

amplified

edition 2 | 2019



Geoff's Big Walk: Shining a Light on Amputees

Are you ready? Amp-ed Up! 2020

Bianca shares her reason to smile

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Welcome to our final edition of Amplified for 2019

In this edition we share just how our limb loss community celebrated National Amputee Awareness Week, hear from Bianca Bassett and her 'reasons to smile', and are introduced to Charlotte and her 'little arm'.

We also announce that our second **AMP-ED Up!** conference will be held in Melbourne in 2020, bust some NDIS myths, outline our involvement in the *Assistive Technology for All Alliance*, and summarise our recently released *Impact of Australian Domestic Airport Security Screening Process on Amputees Report*.

Inside you'll also find tips to prepare for extreme weather conditions, details about how you can become a Peer Support Volunteer, and ways of preparing for travel with children so that it's as smooth as possible for your family.

On behalf of Limbs 4 Life we extend you a happy and safe time over the holidays and look forward to engaging with you again in 2020.

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Bianca's story:

Supportive people, caring communities and reasons to smile



It was Mother's Day 2016, I should have been in bed with a cup of tea and vegemite toast. Instead I was dictating a final farewell to my three children, through an oxygen mask. I could barely speak, but my Dad did his best to write down what I must have known would have to be the most important words I would ever say. And what made it more difficult, was that my children had lost their own Dad in 2012 after a short battle with bowel cancer. What could I have said to them that would be enough to last their lifetimes?

My name is Bianca and I am married with five children, three mine and two his so we're a bit like the Brady Bunch. I was born in 1980 with a rare blood disorder called Pyruvate Kinase Deficiency, which has meant a life time of blood transfusions, tests and daily infusions. My bone marrow doesn't produce enough red blood cells so I am always anemic, requiring monthly blood transfusions. Unfortunately, one of the side effects of having regular blood transfusions is that I have excess iron build up in all my major organs. This can cause a multitude of issues such as cancer, heart and liver failure, and severe fatigue.

In April 2016 I began feeling unwell. I presented to my GP where she found I had a temperature and was concerned enough to have me admitted into our local hospital. Four days later I was being flown to an Intensive Care Unit (ICU) in Melbourne as my health had deteriorated rapidly. My lungs were failing to allow me to breathe on my own and after some time I was put into an induced coma, and that's when things got interesting.

All the tests the doctors put my then frail body through were coming back negative and the many drugs and antibiotics were not making any difference to my condition. A couple of days after I was placed into a coma the healthcare team noticed my toes beginning to take a concerning shade of purple. It was discovered my blood was thickening, causing it to clot. One very large clot had formed in my main artery and the vein in my left leg. The doctors attempted many procedures to remove and dissolve the clot, but to no avail. By now I was so sick, it was deemed too risky for me to have surgery. So, it was a very difficult waiting game.

During this time the doctors decided to give me a very expensive and rarely prescribed anti-fungal medication based on my unusual symptoms and medical history; one that's only used for a very rare fungal disease called Zygoismycosis which is an extremely difficult infection to treat and comes with a less than 10% chance of survival. I began to improve, enough to have my left leg amputated above the knee. So, the amputation took place and to the doctor's amazement I began to wake the following day.

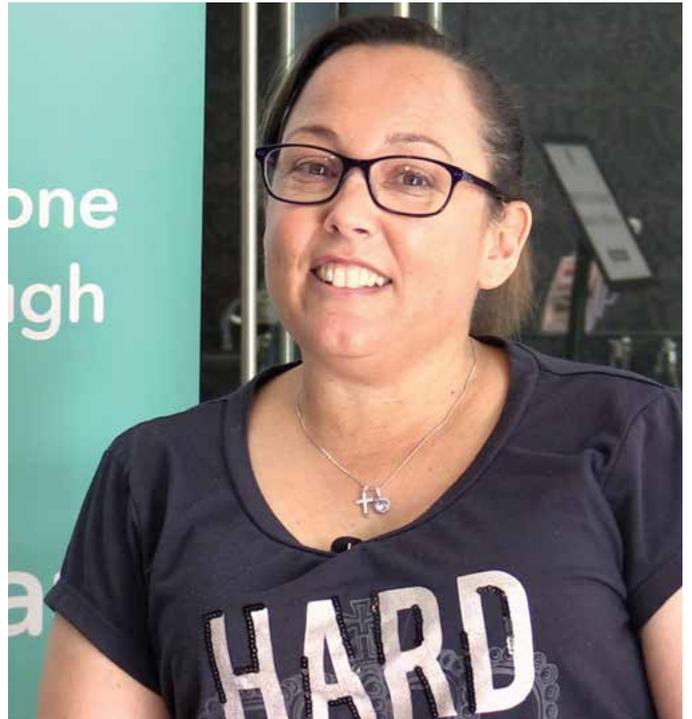
Although I knew my leg was gone, it took a few days to really register because I could still feel it hanging under the bed! A very weird sensation, known as phantom pain, that I've since found out many amputees experience. I remained in ICU for a couple more weeks until I was moved to another ward whilst waiting for transfer to a rehabilitation bed closer to where I lived. Prior to losing my leg I was always very busy. I was nicknamed the 'pocket rocket' because I only stand at 5 ft, and the faster I could move the better. I owned a busy café and had five children at home. Every part of my life was moving at high speed. The only way I was ever going to slow down was if I lost my leg, and who would have thought that would actually happen!

Life has changed a lot since losing my leg. Life is definitely a lot slower, and although I do miss some of the things that I was able to do before, I have learned to appreciate the things I have gained. I am so much closer to my children and have been able to be a lot more available for them. Where I can, I give more time to my community; the generous community who supported my family when I was sick and recovering. I'll forever be grateful for the immense support we all received. I don't sweat the small stuff anymore, and life's priorities have definitely changed.

