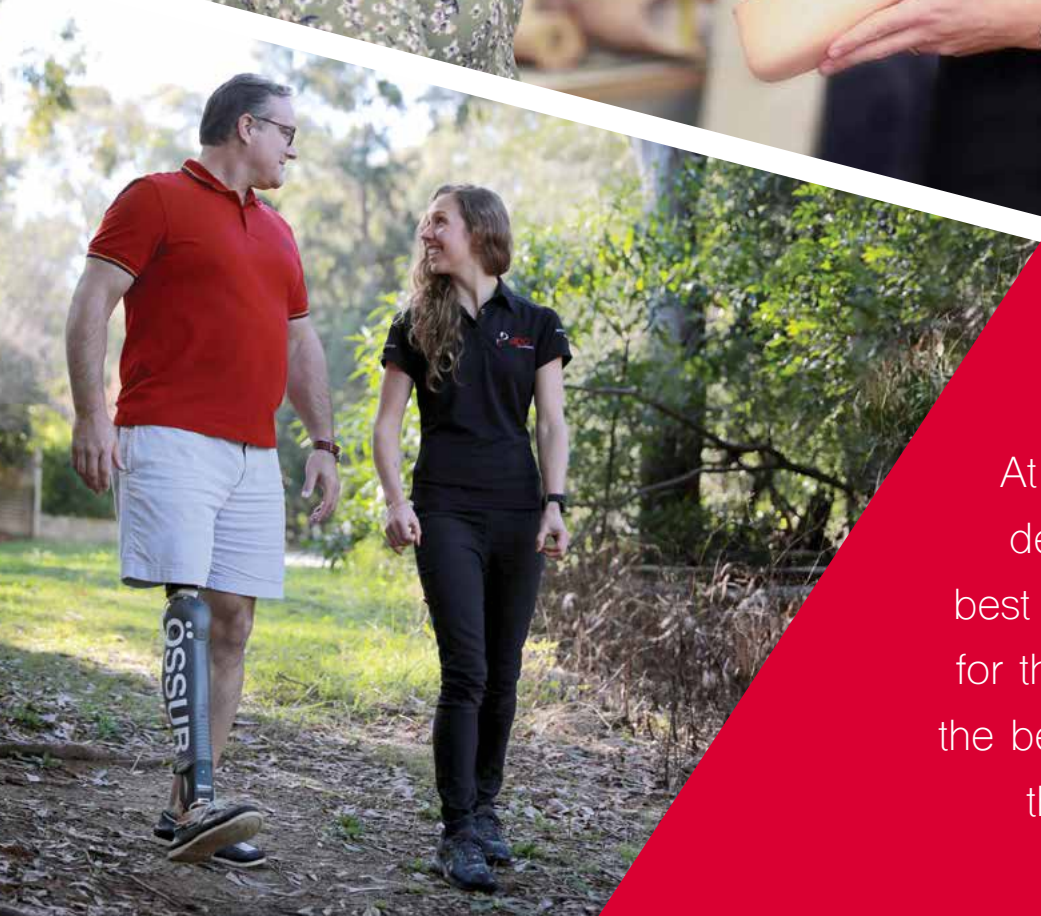
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Practical coping strategies to help amputees and their families

The loss of a limb can be devastating and is likely to cause significant disruption to many aspects of a person's life. As well as the expected effect on a person's mobility, independence and participation in day-to-day activities, it can also have a significant impact on one's occupation, relationships, community and leisure involvement. Moreover, for some, an amputation can disrupt plans for the future and affect how they view themselves and the world. Amputees are often required to cope with ongoing health issues (e.g. pain), learn new skills and sometimes even modify their expectations in relation to their capabilities. Therefore, the loss of a limb requires major adjustment, both for the person and their family/friends.

Feelings of shock, anger, frustration, sadness and grief/loss are all common and normal, particularly in the initial stages. People also tend to experience increased stress and worry (eg. due to financial strain), along with feeling a lack of control and a sense of isolation. Given the challenges people face, it is not surprising that symptoms of depression and anxiety are common. **'Studies have found that after an amputation the prevalence of depression and anxiety is as high as 41 per cent.'** Therefore, it is important that people take steps to tackle symptoms of depression and anxiety, as when left untreated they can have negatively impact on a person's recovery and rehabilitation, and physical and mental health.

There are a number of things people and their families can do that may help to facilitate the process of coping, with some coping strategies below.

