# A Step Ahead

**SUMMER EDITION 2024** 



# **CENTRAL OFFICE**

Ben Mathews Playground Community Centre 47-55 Ellen Street, Logan Central Qld 4114 PO Box 31, Kingston Qld 4114

Monday to Thursday 9:00am to 4:30 pm Friday 9:00am to 2:30pm

T: 07 3290 4293 | W: www.amputeesqld.org.au E: admin@afsg.org.au or lynda@afsg.org.au



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We would like to thank InHouse Print & Design for the printing of our quarterly newsletter. Please contact them for all your printing requirements.

**Disclaimer:** Amputees Queensland Inc does not provide specific medical advice or endorse any specific treatment, technology, company or device. Consumers are advised to consult with their healthcare professionals.

# From the Office!

Welcome to the Summer Edition of A Step Ahead!!

We have been very busy in the office and have welcomed a new staff member Donna-Lee. Donna joined the team and is looking after our Intergenerational Program which is funded by Brisbane South PHN.



The Intergenerational Program is a new program, we join in with a

local early learning centre and take part in their program whilst educating the children on people with a disability and the ageing. If you would like more information on joining the program please contact donna-lee@afsg.org.au.

In November we held a Support Group meeting at Geebung RSL, Brother's Leagues Club, Ipswich as well as Hervey Bay. If you are interested in a group please contact the office. We will be holding regular meetings in the new year.

We also held Peer Support Training in Cairns in November and are pleased to have some new volunteers on board to provide Peer Support. We will be working towards a social group starting in February, please contact the office if you would like more information on the group.

All our events, information sessions and news is kept updated on our website, socials and e-news, keep a look out for the new social group meetings near you!

If you would like to share your amputation or limb difference journey you can contact me at the office or via email lynda@afsg.org.au. The sharing of your journey helps to raise awareness of amputation or limb loss, it help support individuals who have just lost a limb by seeing the accomplishments, resilience and strength that people have and how they find new ways to accomplish every day tasks.

As we prepare for the Christmas season several of our programs will take a break from mid December, these include the FREE adaptive exercise programs which will restart from 28 January. These sessions are fun and fully adaptive, they work on your balance and strength.

The office will close from lunchtime Friday, 20 December and will re-open on Monday, 6 January 2025. Throughout the closure period we will still be providing peer support as needed, the only days that we will not be operating will be the main days Christmas Day, Boxing Day and New Years Day.

Thank you to everybody who has attended an information session, exercise program or event this year, we have had a very busy year and are looking forward to 2025!

Lastly, thank you to all the volunteers, you make a difference every day to the lives of people living with amputation and we couldn't do what we do without you.

Wishing everybody a Merry Christmas and a safe new year!

Lyna

Lynda Tilley | State Coordinator

Amputees Queensland Inc. is partially funded by Queensland Health.

# **Amputations in Australia**

Limb amputation is one of the earliest forms of surgery, allowing a person to survive severe injuries and infections. Historically the main causes of amputation were trauma and wound infections.

However in first world countries trauma is no longer the main cause of amputations because:

- Emergency medicine has greatly improved and more limbs are saved because a person can be transported to hospital quickly.
- Some amputated limbs can now be reattached with microsurgery.
- The number of workplace accidents have dropped significantly due to Health and Safety laws.
- Surgical sterilisation techniques and antibiotics control most infections.

In a modernised country such as Australia the main causes of amputations are vascular disease and diabetes. Other causes of amputation are traumatic injuries, infections, tumours and congenital deformities.

Vascular Disease: Vascular disease occurs when the arteries in the legs become blocked. This condition can happen to anyone but is more severe in patients with diabetes. The narrowed arteries prevent the heart from pumping enough oxygenated blood to the feet, resulting in severe pain in the legs, foot ulcerations and ultimately gangrene of the toes/foot.