People and the connections we make along the way, as well as how we can all do the smallest things to make a positive impact on others, is far more important to me now. I know that many amputees encounter people who want to help all the time, even though we don't need it or, sometimes, even want it. And as frustrating as it can sometimes be, I will always find a way for those who offer help to give that assistance to

me. I take the opportunity to create a moment in time that may help that person feel like they've made a difference to someone else's life. It may even help them feel like they have purpose, and with the rising rates of mental health problems in the world we could all do with feeling like we have purpose and are needed.

I don't know what the future will hold now, and that's ok. I just know that whatever it is I want to take it on with a smile and hope that others will smile along the way with me.





National Amputee Awareness Week Wrap Up!

October 4 - 11 saw the limb loss and wider Australian community celebrate National Amputee Awareness Week (NAAW). This important event provides a chance to raise awareness of amputees and people living with limb differences across the nation. This year saw Limbs 4 Life engage in three important campaigns, all of which helped in opening up conversations about amputation and limb loss, dispel some myths and break down barriers.

'Get Your Ribbon On' Campaign

Limbs 4 Life ran the third year of its 'Get Your Ribbon On' campaign. We shipped more than 8,500 ribbons to people with limb loss, hospitals, rehabilitation facilities, community organisations, prosthetic providers and Members of Parliament across Australia. We were thrilled to see so many people send photos of themselves, family members and colleagues wearing their ribbons with pride - with hundreds of those images uploaded to our social media channels! We are also incredibly appreciative to the great many members of our community who held special awareness raising and information events, morning teas and presentations in hospitals, workplaces and schools!

'Shine a Light' Campaign

We were thrilled to initiate the 'Shine a Light' campaign during NAAW. This campaign saw 23 significant buildings and landmarks across Australia lit up in green to 'put a spotlight' on amputation and limb loss. The lighting up of landmarks, and the sharing of information from participating government bodies, venues and business, enabled us to greatly extend our awareness raising message with everyday Australians. It was also an opportunity for people to visit 'green landmarks' in their own communities. We thank all of the organisations that made this campaign so successful and we look forward to even more community landmarks 'shine a light' in 2020.



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'Geoff's Big Walk'

The incredible Geoff Chandler undertook the journey of lifetime during NAAW, walking fifty kms a day in various towns and cities across Victoria. Geoff, who became an amputee in 2010 after a long battle managing the impact of

a serious accident in 1985, took it upon himself to raise awareness of amputees and Limbs 4 Life during his 'Big Walk'. While Geoff intended walking 400kms in eight different towns, his walk was briefly suspended when his vehicle was broken into. Not one to let this unfortunate incident deter him, Geoff was back walking within a couple of days and completed 300+ kms in six locations! We, and everyone who came and walked some laps with Geoff, were in awe of his determination and commitment to encourage others to get into fitness, learn about his personal journey of amputation and understand just why NAAW is such an important event on the limb loss community's calendar.

National Amputee Awareness Week builds community knowledge of limb loss, works to break down misconceptions about amputees, supports good quality of life outcomes, and educates the wider community of the prevalence of amputation in hope they best manage their healthcare. We're already looking forward to NAAW in 2020!

The Impact of Australian Domestic Airport Security Screening Process on Amputees Report

In August Limbs 4 Life sought feedback from amputees and parents of children with limb differences regarding their experiences passing through security checks in domestic airports. 110 people responded to this survey which then informed our *Impact of Australian Domestic Airport Security Screening Process on Amputees Report*.

While all travellers are required to take part in mandatory airport security checks, amputees who rely on assistive technology (e.g. prosthetics/orthotics and wheelchairs) for mobility and independence are usually required to take part in additional airport screening checks. This report draws upon the results of a survey responded to by 110 amputees and parents of children with limb differences, who shared insights into positive and negative airport security screening experiences encountered when passing through Australian domestic airports in the past 12 months.

It is alarming that almost eight in ten respondents expressed a high level of concern about

being parted from personal items during mandatory body checks, and that seven in ten had encountered a negative security screening experience in a domestic airport. It is particularly concerning that some respondents described incidents where their physical and mental health and wellbeing was put at risk during security screening; actions which may have even contravened disability and human rights and/or national security screening guidelines.

This report offers a range of recommendations which Limbs 4 Life intends using to influence policy and practice change at government, institutional and company levels. It will also be used to inform the development of resources to empower and upskill the limb loss community about their security screening rights and responsibilities.

If you would like to read the full report it can be downloaded from the 'Research and Submissions' section in 'About Us' area of our website.

2020

AMP-ED Up!

EDUCATE • EMPOWER • ENCOURAGE

NATIONAL AMPUTEE CONFERENCE

14-15 AUGUST 2020 MELBOURNE

THE HYATT PLACE, AUSTRALIAN EVENTS CENTRE, ESSENDON FIELDS

"I loved the 'Bling your Limb' competition! It was fun dressing up my prosthesis and checking out what everyone else had done to theirs."

"It was a very well organised conference. The trade show was awesome and I learned a lot by talking to all of the suppliers. I now know about some new options for me which I wasn't aware of before."

"This was an awesome event. Meeting other amputees and learning what is actually possible was fantastic! Bring on AMP-ED Up 2020."

"I now have contacts in relation to my amputation and prosthetics so I can make an informed decision on who and where to go. Terrific chance to learn more about new options which might suit me!"

Join us in Melbourne for AMP-ED Up! 2020

Following the great success of our first **AMP-ED Up!** conference early this year we realised that there was a genuine desire from our community to connect, learn and engage in future conference events. So, we are pleased to announce that our second conference will be held from 14 -15 August 2020 in Melbourne.