Amputees experience various challenges and will have different reactions and needs dependent on the stage of their journey. For example, the challenges after surgery vary compared with challenges faced by someone learning to use a prosthesis.

In the initial stages, amputees may experience emotions such as sadness, shock and anger. It may be useful to discuss these feelings with others. This could be with a trusted family member, friend, or professional. Moreover, reminders that such reactions are normal and will typically pass with time are also helpful.

The initial stages can also be stressful. Therefore, practical strategies for self-care are recommended. This includes ensuring one has adequate sleep and is maintaining a good diet. Furthermore, relaxation, breathing and mindfulness exercises are beneficial when experiencing increased stress. Should stress begin to disrupt one's life, it is important that they seek support from a qualified professional. And, the earlier the better as mental health issues such as depression are treatable.



When one is faced with health issues and associated life changes, countless research has shown the significant role that social networks play in facilitating coping. This is also true for people following an amputation. Therefore, staying well connected to family and friends is valuable. Family and friends can often provide practical and emotional support and can reduce the sense of isolation that is commonly experienced. Additionally, peer support, whereby one can observe and talk with other amputees who have “successfully” managed challenges, may also help with coping and reduce the fear of the unknown.

A lack of control over the situation is also frequently experienced following an amputation. A useful tip to manage this is being involved in your care by asking questions of the doctors, nurses and therapy team.

This allows the amputee and their family to gather the information required to tackle any concerns, reduce uncertainty and plan for the future, thereby creating a greater sense of control. Remember there is never a silly question!

Having goals to work towards, particularly during rehabilitation, is imperative. Goals should be meaningful to one’s life but also attainable and realistic and your therapists will be able to help develop such goals. Setting and achieving goals often provides people with a sense of purpose, structure, and improves confidence and self-esteem.

Similarly, having a daily routine and planned activities is a useful strategy that helps one to cope. It may keep people occupied, acting as a distraction, and prevents them from dwelling on their situation, which over time can be detrimental to physical and mental health.

However, one cannot always keep themselves busy. There will be times when worries pop up and may cause distress. Helpful tips for dealing with worrying thoughts include problem solving, taking action if able, relaxation, mindfulness and “letting go” strategies. It may also be useful to try to adopt an attitude of “taking things as they come”.

Amputees have found that maintaining a positive/optimistic attitude can help with coping. “Put things into perspective” and reminders of one’s achievements (both relating to rehabilitation/recovery and life in general) can encourage a helpful attitude. It is also beneficial to engage with a professional, such as a psychologist, to develop further coping strategies.

Finally, a key area in facilitating one’s coping following an amputation is to ensure they are able to again participate in meaningful life activities, to re-establish a sense of normality and self-worth. This includes important life role, such as caring for themselves, being a family member and returning to work, driving and hobbies. Having a prosthesis can assist with one’s integration back into such activities. Furthermore, we know from mental health research, participation in pleasant, community and social activities along with having a general purpose in life, are beneficial to one’s physical and emotional wellbeing. Lastly, re-engaging in life’s activities demonstrate to the amputee and their family that the loss of a limb does not define them.

Adjusting to an amputation takes time and people experience a variety of emotions throughout the journey. Utilising practical strategies such as self-care, staying in touch with support networks and being informed and involved in the recovery process can all facilitate the process of coping, leading to positive health outcomes.

***Sarah Fitzgerald (Clinical Psychologist
- Royal Talbot Rehabilitation Centre)***

(re Amplified Winter 2016)



2020 National Amputee Awareness Week *wrap-up*

October 4 – 11 saw the limb loss and wider Australian community celebrate National Amputee Awareness Week. This important campaign provides a chance to raise awareness of amputees and children living with limb differences across the nation. It's an event that's been running since 2013, getting larger and stronger from one year to the next.

Like most events and campaigns this year, the 2020 National Amputee Awareness Week was impacted by COVID-19. The pandemic presented us with uncertainty, the introduction of health restrictions, and the need for some people to stay home and maintain physical distance to stay safe. So, while we couldn't facilitate National Amputee Awareness Week in the ways we ordinarily do, 2020 did see the community celebrate 'our week' in new and innovative ways. With a number of physical events and activities put on hold we had fun online and virtually. While we certainly missed some of the morning teas, gatherings and outdoor events, a number of facilities were still able to enjoy the week by bringing their clients and patients together. Regardless of how it was celebrated we still felt the great sense of community connection and the recognition that this week is all about!