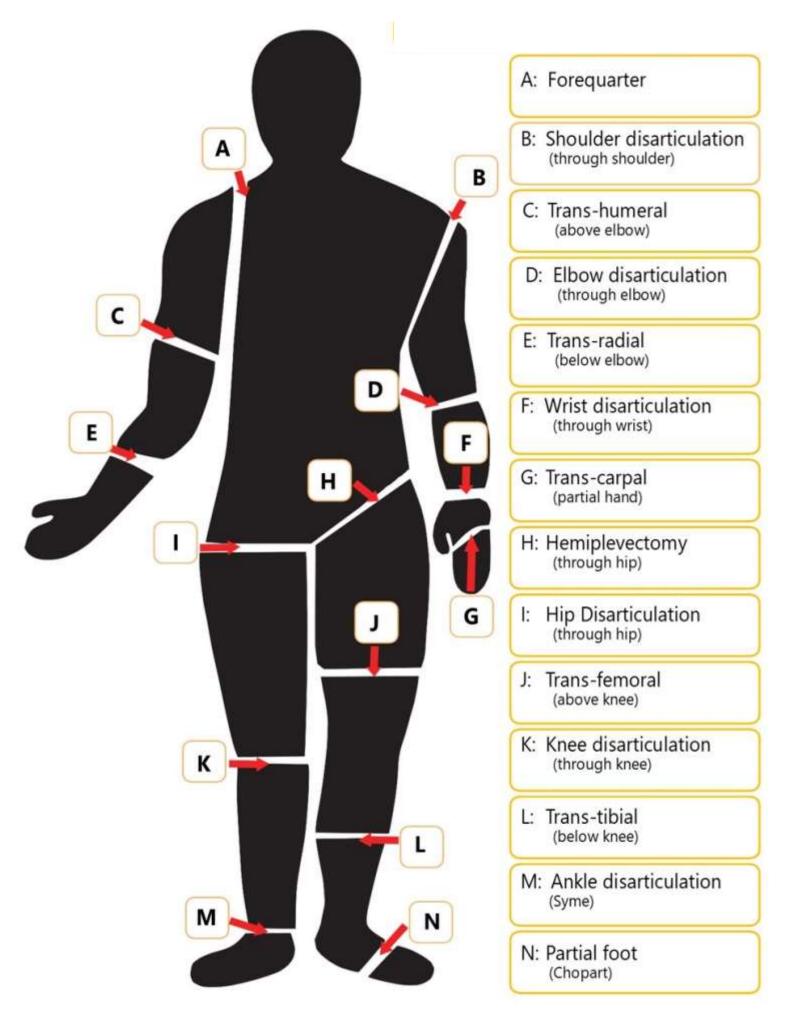
**Diabetes:** Diabetes is the cause of half of the amputations performed in Queensland. Diabetes does not just increase the severity of vascular disease it also reduces feeling in the feet and slows wound healing; resulting in foot ulcers. People with diabetes are more prone to skin infections and gangrene or sepsis may occur, resulting in amputation.



**Trauma:** Trauma resulting in amputation is most frequently related to motorcycle, motor vehicle and industrial accidents.

Other causes are home accidents and burns. Most upper limb amputations are caused by traumatic injury. Trauma is the most common cause of amputation for young adults.

# **Amputation Levels & Names**



# **Amputee Awareness Week!**

Thank you to everybody that joined in our Amputee Awareness Week activities in Queensland!

Amputee Awareness Week runs nationally from the 4th to the 11th of October each year. In Queensland we help raise awareness in the community of people living with limb loss or limb difference through a range of activities and awareness events.

This year we kicked off the week by joining our friends at Fishability Queensland to hold our annual fishing charter, this is always a great day and as usual everybody had a wonderful time and caught fish for dinner!

We held a display at the Princess Alexander Hospital for the week and we also raised money and awareness at our Bunnings Sausage Sizzle!





Pictured (L-R): Emma Dyson & Des Merry



Pictured (L-R): Sue Merry & Emma Dyson



Princess Alexander Hospital foyer Pictured: Lindsay Isenberg



**Bunnings Compton Road** Pictured (L-R): Dani Woods, Judi Corrigan, Owen Rice & Joel Farmer

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# Enjoying your Holidays!



Everybody loves a good holiday and it is getting to be that time of year when we are planning our interstate or overseas travel!

The excitement of a holiday gives us something to look forward to and getting away to relax or catch up with friends and family rejuvenates our soul. Whether you go for a night, weekend or a long trip the thought of leaving the comfort of your home can be daunting, but a little extra planning goes a long way towards having a fun and relaxing trip!

People with disability can face obstacles along the way, so we have looked at the challenges and the how-to of accessible travel and put together top tips for travelling with a disability or travelling with a person who has a disability.

#### Air travel

Airlines and airports are bound by the Disability Discrimination Act (DDA) to provide services for people with a disability.

Some airlines have a limit of only two wheelchairs on each domestic flight (or one if it is an electric wheelchair). So, it is a good idea to book flights in advance, if you use a wheelchair are travelling with a guide dog or need to bring medical equipment like a CPAP device or oxygen onboard with you. There is no cost for transport of mobility aids on an aircraft in Australia.

Remember, if you are travelling alone or need an extra hand then staff on a flight should be able to assist with:

- getting around the airport
- handling baggage
- getting on and off the plane
- getting to and from the plane toilet
- delivering safety briefings in a way that all passengers can understand.

With bright lights, loud announcements, bustling crowds, airports can be overwhelming for anyone - especially those with sensory sensitivities and people with autism, dementia, or anxiety.