This two-day conference will bring together amputees, family members, prosthetic manufacturing companies, assistive technology suppliers, support services, disability employment services and a variety of speakers together. Delegates will have an opportunity to hear from a wide range of speakers, learn about the latest in prosthetic technology, interact with prosthetic and mobility aids suppliers, take part in workshops, listen to disability advocates, learn about support for those aged over 65 years, meet other amputees, plus much more!

We want delegates to leave with greater knowledge about prosthetic options, feel empowered to make informed choices and decisions, and encouraged to live independent and fulfilled lives.



Location

AMP-ED Up! is being held at The Hyatt Place, Australian Events Centre, Essendon Fields in Melbourne. It's only 15 minutes from the airport and there is a free shuttle bus for those staying at the conference venue.

Registration

Early bird registrations are open now. You can book via our website or alternatively we can send you a manual booking form. Don't miss out on this amazing event!

Funding

Remember if you are an NDIS participant you can include the cost of registration for you and a carer as part of your NDIS Plan (core support). If you need assistance speak to your support coordinator, Local Area Coordinator or Planner to find out how.

Funding support

You may recall that we received small government funding to assist individuals on low incomes and/or from rural and regional locations to attend the **AMP-ED Up!** Conference this year. We have applied again but won't know of success until early next year. In the meantime we recommend registering now, and if we are successful we

will speak to eligible attendees about how we can assist in subsidising your costs.

More information

If you have any questions about this exciting event call us on **1300 78 22 31**



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Myth busting the National Disability Insurance Scheme



Limbs 4 Life spends a considerable amount of time assisting amputees and parents of children with limb difference to transition into and navigate NDIS pathways. We also play a role in assisting NDIS Local Area Coordinators, Support Coordinators, Planners and providers to understand limb loss and the needs of our community. Increasingly we are engaging in individual and systemic advocacy, as well as ensuring that people living with limb loss are represented during NDIA and government inquiries.

We recently reviewed some of the most common questions we receive and provide

answers to these below. But remember, if we haven't provided an answer to a burning question you have don't hesitate to get in touch. And don't forget we have considerable information, resources and guides in the 'funding' section of the Limbs 4 Life website.

What does core support mean?

Core support enables a participant to complete daily activities and split across four categories. This includes:

- Assistance with daily living, such as showering, shopping or home cleaning
- Transport, such as specialised transport to access the community, employment or studies
- Consumables, such as prosthetic liners, gels or lubricants
- Social and community participation, such

as tuition, classes and learning programs – including the Limbs 4 Life **AMP-ED Up!** Conference in August 2020.

What does capital support mean?

Capital support covers funding across four categories:

- Assistive technology, such as prosthetics, wheelchairs and mobility aids (including assessment, delivery and maintenance costs)
- Home modifications, such as installation of handrails, anti-skid resistant flooring or ramps
- Vehicle modifications, such as installation of spinner knobs or left foot accelerators
- Specialised Disability Accommodation, such as funding to assist in the cost of specialised accommodation for people with extreme functional impairment or very high support needs

What does capacity building support mean?



Capacity building support enables a participant to build independence and skills, with nine support categories. The goals in your NDIS Plan will help to determine which supports you need.

- Coordination of supports, such as paying for a Support Coordinator (remember you can only request Support Coordination for your first two plans after that, you are expected to understand how to coordinate your own supports)
- Improved living arrangements, such as assistance to help you find a suitable rental property

- Increased social and community participation, such as to community or group activities
- Finding and keeping a job, such as assistance to prepare for job interviews or school-to-work transitions
- Improved relationships, such as social skills development or behavioural support planning
- Improved health and wellbeing, such as use of a dietician to assist in developing a healthy eating plan or an exercise physiologist to increase physical activity
- Improved daily living, such as assessments and sessions with a physiotherapist, occupational therapist or speech therapist
- Improved life choices, such as NDIS Plan management support or training to self-manage your Plan
- Improved learning, such as assistance to access and retain study or training.

Can I choose who provides me with NDIS funded support?

Yes, you have the right to choose who provides your supports! The NDIS was established to give participants 'choice and control', so if you experience difficulties with service providers you have the legal right to make a complaint and if the matter cannot be resolved you can select a new service provider. You are encouraged to create a service agreement with your providers, so that you, and they, know what is included.

Do I have to share my NDIS Plan with a provider?

No, your NDIS Plan is your plan and you are not required to share it with others if you don't want to.

What can I do if my NDIS Planner or Local Area Coordinator (LAC) doesn't understand my needs as an amputee?

You may find that your Planner or LAC has not worked with an amputee before and doesn't understand what a person with limb loss needs to achieve their goals. So, it's important to record

what your needs are and the 'reasonable and necessary' supports you are requesting from the NDIS. We recommend that you review the NDIS documents available on the Limbs 4 Life website as these can assist you to consider all Assistive Technology (aids and equipment) and supports you might need. These documents are also useful for NDIS staff and providers – so let them know there's lots of information on our website or to give us a call if they need support learning more about limb loss.

What are 'reasonable and necessary' supports?

The NDIS will only fund supports they deem are 'reasonable and necessary', which means they only pay for things that will help you achieve your goals and not the things that you could reasonably be able to access from others or for less money. The NDIS uses a set of criteria to determine this such as:

- that the supports are helpful given your needs and circumstances
- represent value for money
- what is reasonable to expect of family, carers and/or other informal supports.

To demonstrate that supports are reasonable and necessary, your NDIS Planner may seek evidence (proof) that assistive technology (e.g. prosthetic device), home or vehicle modifications or therapy will assist you to achieve your goals. Your NDIS Planner may also request a second opinion for level 4 assistive technology or other supports (such as home modifications). Prosthetics all come under the level 4 category.