Get your Ribbon On

For the fourth year the 'Get your Ribbon On' campaign created a buzz on social media. People changed their profile picture to the green ribbon in support of the week and we witnessed a sea of green on people's clothes, prostheses, pets, hats and other creative places. And speaking of sea, we do think that our volunteer Bruce Jacques' photos of ribbons adorning a commercial ship stationed hundreds of kilometres off the Western Australia coast might just be the farthest distance a ribbon travelled this year!

This year we distributed thousands of ribbons to individuals, healthcare providers and community members, with the distinct ribbon acting as the official symbol for promoting public awareness of limb loss.

We learned about the conversations that started when people in our community were asked about what the ribbon represented. That alone led to discussions about personal stories of amputation, limb loss facts and a general interest in why it's important that the public become more 'amputee aware'. After all, the week is all about awareness raising, reducing stigma, breaking down barriers and broadening the public's mind. Thank you to everyone who wore their ribbon with pride.

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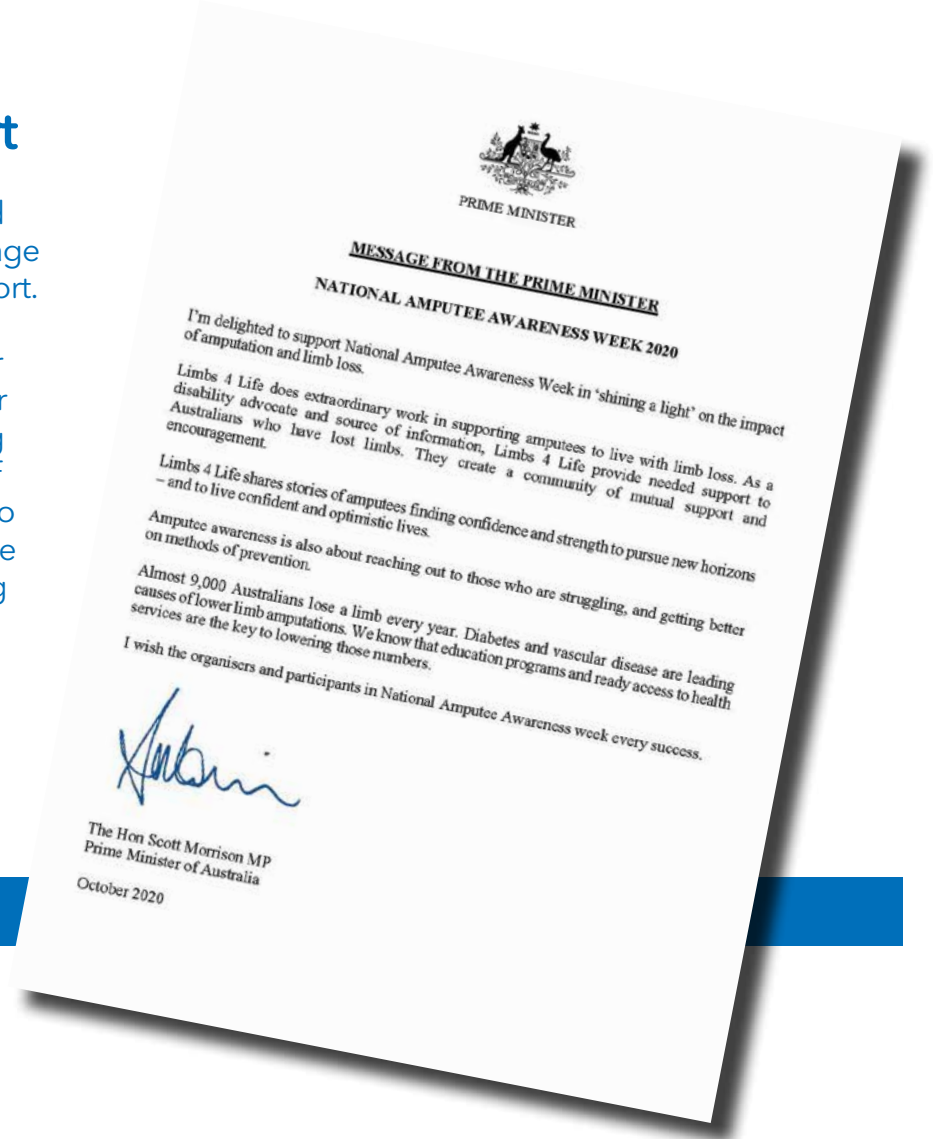
2020 was the second year of our 'Shine A Light' campaign. Building upon the success of our first year, we more than doubled the number of landmarks, venues and buildings illuminated in green to celebrate National Amputee Awareness Week across Australia. The 51 iconic landmarks operated by a mix of local governments, commercial operators and government agencies provided us with a significant opportunity to raise awareness, share messages and images across social media and attract ongoing opportunities to 'light up' again in 2021. It was wonderful to see so many members of our community visit locations and take photos of the magnificent landmarks lit up in honour of all people living with limb loss. And in the difficult times of social restrictions and lockdowns, the lighting up really did provide a message of hope and togetherness.