If you are worried about your safety in bustling crowds a walking stick can help with stability and give you the extra assurance for your safety.

Thankfully, some airports are now introducing programs like Hidden Disabilities, which was first trialled in Australia at Brisbane Airport. The program provides extra support for travellers who may need additional assistance by collecting a sunflower lanyard to wear throughout Brisbane Airport.

Wearing the lanyard when you are at the airport is a way for you to indicate to staff that you may need a little extra help, guidance or time with the airport process. Brisbane Airport staff have been trained to recognise the sunflower lanyard and to provide you with any help you may need. For example: if you are feeling overwhelmed we can slow down the process, keep things quiet, offer assurance and be as accommodating as possible.







#### Use the special assistance lane at security screening

The lanyard does not give you fast track access through Security or Passport Control. When entering the security area please use the special assistance lane and you will be pointed to the shortest available lane. Where possible, you might be shown to the front of the queue – although we cannot guarantee this.

Ensure that you let security know that you wear a prosthetic, prosthetic users are not required to remove their shoes as in some cases this may be a falls or slips hazard for you. If you do need to remove your shoes ask for a seat over at the side so that you can do some comfortably and safely.

#### Help with luggage

The lanyard does not provide guaranteed help with your luggage. If this is something that you specifically require help with, please contact your airline to see what special assistance they are able to provide.

Ensure your luggage is light and easy to manage. Luggage comes in a range of sizes, shapes and colours....if you want to find your luggage easily then pick a bright colour or pattern...you won't lose it! Alternatively there are always luggage tags which will also help identify your luggage.



#### Don't forget your travel insurance

To get the right level of travel insurance, make sure you provide your insurer with information about your disability. You might want to shop around – some insurers cover more pre-existing medical conditions than others.

Before you buy your insurance, just make sure that you're comfortable with what's covered and what's not.

#### Getting ready for take-off

With accommodation, travel and insurance booked the hard work is done and it's time to start packing! As well as your favourite holiday read, remember to pack an emergency repair kit if you use a wheelchair or mobility device; spare batteries if your device uses them; and extra supplies such as donning aids (gel, spray or donning sleeve), lotions or creams as well as shower/wet covers if needed. A letter from your doctor explaining your disability and any medications you require is also a great idea. If COVID has taught us anything it is to expect the unexpected!

#### Hire cars or a driving holiday

There are cars available for hire with vehicle modifications and most bigger hire car companies include accessible vehicles in their fleets, and some, including Avis and Hertz, offer vehicle modifications including hand controls, swivel seats and transfer boards in some major cities.

# DATES FOR THE DIARY

# Happy holidays!!

Wishing everybody a Merry Christmas and a happy and safe New Year!

Our offices will be closed across the Christmas period from lunch time Friday, 20 December until Monday, 6 January 2025.

#### **JANUARY**

6th Office re-opens

#### **FEBURARY**

5th Simply Your Tech 19th Emergency Preparedness 26th Grocery Bingo

#### MARCH

5th Hearing Health 19th Financial Service Info 26th Grocery Bingo

# All information sessions and support group details will be updated on the website and in our socials!

All sessions will be at our offices at Ben Matthews Playground Community Centre, Logan Central unless otherwise marked.

\* Sunshine Coast Support Group Get Together's will be held at Maroochy River Golf Club, 374-514 David Low Way, Bli Bli at 10am. Please RSVP <u>sunshinecoast@afsg.org.au</u> or call 0475 052 980. \*\* River Cruz Café, 3 Quay Street, Bundaberg Central. RSVP Jan Baldock—0409 492 363



#### Hire cars or a driving holiday

There are also other transport organisations, some of which are listed below:

Disability Car Hire – www.disabilitycarhire.com.au Driving Mobility – www.drivingmobility.com.au Hire Mobility – www.hiremobility.com.au Total Ability – www.totalability.com.au Wheelie Campers – www.disabilitycarhire.com.au Wheelies - www.wheeliesvanrentals.com.au Wheels Away - www.wheelaway.com.au



#### Accommodation

Most major hotel booking sites have the option to filter for accessible accommodation, www.hotels.com is the stand-out, with a range of specific search criteria including facilities for people who are hearing impaired, who require braille signage, accessible parking, a roll-in shower and more.

It's a good idea to ask for photos when researching accommodation options. Accessibility standards vary from country to country – you can ask for a picture of the bathroom, for example, to make sure that it's suitable for you.

It is important to ask for photos or view the room via the website, one of our members who relies on the use of a wheelchair booked accommodation and asked about accessibility but when he arrived at the room there were four steps to enter! The room itself was wheelchair friendly but not the access. Not everybody is aware of your needs, make sure you double check.