Should I include prosthetic or wheelchair maintenance costs in my NDIS Plan?

Yes you should! Your prosthesis may need a repair and/or an annual maintenance check during the course of your NDIS Plan. If a repair is not required it doesn't matter, however you should have funds available should the need arise. Similarly your wheelchair might require a maintenance check over the course of a 12 month period, so include this in your NDIS Plan. Maintaining your prosthesis and wheelchair on

a regular basis helps to ensure it's in working order and that you are safe.

Can I choose where my NDIS meeting will take place?

Yes you can! You are in charge of when and where your NDIS Planning meeting takes place. Meetings can take place in a range of areas that are reasonable and suitable for you. Meetings may take place at an NDIA office, Local Area Coordinator office, your home, a community setting or anywhere else that best suits you and your situation. You may even prefer to have a meeting over the phone, and that's fine too.

Can I take someone to my NDIS Planning meeting?

Yes you can! You can take as many people as you need, as they might be able to assist you in describing your disability and support needs, provide emotional support or take notes so you can record what was said during the meeting.

Will the NDIS support me if I don't consider myself to be disabled?

We understand that you may not identify as being disabled or having a disability, and that's your choice. However, in order to access the NDIS acknowledging your disability is the only way you will be able to access NDIS-funded supports.

Can I ask for funding to trial a prosthetic device?

Yes you can! Whether it's your first or subsequent NDIS Plans you can request that your plan includes funding to trial a new prosthetic device, such as a foot, knee or arm. Remember, not all NDIA staff will understand how important it is to try different products before deciding the one that suits you best – so let them know you would like funding to trial products. In a way, it's no different to trialling different cars before deciding on the one you want to purchase. Speak to your prosthetist and ask them to include a trial in their quote.

What can I do if I'm unhappy with my NDIS Plan?

If you are unhappy with your NDIS Plan, such as the type or amount of support, you can request a review. The NDIA will look at your request and decide whether they will change it or not. There are several types of reviews (although some review processes may change in 2020):

- 1. Internal Review.** This review must be made within three months of receiving your NDIS Plan. The review is conducted by an NDIA staff member not involved in the original decision making. They look at the original facts and any new information, including policy and legal matters, to determine if the original decision was accurate. You will be notified in writing whether the NDIA will change your NDIS Plan or not. The Internal Review Application Form can be downloaded from the NDIS website and includes prompts for how to prepare it.
- 2. Light Touch Review.** If you need an administrative change, such as changing from agency managed to plan managed, you can apply for a Light Touch Review. Whether a review qualifies for this type of review will be determined by the NDIA. It can usually be completed over the phone and approval is generally made within a few weeks. To request this type of review or check whether you will qualify contact your LAC or call the NDIS on 1800 800 110.
- 3. External Merits Review.** If you are not happy with the outcome of the Internal Review decision, you can ask for an External Merits Review. This type of review must be requested within 28 days of receiving an Internal review decision from the NDIA. A request for an External Merits Review is made to the Administrative Appeals Tribunal (AAT). The AAT is separate to the NDIA and makes independent reviews of government decisions. To find out more or request this type of review visit www.aat.gov.au or call 1800 228 333.
- 4. Plan Review.** This is a review of your whole NDIS Plan and you can request this at any time if you think that your current one is not meeting your needs. The NDIA must advise whether your Plan Review will be granted

within 14 days. If the NDIA decide not to review your NDIS Plan when requested this becomes a reviewable decision, and the Internal Review happens automatically. If you don't hear anything within 14 days contact your LAC or the NDIS on 1800 800 110 to find out the status of your request and any next steps. When requesting a Plan Review call or email mark it as 'Request for an Urgent Plan Review'.

What if my situation changes?

If your circumstances change it is your responsibility to notify the NDIA as soon as possible. You can do this by contacting the NDIA on 1800 800 110, using the Participant Portal or submitting the Change of Circumstances form (available on the NDIS website). A change in circumstances may result in your NDIS Plan being reviewed, but it will not automatically trigger a Plan Review. You can request a review by calling the NDIA or using the Plan Review form. Change in circumstances include:

- changes to disability support needs
- informal care arrangement changes
- you apply for, receive or are entitled to compensation for injury
- you plan on or have moved house
- you plan on or have moved overseas
- you plan on or have moved into aged care residential accommodation.

Upcoming Changes to the NDIS

On the 14th of November the Hon. Stuart Roberts, Minister for the NDIS, announced some NDIS changes which will take effect in the coming year. Key changes include:

- Greater flexibility of funding. From July 2020 people will be able to use their funding more flexibly - including moving between core and capacity building.
- Help with assessments. Next year the NDIA will begin rolling out independent assessments for people applying for access to the NDIS. These assessments will be paid for by the NDIA. This is important because

up until now people had to pay for their own assessments – or wait for really long times on public waiting lists.

- Draft plans. From April 2020 the NDIA will roll out what they are calling joint planning involving a Local Area Coordinator, a planner and a participant. At that meeting people will be able to see a draft of their plan before it is approved.
- Longer Plans. Participants are now able to request plan durations of up to three years. For participants with support needs that are unlikely to change, a long plan duration means you don't have to go through frequent plan review processes.
- Reviews. As part of the Participant Service Guarantee to be introduced in 2020, participants will be able to make small changes to their plan without triggering a full-blown review.

Limbs 4 Life will keep you up-to-date with changes, but in the meantime if you would like to learn more visit www.ndis.gov.au (news and events).

Tip

Ensure you have a good working relationship with your prosthetist! Get to know each other and learn about what they can do to assist you to achieve mobility and functionality goals.

Tip

Check out the 'funding' section of the Limbs 4 Life website where lots of NDIS information and resources are available.