We are enormously grateful to all of the passionate participating organisations for embracing our Shine A Light campaign with such respect, commitment and a desire to demonstrate inclusivity and raise awareness. We look forward to even more organisations and institutions glowing green and shining brightly during National Amputee Awareness Week in 2021.



Government support

This year saw many local, state and federal politicians share our message of awareness, inclusivity and support. While there were many, we were pleased to see the federal Minister for Health, Greg Hunt, and Minister for the NDIS, Stuart Robert, among the ranks who shared messages of support. We were also honoured to receive a personal letter from Prime Minister Scott Morrison supporting our efforts in 'shining a light' on amputees and acknowledging the work that Limbs 4 Life does in creating a community, advocating, and being a credible source of information.



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The journey for carers and supporters

Carers can come in many forms. A carer could be your partner, spouse, family member, grandparents, or simply your friend or neighbour. Knowing that you have a person that cares for you and about you during a life changing time, is extremely important.

For many amputees, Carers play an important role in providing physical and emotional support. Carers will often advocate for you, be your voice if you are feeling unable to speak up for yourself, they will listen to your fears and concerns and provide support that often no one else can.

Carers Australia state that 'Carers are people who provide unpaid care and support to family members and friends who have a disability, mental illness, chronic condition, terminal illness, an alcohol or other drug issue or who are frail aged.'¹

Carers play a vital role in helping people to recover and provide support on a day to day basis. In fact, without carers, many people could struggle to deal with daily tasks. In Australia there are more than 2.7 million unpaid carers.²

Caring for someone

For many Carers, the 'role' of caring can sometimes be stressful and sometimes demanding, especially if you have other responsibilities such as; children, family or work.

What does being a Carer mean?

Carers help with a variety of tasks such as: dressing, showering or providing transport. Carers also provide emotional support. Being a carer means that you are willing to give of your time to assist someone else.

What if I am new to being a 'Carer?'

In the case of your loved one having an accident or injury; carers can often be thrown into the Carers role with little or no time to prepare. Similarly, you maybe be notified that your partner, spouse or parent is about to undergo life-changing surgery, such as an amputation and find yourself in a similar position. If you are feeling overwhelmed and unsure of where to begin and/or how you can best assist and support your loved one speak to the people around you.

Where can I find help?

As a Carer there are a number of ways that you can find support:

- If your loved one is in hospital or rehabilitation, request a meeting with the social worker. The social worker will help you to navigate pathways moving forward.
- You may wish to speak to a Peer Support Volunteer who has adapted to limb loss and understand the pathways forward. You also wish to speak to the partner of a Peer Support Volunteer as they are able to share the own journey with you.
- Your local doctor can be a great resource when it comes to support. They will know of options to assist you and what supports are available to you in your local community.
- Contact Carers Australia on 02 6122 9900 to find out what support is available

Seven Tips for Carers

- 1 Do something for yourself that makes you happy.
- 2 Meet up with other carers in a social setting; other carers can be a great source of support.
- 3 Join a local carers support group
- 4 See if there are local supports available to enable you to have a break. This may mean that someone else washes the floor or vacuums for you.
- 5 Allow yourself to have a bad day, it's okay.
- 6 Take some time-out every now and then.
- 7 Ask for and seek support when you need it.



We asked amputees... What did having a Carer mean for you?

"Knowing that my wife would support me through this journey made the decision to amputate my leg easier. I could not have gone through this without her support and knowing that she would always be there for me."

Andrew - Perth WA below knee amputee.

"My support network came from my friends and family. I was not in a relationship at the time of my accident and relied on the support of my parents and close friends - they always there beside me on my road to recovery."

Julie SA - above knee amputee.

"I was a long way from home when I had my amputation which made it difficult for family and friends to visit. I was lucky to be supported by my physiotherapist and social worker at rehab centre I attended. They were wonderful to me."