Tip

Ask your provider to give you a copy of your quote for prosthetics. You should have access to this information.



NDIS Update

Ian Robertson, Manager, APC Prosthetics

Much has changed since the NDIS commenced their three-year pilot program on 1st July 2013 in five areas across Australia. APC was fortunate to have been involved in the Hunter region NDIS pilot program and manage approximately half of the NDIS amputee clients who went through the trial program in the three-year period.

Throughout the trial, and following the 1st of July 2016 roll-out, we have seen significant change and have been active in working with our NDIS partners to shape the processes for amputees. The NDIS systems are strengthening and becoming more consistent as time moves on.

The NDIS is a CLIENT FOCUSED and CLIENT DRIVEN program. The NDIS is insisting on clients advocating for themselves, and not relying upon service providers to do this for them as they have in the past. The NDIS is empowering amputees to take care of themselves and take control of their prosthetic care.

One constant with the NDIS system is the input needed by the participant to create their plan. Participants have the power to expedite their plan approvals and outcomes. The participant driving their own care is the backbone of the NDIS and, as participants, the importance of

follow up calls and emails to your NDIS Planner and Local Area Coordinators cannot be underestimated.

The focus in the planning meeting should be on the inability to perform tasks and other hurdles experienced on a day-to-day basis by the amputee. The solutions to the listed limitations can then be addressed by your prosthetist and as achievable goals with the provision of the correct Assistive Technology (AT). This is a total change of thinking needed from the amputee population, as historically the mindset has always been on what the amputee can do, not what they cannot do. The key point to be made here is that your prosthetist will find a solution to those listed difficulties through the provision of the appropriate technology.

As a prosthetic service provider, one of our constant hurdles is the approval of the treatment plan, and the subsequent allocation of funding for the treatment. If the correct NDIS procedures are followed by your planner, things simply work. The importance of working with your prosthetist is paramount to achieve a timely and positive outcome. Our client/NDIS interactions now run into the many hundreds and our knowledge and experience in the NDIS system has enabled us to guide our clients through the system in an efficient way. We have found that when things deviate from the normal NDIS process, long delays and client frustrations are the result. I strongly suggest you have discussions with your prosthetist prior to attending your planning meeting.

Some points to remember are:

- Talk to your prosthetist prior to your planning meeting
- Attend your planning meeting with a specific list of achievable goals
- A goal of “want to get on with life” is not helping your prosthetist find a solution to your limitation
- Remember that ongoing maintenance of a prosthesis is just as important as the prosthesis provision itself
- Funding must be allocated in the correct category for the system to work

- If your planner is unsure of anything, ask them to contact your prosthetist
- The participant is the driver so be proactive
- Your prosthetist will know the NDIS system involving prosthetics better than your planner so ask them for advice

The NDIS are asking all registered service providers to have a quality system in place, and the NDIS will audit all service providers in 2019 to ensure they comply with NDIS standard and requirements. APC are currently engaged in this audit process, which will demonstrate APC has the systems and processes in place to meet the needs of NDIS participants. These audits will continue to take place on an annual basis, and successfully completing the audit is a prerequisite in continuing to be able to provide services to our NDIS amputee clients.

This industry wide audit process will involve all NDIS service providers involved in prosthetics and orthotics and raise the professionalism of our industry. Our professional association AOPA is also heavily involved in assuring the service provision for the amputee participants is at the forefront of care. This governance and guidance based around the NDIS system will set the stage for the continued successful service provision for our clients.

As the landscape changes and we adapt and grow in our knowledge of the system, our clients can be assured that amputee care is in a far better place than it was prior to the start of the NDIS in 2013. We continue to make ourselves available to support our clients as they work their way through the new system.

Tip

Setting goals in your NDIS Plan is important – as goals will assist in identifying the supports you need to achieve these. Do not believe what you hear, you can set as many goals as you need, but NDIS may not fund supports for all goals. Just remember all supports you request need to ‘reasonable and necessary’.

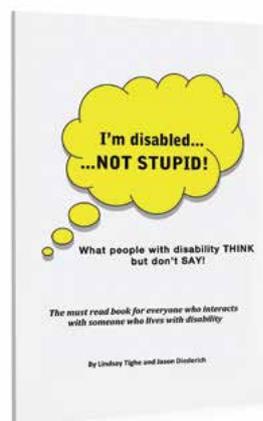
New book and giveaway!

'I'm Disabled ... NOT STUPID!'

by Lindsay Tighe and Jason Diederich

This easy to read book is written for everyone who interacts with people living with disability and aims to help them become more aware of their unconscious communication style, which can sometimes be unintentionally disrespectful and demeaning. Lindsay and Jason not only raise awareness about the consequences of this communication style, they also help us to see how society's expectations of people with disability can also have a detrimental impact upon them.

This resource shares some really simple and practical tips that can help us all to improve our way of communicating. These tips not only enable people with disability to be empowered, achieve their potential and maximise their opportunities for independence, they help us to improve our communication with everyone that we interact with.



Books can be ordered at www.betterquestions.com.au/products/im-disabled-not-stupid/216/1 and 20% of the proceeds are kindly being donated to Limbs 4 Life.

We have 3 copies of this fabulous book to give away!

Send us an email to info@limbs4life.org with the title of the book, your name and postal address. All names will be put into a draw, with the first three pulled out receiving a copy!

Winners will drawn Monday 3 February, 2020.

Assistive Technology for All Alliance

In late 2018 Limbs 4 Life was invited to join the *Assistive Technology for All Alliance* initiated by the Council on the Ageing (COTA). The purpose of this Alliance is to work towards ensuring that there is an equitable approach to the assessment, provision of information about, and supply of assistive technology (AT) for people ineligible for the NDIS (e.g. those aged over 65 years). The Alliance believes that these issues would be best resolved through establishment of a nationally consistent AT program to support people in need, including people living with limb loss and in need of prosthetics, wheelchairs and other mobility aids. The Alliance will soon start a campaign lobbying the Federal Government and is sending a Submission to the Royal Commission into Aged Care Quality and Safety.