Gary NSW - below knee amputee

"I lost my arm in a workplace accident. I never thought that I would be able to do all of the things that I can do now. My wife was my rock. Without her support and encouragement, I don't think I would have got through this."

Peter - Regional Victoria
- below elbow amputee

Visit the Limbs 4 Life Youtube channel to find out more.

¹Carers Australia website (2019) <http://www.carersaustralia.com.au/about-carers/>

²Australian Bureau of Statistics (2015) Survey of Disability, Ageing and Carers.

Victorian Limbs Loss Empowerment Project Update

Limbs 4 Life are delighted to be rolling out the Limb Loss Empowerment project around Victoria. The goal of the Project is to build community-based support network where amputees can connect, share, learn, support and empower each other to lead a fulfilled life.

We want you to feel connected; learn about the things that matter to you and inspire one-another to be your best self. Over the next 2.5 years, we will be establishing 10 locally-based amputee support groups in key locations throughout Victoria, including four in Metropolitan Melbourne groups, and six in regional Victoria. These groups will provide a safe and supportive environment for amputees of all ages and stages of their journey, to further build their capacity to self-advocate, connect with community-based support services, receive amputee specific content, and facilitate critical peer/social connections.

We believe that creating a platform for greater community connection is essential for amputees around Victoria. We aim to build a long term, robust, sustainable support system that will help amputees build their capacity to live fulfilled, empowered, and independent lives. We encourage all amputees and their partners/carers to get on board with this project as it rolls out around the state in the coming months.

The Amputee Advisory Committee

We have established an Amputee Advisory Council made up of members from our Peer Support Network to guide the establishment of the project. The Council are responsible for oversight of resources and information that we will develop during the course of the project.

Local area support groups

Locally based support groups are a great way to connect with your community. If you are



interested in joining a local area support group or would like to know more, please email us at peersupport@limbs4life.org.au

Support group leaders and 'Group Leaders Network'

As part of this project we will be creating a team of Support Group Leaders. We will provide you with the skills you need to run a successful support group and directly support you to gain the best possible outcomes you can.

Empowerment workshops

These workshops will help to teach you resilience, gain skills on how you can achieve the outcomes you want to achieve and help you to build individual capacity, increase your confidence so that you can make informed decisions.

Become a Peer Support Volunteer

Our peer support volunteer network provides face to face one-on-one support to people facing amputation and their families. Our peer supports value 'giving back to their community' and helping new amputees 'navigate the pathway' back to independent living. If you are interested in becoming a peer support volunteer or would like to know more, please email or get in touch.

We want to hear from you!

To get involved in the Limb Loss Empowerment project or find out more information why not contact Mike today on **1300 78 2231** or email mike@limbs4life.org.au



Welcome to the team - Rosy

Limbs 4 Life is thrilled to announce the appointment of Rosy Interrigi to our team as our Communications and Content Specialist. Rosy is responsible for our social media posts and engagement, management and oversight of our websites and publications along with supporting the roll-out of our marketing and communications strategy.

Rosy brings a vast amount of knowledge in marketing, communications, and content. Completing a double business degree from Monash University and working in the not-for-profit space for over 4 years, Rosy is looking forward to using her skills to contribute to the amputee community in Australia. Rosy loves volunteering in her spare time, having previous roles with the Special Olympics and her local tennis club.



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Changes to the NDIS Independent Assessments



In 2021 the National Disability Insurance Scheme (NDIS) will be improving ways that people access the Scheme. The goal behind these changes is to make the NDIS simpler, easier to use and more consistent.

Independent assessments create a complete picture of how you manage tasks and activities in your everyday life. How you do things like school or work, or take part in your community.

An independent assessment will mean that you don't need to organise an assessment or collect evidence to show the impact of your disability. This new process will save you time and money.

Independent assessments will mean you have quick access to internationally recognised tools and qualified health professionals no matter where you live, or what your circumstances are. From mid 2021: independent assessments will also be required as part of the plan review process. This is part of a new approach to planning that will mean plan reviews are based on life stages, instead of a year or two. Independent assessments are common, streamlined approaches used by many funding bodies, in fact organisations like Victoria's Transport Accident Commission (TAC) have been using them for years.

For a person with disability, functional capacity is a positive way in determining eligibility for the NDIS, as well as to get an indication of the kinds of supports that will benefit you the most. Instead of focussing on everything that is

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“wrong” with the person and what they can’t do, a functional assessment captures information about what they can do. Functional capacity is the ability to be involved in different areas of life like home, school, work and the community and to carry out tasks and actions. It takes into account other factors in a person’s environment that may impact day to day life. Some examples of questions that might be asked by trained allied health professionals using the validated assessment tools include:

How much difficulty do you have in:

- Standing for long periods such as 30 minutes?
- Getting into and out of your home?
- Walking a long distance such as a kilometre?
- Washing your whole body?
- Taking care of your household responsibilities?
- Joining in community activities?

In these examples, the person being assessed is able to answer with “none, mild, moderate, severe or extreme / cannot do” and then may be asked to provide further information or examples.

How will the Independent Assessment approach make things better?

Independent Assessment approach will:

- lead to more consistency in decision making when people request access to the NDIS and in the planning process,
- make the process fairer and more equal by removing the financial burden on potential participants to provide the information required;
- take into account how a person’s functional capacity is influenced by their environment, their health and other individual factors, not just their disability;
- introduce an assessment process that recognises that a particular condition or disability does not necessarily have the same impact on everyone,
- shift towards a whole of person assessment; and
- focus on function rather than diagnosis.

Some people have expressed concerns over privacy with these assessments. The nature of the interview-based assessments mean that the person is able to provide as much information as they are comfortable in doing. They have control over what they share.

Others have stated they feel the assessments will be used to kick people out of the scheme, or will be used to reduce their funding. The NDIS is a world leading scheme that is the first of its kind. After years of lobbying from the disability community, the Australian Government has established a single national scheme that focusses on enabling people with disability to maximise their independence and build their capacity to achieve their goals with reasonable and necessary supports. This once in a generation reform is enabling many people with disability to receive supports for the first time ever. It is not a welfare system, and so of course there are checks and balances in the overall process to make sure that the valuable taxpayer money goes to those who need it most, and that people get the level of supports most appropriate for them. Everyone’s needs are different, even those with the same disability, and these independent assessments will help identify how best to meet those individual needs.

The National Disability Insurance Agency (NDIA) are committed to working with participants, their families and carers, peak bodies, disability organisations and peer and family networks to make sure they work effectively for participants.

To find out more about this process you can visit the Frequently Asked Questions section of the NDIS website www.ndis.gov.au/participants/independent-assessments/independent-assessment-q-and call the NDIS on 1800 800 110 or contact Limbs 4 Life for more information.

Have your say!

Limbs 4 Life will be providing feedback to the Agency, so if you have any thoughts about the Independent Assessment process please share those with us today, so that we can share them with the Agency.

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Due to the unpredictability of the health situation across Australia this year, party organisers have advised that for the safety of everyone involved, the difficult but essential decision was made to cancel all 2020 events.

Organisers made this decision taking into consideration the potential of exposing children with multiple disabilities, co-morbidities and compromised immune systems. Their main priority was to ensure the safety, health and wellbeing of children, families, carers, volunteers, supporters, entertainers and staff.

If you made an application for a ticket for your child to attend a 2020 event, a Limbs 4 Kids team member will contact you to confirm your event cancellation.

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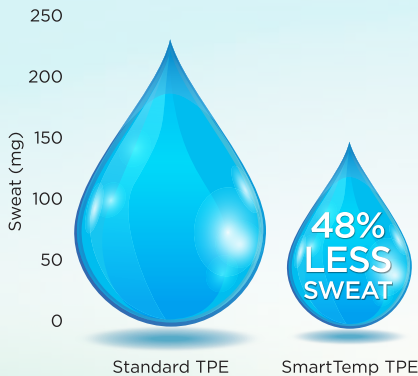
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*Study data on file and online at willowwood.com/core



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Ramping up4work

Ramping Up 4 Work (RU4W) is an initiative of Limbs 4 Life, and was developed to support amputees regain employment, realise employment opportunities and return to meaningful work. The project is supported by a Program Coordinator and our trained peer support volunteers who act as Job Motivating Mentors work to assist recent amputees to realise their employment opportunities. Funded by the Western Australian Department of Communities, this project is proving to be a valuable service for people living with limb loss.

In this article we meet two amputees who have both engaged in the program and have found new employment pathways.

Meet Bruce



Bruce underwent a below knee amputation approximately six months ago. Up until that time Bruce had been working as truck driver, driving every kind of truck imaginable; his favourite being the B-Double long-haul, a role

he embraced and did for more than ten years. Following his amputation, Bruce knew that continuing to drive would be limiting and he wanted a job that would be flexible enough to allow Bruce to manage his prosthetic appointments. Bruce learned about the RU4W project at his prosthetic facility and reached out to Andrew.