The *Assistive Technology for All Alliance* is made up of like-minded organisations wanting to ensure that all Australians get timely access to AT to live safe and engaged lives. Alliance members include: COTA; People with Disability Australia; MS Australia; Vision Australia; Motor Neurone Disease of Victoria; Blind Citizens Australia; Polio Australia; Parkinson's Victoria; Australian Rehabilitation and Assistive Technology Association; and, Australian Federation of Disability Organisations.

The purpose of the Alliance is to listen to the voices of those affected by limited access to AT, raise awareness of the importance of AT for independent living, and lobby Governments for better supports. So, watch this space as we will be seeking input from our limb loss community to assist in campaign activity!



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Videos from Our Community

This year we compiled a series of videos featuring amputees in our community. In these videos our members discuss everyday issues and challenges, and their hard-earned tips and solutions. We also interviewed stakeholders from the prosthetic, healthcare, community sectors sharing engaging information and advice.

But wait there's more...stories from a range of our Peer Support Volunteers highlight the benefit of peer-to-peer interactions and the transformative rewards of being a member of our growing volunteer team!

Videos cover:



- Benefits of peer support
- Benefit of volunteering
- Financial counselling
- Disability employment
- Being a carer
- Physical health
- Trust and acceptance
- Relationships
- Keeping positive
- Getting information

Why not check out these, and past, videos on our Limbs 4 Life website or YouTube channel!



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Preparing for Weather Events



With the summer season fast approaching it is important to prepare for any potential catastrophic weather events, such as storms, bushfires or cyclones. Keeping informed, evacuation planning, prosthetic and mobility aids planning, and preparing an emergency kit is vital.

To assist you we have provided some tips which we hope will assist you to get ready should you face an unexpected weather event.

Keep informed:

- **Information services.** The ABC radio station and emergency authorities are a great source of emergency details in your local area.
- **Emergency Apps.** Many emergency services now have free apps for smartphones or tablets which alert you to weather warnings in your area. Consider adding the relevant app to you phone so you can remain up-to-date with local information.

Evacuation planning:

- **Evacuation plan.** Contact your local emergency agency, such as country fire authority and/or state emergency service, for help in evacuation planning. Many have accessible planning tips and resources

on their websites, which can assist you to create a plan. Planning for weather events is essential for everyone, but particularly important if living with limb loss. If you don't have access to the internet or a computer ask them to send you some information. If you use a wheelchair and fire is close to your property, can you leave safely via a ramp? If not, it might be time to have your ramps inspected to ensure that you can leave your house safely.

- **Temporary relocation.** Start planning for temporary relocation with members of your support network, as well as the location of your nearest safety shelter, so you know exactly where to go if you need to leave your home.
- **Practice.** If a dangerous storm is predicted or you live in a high-risk bushfire area and the day is rated as severe, extreme or code red then your safest option is to leave early. If you drive, practice packing your car so you know how long it takes to leave your home. If you need assistance to leave, determine who will assist you.
- **Communication.** If you leave your home contact members of your support network to let them know you are safe and away from danger. If you have time leave a note on your front door indicating that you have left and where you have gone.

Prosthetic and mobility aids planning:

- **Prosthetic materials.** If leaving your home be sure to pack extra liners, socks, gels and any other supplies you need to correctly use your prosthesis.
- **Prosthetic protection.** If your prosthesis requires charging or is not waterproof, make sure you have an alternative mobility aid in case it's damaged or not working. If your prosthesis requires charging be sure to bring your charger if leaving your home.

- **Mobility aids.** If you rely on other assistive technology such as a wheelchair, be sure to pack these if leaving the house or make them easily accessible if remaining in the home.
- **Instructions.** Practice explaining in a clear and concise way what your medical or health needs are, in case you need to provide instructions to a first responder (such as police or ambulance).
- **Toiletries.** Have a good supply of essential toiletries on hand, as these will assist you to feel fresh even if you are unable to wash.
- **Chargers.** Charge your phone and computer in advance of an emergency in case you lose power. But be sure to have chargers, or a charged battery pack, ready to use if leaving your home.
- **First aid kit.** It's a good idea to have a first aid kit available for use in your home and car, so consider buying these and place them in easy to access locations.

Emergency kit:

- **Radio.** Be sure to have a radio, with new batteries, on hand to keep up to date with information about the weather event.
- **Torch.** Be sure to have a powerful torch, with new batteries, in an accessible location.
- **Water.** Keep some airtight water available in case you lose access to safe drinking water. And remember to never drink tap water after an emergency and/or before authorities advise it is safe to do so.
- **Food.** Have at least three days of non-perishable food, suitable for all members of your household and which meet any dietary requirements, in case you have to leave your home. If staying at home have food with a long shelf life in the house.
- **Protective clothing.** In the event of a bushfire ensure you have protective clothing for all members of the family - long-sleeved, made from natural materials (such as cotton or wool) and sturdy footwear.
- **Protective blanket.** Place woollen blankets in your car for extra protection in case you get caught out while evacuating from a bushfire.
- **Clothing.** Pack essential day and night clothing for all members of the family.
- **Medication.** Ensure you have 14 day supply of medications, a list of these (including dosage), prescriptions and doctor contact details.
- **Important documents.** Place copies of important documents (such as birth certificate, licences, insurance papers, photos) in a safe fire/water proof container or scan these onto a memory stick. Alternatively you may wish to have copies made and leave them with a friend for safe keeping.
- **Pets.** Ensure you have enough water and pet food on hand, ID tag, veterinarian contact details, and any medications your pet takes. If you need to move your pet be sure to have equipment, such as carriers and leads, easily accessible.
- **Support network list.** It's a good idea to create a list of emergency contact details and place this in an easy to access location (such as on your fridge). Names and phone numbers to include on this list - emergency services, utilities, council, insurance, personal contacts and local radio frequency.