"I am very analytical, and this project has helped me to build on my employment and recreational ideas. It has helped me to develop a strong focus on those ideals and develop confidence regarding my employment opportunities. Andrew has helped me to see that the traditional idea of employment may not work for me and using the tools of the project we have explored options for small business and micro enterprise development. This has eventuated in the development of 'Bruce's Test and Tag.' Starting up a new business can be nerve racking but with Andrew's support and the information that this program has afforded me, I believe that I can make it a success," Bruce shared.

Has your mindset toward employment changed since you have become an amputee?

I think it has. I think about things such as how my disability may impact upon my employment, something which I have never had to consider during my working life. I also think about things such as accessing a potential client's workplace. I wonder if they will treat me differently when I turn up on site to test their tools? I have had to think very hard about what I want to do. Gaining support from the RU4W program has been invaluable for determining what kind of role would best suit me. I have a long and varied resume and as an amputee, I have to ask myself, can I still do that job, or am I going to have to change it. I have to be realistic and I realise that there are some things I used to do that I cannot do now. This is why starting a new business and being my own boss will be invaluable.

What was your experience re-training as a 'tag and tester'?

I enjoy learning new skills and it was everything that I expected it to be. A good mix of both practical and theory-based learning.

Has the RU4W project helped you to realise your employment opportunities?

Yes, it has. It has helped me to focus. Having the focus back on employment means that I have a 'light at the end of the tunnel' moment. I have clarity and something to work toward. Working with Andrew has helped me to develop and navigate pathways to move forward and I know if I continue to follow these pathways, I will achieve success.

A final word from Bruce.

"There is nothing wrong with dreaming, but you must be realistic and focused!"

Meet Tracey



Tracey was in and out of hospital from the age of 15 where she was undergoing dialysis for kidney disease. 13 years ago, after moving from Albany to Perth, she was diagnosed with Avascular Necrosis of the left ankle, and 2 weeks later had a left below knee amputation. 5 years ago Tracey had a kidney transplant.

Tracey studied at both Tafe and University. She holds a Diploma in Disabilities and Aged Care along with Degrees in Criminology and Law. Tracey is also a qualified Personal Trainer.

Tracey learned of the Ramping Up 4 Work Project whilst researching information about the National Disability Insurance Scheme (NDIS) on the Limbs 4 Life Website.

"I was looking for someone to help me to realise my dream of working with people with disabilities," Tracey stated. "I was doing some work in a few different gyms and I even tried selling jewellery, but the dream of supporting people with disabilities would not go away," shared Tracey.

Has your mindset toward employment changed since you have become an amputee?

I had my amputation prior to completing my degrees, but I felt that every time I interviewed for a job the stigma of being a person with a disability was there. This weighed heavily on me and my mental health. I found it hard to gain employment in my chosen field.

What was your experience learning how to navigate the self-employment space?

I have found pathways that have helped me to understand myself and how I react or respond to things. Knowing this has helped me to realise that I can be strong and be in charge of my own future.

Has the RU4W project helped you to realise your employment opportunities?

Having a mentor to work with has assisted me to continue to build and expand my Personal Training business. I am now working with both NDIS and non NDIS participants, helping them to reach their personal goals. I have had my ideas challenged by Andrew. Together we have explored the way I do things and how I can change myself to cope even better with any setbacks that my business may have. I've also learned that it is ok to be ambitious. This has helped me to maintain a focus and better cope with tough situations because now I have something to work toward.

A final comment from Tracey.

"I am a fighter, I have overcome many battles, I have the strength and power, I will never give up and I will never back down."

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Peer Support Volunteer Anniversaries

Thank you to all of our Peer Support volunteers for your continued dedication to the amputee community. Your continued support, passion, and energy contribute immensely to empowering, supporting, and being there for new amputees and their families across Australia.

The Peer Support Volunteers celebrating anniversaries this year are:



5 YEARS

Ian Bagshaw SA
Jason Honeychurch SA
Lou Skeklios SA
Ben Brizzi VIC
Kate Prowse VIC
Renee Sharpe NSW
Fay Keegan NSW



10 YEARS

Alan Hare VIC
Liz Healey SA
Mark Clarke VIC
Winston Long VIC



15 YEARS

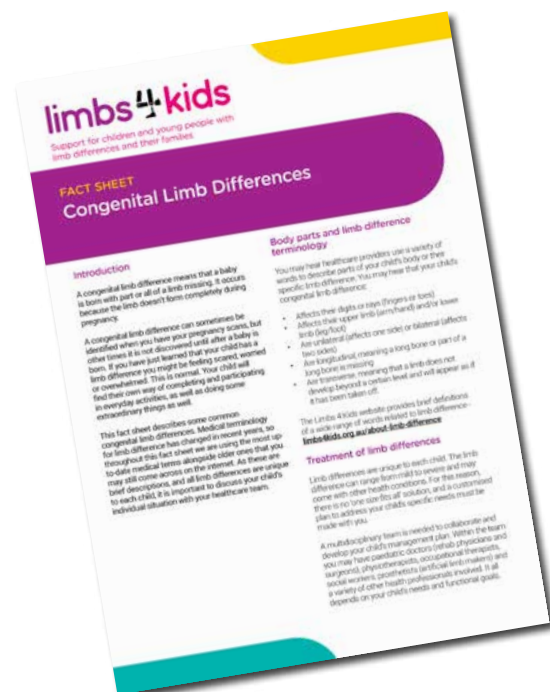
Ian Gooch VIC
Jason Harrigan VIC
Sarah Walsh NSW
Patricia Walsh NSW
Wayne Kiven VIC
Terry Lee VIC
Venise Campbell TAS
Mike Rolls VIC
Gary Johnston VIC
Annie Pateman VIC

limbs 4 kids

New fact sheet: Common congenital limb differences

Limbs 4 Life is pleased to announce the release of another Limbs 4 Kids fact sheet, which briefly describes many common congenital limb differences and helps families to gain a greater understanding of these. This fact sheet was actually an idea proposed by Shail Maharaj, the well-known and respected paediatric physiotherapist at the Queensland Children's Hospital, who identified a gap in this type of information.

So, with the support of doctors and allied health clinicians in the Queensland Paediatric Limb Difference Clinic Team we collaborated to co-design and develop this resource. We hope this fact sheet assists our community to learn more about the wide range of limb differences present at birth, and some of the professionals and treatments available to support children fulfil their potential.



And don't forget, you can find more information, fact sheets and other resources on our Limbs 4 Kids website www.limbs4kids.org.au



Limbs 4 Life submissions and advocacy efforts

Often governments, and other organisations, seek feedback from consumers (e.g. amputees) and consumer-based organisations, such as Limbs 4 Life, about issues that matter. Limbs 4 Life responds to these consultations and inquiries by making submissions in order to advocate on behalf of our community of amputees and children with limb differences. A critical aspect of Limbs 4 Life's theory of change is that we listen to, and be the voice for, people with limb loss so that we can lobby for better community outcomes. Our submissions are always grounded in, and informed by, an evidence base of research and consultation, meaning that our community's point of view and concerns are included.

In recent years we have made submissions to the Productivity Commission, National Disability Insurance Agency, Royal Commissions, National Disability Strategy, state-based Disability Plans and other relevant inquiries. We have also worked with other organisations to make joint submissions. Some of the issues we have commented and made recommendations on include: introduction of the NDIS; improvements

to the NDIS; access to assistive technology (e.g. prosthetics) for older amputees; human and disability rights; accessibility; employment rights; fairness of prosthetic provision and maintenance; and, minimum standards of care for amputees, to name but a few.

In addition to responding to government-led inquiries we also initiate our own research about issues so that we can advocate for change; not only with governments, but also business, service providers and training providers. Our Airport Security Report is just one such example.

While not all government inquiries will result in practical change or policy shifts, we believe it's essential that the voice of our community is heard and documented. Indeed, some government inquiries have led to significant positive systemic policy changes that directly affect the lives of people living with limb loss. So, we will continue to ensure you are heard and champion improvements.

Often you can voice your opinions directly too. We announce opportunities to participate in public consultations on our website and in social media, along with information about how you can take part. And if you have a burning issue you would like to raise with government you can also get in contact with your local Member of Parliament to let them know. Feel free to contact our Policy Manager Fiona, via fiona@limbs4life.org.au, if you need assistance or advice about responding to an inquiry or to understand the best way of contacting your local representative. We're always here to help.

Thank you to everyone who has responded to surveys and shared personal stories to make sure that our submissions always feature meaningful insights and feedback from members of our community.

Why not check some of our submissions on the Limbs 4 Life website via the research and submissions page.

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