Remember, in an emergency situation first responders may not be able to enter an affected area - making planning and preparation critical.

Many emergency authorities have detailed checklists you can use to prepare - why not check them out and consider following their tips and instructions!



Justin Godfrey
2018 Male Paratriathlete of the Year

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Become a Peer Support Volunteer

2019 marks the 14th year of our successful best practice Peer Support Program. With close to 180 volunteers located across Australia, Limbs 4 Life is keen to expand our passionate and generous volunteer team to meet increasing demand. So, if you are an amputee and would like to be trained to support others just commencing on their limb loss journey then why not consider becoming a trained Peer Support Volunteer?

What's involved?

Peer Support Volunteers are highly valued members of the Limbs 4 Life team, and people who have lived with and adapted to the challenges of limb loss over a number of years. Peer Support Volunteers need to be at least three years post their amputation and ready to support others. Our Peer Support Volunteers play a vital role in the lives of individuals who are facing or have just experienced amputation, and their families. Our volunteers provide emotional and practical support to help alleviate feelings of being alone, sad and fears associated with amputation. They can answer questions that only another amputee can respond to. Volunteers make visits to hospitals, rehabilitation facilities, prosthetic facilities and community settings and sometimes provide support over the phone.

How is training provided and volunteers protected?

All volunteers receive training, which is delivered in various locations across Australia throughout the year. The Peer Support Program is grounded by best practice policies and procedures to ensure that the volunteers and program recipients are always protected and supported.

Candidates must submit a formal application undergo a national police check, provide referees and take part in training.

Why volunteer?

Our Peer Support Volunteers benefit from being part of the program in ways such as:

- developing and learning new skills and knowledge
- giving back to their community
- feeling 'good' about donating their time to assist others just commencing on the limb loss journey.

How to apply?

If you think you have what it takes to become a Peer Support Volunteer please complete the online application form www.limbs4life.org.au/peer-support Or, contact us to have a hard-copy application form sent to you.

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Charlotte's Little Arm

Charlotte is an eager, enthusiastic and excited child. At seven years of age Charlotte is always keen to try new things, ready to find solutions and willing to explore her world. One wonders if this inbuilt enthusiasm for life played a part in Charlotte prematurely entering the world with her "little arm" at 29 weeks.

Narelle and Shaun learned their daughter would be born missing her left arm above the elbow at the 13-week pregnancy scan. "When Charlotte's limb difference was discovered doctors ordered an array of tests and scans which, thankfully, revealed that our daughter was unlikely to have any compromising health issues," Narelle shared. So, with relief, at 28 weeks Narelle looked forward to enjoying the pregnancy.

But Charlotte had other ideas. "I went into early labour at 28 and a half weeks and despite the medical team's efforts to prevent an early birth Charlotte was born a few days later," Narelle explained. Charlotte astounded her parents and the medical team by quickly breathing on

her own, adapting to breastfeeding and being discharged a mere eight weeks after birth. "We were so grateful that Charlotte was healthy that the fact she was born missing part of her arm was a secondary consideration - not just for us but also for Charlotte's siblings as well," Narelle recalled.

Early on, Shaun and Narelle decided that they were not going to treat Charlotte any differently to her other siblings. "We wanted Charlotte to be her own person first, and not let her little arm be her defining feature, either within or outside of the family," Narelle noted. "We also decided that we would support Charlotte to learn how to do things in her own way, and only step in when we identify she needs assistance or when she asks for help," Narelle explained.

This year Charlotte has learned to ride her bike without training wheels and can confidently use her scooter; skills that some children of the same age are yet to master. "Charlotte amazes us at her willingness to try new things and work towards achieving goals, often without asking

us for help," Narelle said. "Just recently Charlotte wanted to play with a children's bow and arrow set and, although we thought that would be impossible for her, to our astonishment she found a way of holding the bow and was shooting arrows in no time," Narelle explained.

But Narelle and Shaun acknowledge that in order to prevent any potential physical or social impacts associated with Charlotte's limb difference, early intervention strategies and drawing upon professionals are important. "We now have an NDIS Plan for Charlotte and have psychology, occupational therapy, physiotherapy and assistive aids included and we can draw upon these if we think she needs external supports," Narelle explained. Similarly, Narelle and Shaun have worked closely with Charlotte's primary school to ensure that she has the right tools and technology to assist in learning and staying on par with her peers.

For the most part Charlotte is happy and confident in herself, refers to her left arm as "her little arm" and is happy to tell people "I was born like this" if ever asked why she has a limb difference. While Narelle does acknowledge that Charlotte doesn't always want to draw attention to her little arm at other times she confidently shows her difference off; with her choice of Halloween costume this year being just such an example.

After discussing Halloween costume ideas, Charlotte decided she wanted to dress up as a zombie. Wearing a dirtied tutu, grey makeup, fake blood on her little arm and carrying a bloodied fake severed arm Charlotte epitomised trick-or-treating fun! "Between the fantastic comments received at the Halloween party, and the likes and feedback from my friends and the Limbs 4 Life community Charlotte truly felt she was famous," Narelle shared. Without giving too much away, or needing to issue a spoiler alert warning, Charlotte has already decided that her 2020 Halloween costume will involve a Toy Story 4 character who develops a limb difference.

Charlotte has attended a number of Limbs 4 Life events in South Australia this year; opportunities which have enabled Charlotte to feel more confident in her body and learn how to talk about her little arm. "Being connected to Limbs



4 Life, Kylie, other children and families, and adult amputees has helped Charlotte to realise that she is not alone and not different," Narelle shared.

When asked to share learnings with other families just commencing on the limb difference journey Narelle's simply says "don't underestimate your child and think that they can't do something, as you will be amazed by the innovative and unique ways they will find a way".

Limbs 4 Life thanks Narelle, Shaun and Charlotte for sharing their story. We wish Charlotte all the best with the street dancing and singing lessons she is taking up in the new year, and we wait with bated breath to see her 2020 Halloween costume!



Travel and holidays with children

With the holiday season fast approaching, you may be thinking about ways of making your travel as smooth as possible for your child and the rest of your family. The fact that your child has a limb difference shouldn't stop your family from travelling, but it may require a little more planning and consideration beforehand. When travelling away from home with your child, or when your child is travelling alone, it is a good idea to be well prepared for the journey ahead. To assist you we have provided information about airplane travel, travel security checks, accommodation and other general travel tips.

Airplane Travel

Travelling on airplanes, particularly when prostheses are worn or additional mobility devices are used, can sometimes be stressful for travellers. All airplane companies are required to support the accessibility needs of travellers but it is important to make the company aware of any individual needs when booking. For information about the accessibility and disability policies of airlines visit the special needs sections of their websites or call the company directly.

Other airplane travel tips:

- As an airplane is a pressurised environment it may not be appropriate for your child to remove their prosthetic limb during the flight. If your child takes off their prosthesis during the flight you may find that the limb has swollen, making it difficult to get it back on. For this reason it is wise to leave a liner on, or use a 'shrinker' in place of the liner. Before travelling in the air it is a good idea to discuss this issue and seek advice from your doctor and/or prosthetist.
- Some airports can be very large and have long distances between where you check-in and where you board your plane. If your child has difficulty walking long distances you may want to request wheelchair assistance (either in the form of a motorized vehicle or travel chair) and/or baggage assistance to get to and from the gate lounge. This can be particularly useful if your family have to rush to catch a connecting flight.
- Sometimes an aerobridge (an enclosed tunnel allowing passengers to board or

disembark from a plane without going outside) to link the airport terminal gate to an airplane is not used. If one is not used, generally passengers will need to use stairs. If your child can't manage stairs, airplane staff and ground crew can assist your child to access their airplane in a wheelchair via use of an electric portable lift (cherry picker).

- If your child is unable to walk to their seat ask whether the airline company can provide you with an 'aisle chair' (a collapsible narrow wheelchair that can travel along the aisle). An aisle chair will allow your child to move easily between the chair and the seat and provide access to the toilet during the flight. Most toilets in airplanes have handrails for support.
- Comfort and accessibility is important, particularly during a long flight. If your child has a lower limb difference, you may want to book an aisle seat that is near the toilet or a seat with more leg room. If your child has an upper limb difference, you may find that a window or aisle seat on the same side as the limb difference will enable your child to collect food and beverages using their sound limb.

Travel Security Checks

If you are travelling by domestic or international airplanes you child and your family will go through security checks. However, if you are travelling by cruise ship or some international railways you may also be subject to security checks. Because of this, and that people with limb differences often face some additional checks, it is important to get to any terminal early.

Other security check information and tips:

- If your child wears a prosthesis, be prepared for an alarm to be set off when your child walks through a body scanner. It's a good idea to let staff know beforehand that your child is wearing a prosthesis. Security staff will then scan your child with a hand-held wand to locate any metal objects, such as their prosthesis. They may also ask if they

can give your child a 'pat down' (i.e. light touch over your child's clothing and body). A 'pat-down' should be done by someone of the same gender of your child and you can be there to watch and support your child while it is taking place.

- If your child has a lower-limb difference, they are not required to remove their shoes. Security staff may ask for the removal of shoes but this is not permitted, instead they can simply scan of your child's shoes using a hand-held wand.
- Mobility aids, such as sticks and crutches, can be taken on planes but they must also be security checked.
- Any member of your family may also be asked to participate in a drug and explosive trace scan. This is a simple procedure where the attendant will use a hand-held wand to lightly tap shoes, bags, assistive devices or any other personal belongings. It usually only takes a minute for this scan.

Any inspections or security screenings should be respectful and conducted within reason. Although security checks may feel intrusive, remember these security checks are in place for the safety of all travellers. Screening points also have chairs available for use during security screening checks.

Accommodation

While more and more hotels and motels in Australia, and around the world, are ensuring that their facilities are fully accessible you may find that some aren't. If your child requires a ramp, room at ground level, and/or an accessible bathroom it is a good idea to discuss their needs with the hotel when making a booking.

General Travel Tips

Regardless of the type of travel your child and your family are taking there are several things to consider before starting your journey. Some general travel tips:



- Ensuring that your child's prosthesis and liners are in good condition, including a pre-travel maintenance check
- Packing essential items in carry-on baggage in case luggage is lost
- Packing items such as stump socks, packing tape, skin dressings, moisturising creams, cleaning agents or spare liners
- Having a wheelchair maintenance check conducted before you go
- Packing two sets of any medications you may need and put one set in your carry-on luggage and one in your suitcase
- Carrying a letter from your doctor regarding any prescription medications you are travelling with, including the names and doses of each
- Carrying contact numbers for your child's doctor and prosthetist on hand in the event of an emergency or you are in need of advice
- Finding out the contact details of prosthetic facilities in the areas you are travelling to, in case unexpected repairs need to be made
- Registering details of any international travel with the free Australian Government 'Smart Traveller' site - <https://smartraveller.gov.au/>



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