Most importantly, enjoy your trip, stay safe and have fun!



Sources: <u>www.accessibleaustralia.com.au</u>

https://www.bne.com.au/passenger/passenger-information/special-assistance/hidden-disabilities www.casa.gov.au/operations-safety-and-travel/travel-and-passengers/passengers-disability-and-reduced-mobility

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# **6 Steps to Healthy Ageing**

Healthy ageing is being able to do the things we value for as long as possible, Keeping your brain healthy is just as important as keeping physically well. Small actions can contribute to the wellness of your brain and in doing so can contribute to overall wellbeing.

These are six core areas where you need to remain active in order to age well.

### Connect- keep in touch with others

Build positive relationships with those around you.

- Call an old friend
- Say hi to a stranger
- Chat to a neighbour
- Interact in online forum
- Attend an event in your community

#### Energise- eat and drink well

Energise your body, feel good, do more.

- Drink 8 glasses of water a day
- Try a new recipe
- Share a meal with a friend or cook for someone
- Keep a regular bedtime
- Follow the Australian Guide to Healthy Eating

### Move your body and stay active

Boost your fitness, energy levels and sleep well.

- Walk in the sun
- Do a fitness class
- Take the stairs instead of the lift
- Do some gardening
- Try to touch your toes every morning

### Be present and have a calm mind

Enjoy life live in the here and now.

- Really listen to someone
- Practice mindfulness
- Get out in nature
- Read a book
- Listen to music
- Take notice of what's around you









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# **6 Steps to Healthy Ageing**

### Learn- be a lifelong learner

Develop an endless curiosity about the world.

- Do crosswords or puzzles
- Work on a skill you have
- Remember names
- Use a new word daily
- Use your non-dominant hand for things like opening door and brushing teeth

### Think positive

Have a positive outlook on life - a glass half full approach.

- Do things you enjoy
- Write down your worries
- Look for the good in those around you
- Say thank you
- Do an act of kindness
- Set personal goals

There are adaptive exercise available, Ottobock have a specific App for lower limb amputees and limb difference.

#### Ottobock Fitness App

Developed by physical and occupational therapists with the goal of helping leg amputees achieve more mobility and to provide professional support in their everyday lives. The fitness app can be downloaded for free from the Apple store by searching "Fitness for amputees". Ottobock also have Tai Chi for amputees on their website. Visit Ottobock.com/en-au/waystokeepactive/taichi for more information.

You can also speak to your physiotherapist or exercise physiologist and have an individual clinical plan written specifically for your individual needs.

The goal is to find what works best for you.



half full approach.







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# **Phantom Pain**

The Who, What, and Why of the Phantom!

Several studies show that between 50 and 80 percent of people with limb loss report experiencing some form of phantom limb sensation at least once, and many people say they have severe phantom limb pain that recurs regularly.

Phantom limb pain is a common problem for amputees, and if you **experience it, don't hesitate to speak up** about it. Many people with limb loss are familiar with it, and your healthcare professionals need to know that you are experiencing it. Be assured, no one will think that you are crazy.



Additionally, learning about others' experiences with it can allow you to see your phantom limb pain as less weird or scary, and you might pick up ideas for treatments you haven't considered. Furthermore, your healthcare team must be informed of it to help you develop a systematic approach to address it.

Mary Ann Miknevich, MD, a physiatrist with the University of Pittsburgh Medical Centre who works with patients with limb loss and moderates local amputee support groups, says her patients have reported numerous types of phantom limb pain, including, but not limited to:

- + Burning
- + Cramping
- ✦ Crushing
- ✦ Electric shock
- ✤ Pricking
- ✦ Stabbing
- ✦ Shooting
- + Throbbing

Amputees also often experience other, non-painful feelings (although some can be irritating) in their missing limb, such as movement, pressure, or itching. Again, the incidence of these sensations ranges from rare to frequent. Miknevich notes that, among her patients, if phantom sensation does not present shortly after amputation, it usually **doesn't occur later.** 

cont. on page 21

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Why phantom limb pain occurs and exactly how it does so are still unclear, although Miknevich says recent studies point to a couple of new theories. One is that neuromassmall, painful bulbs that sometimes form on damaged nerve endings-may generate sporadic nerve activity that the brain interprets as coming from the missing limb.

"The more important theory," the doctor says, "is that it is believed that a reorganization occurs (after amputation) in the cortex of the brain so that nerves that once communicated with the amputated limb now make new connections to muscles or other fibres in the stump."

She adds that following peripheral nerve injury, such as occurs with amputation, the mechanism that inhibits pain signals in the spine may fail, allowing the nerves to go haywire, which could be a factor in phantom pain.

The upshot of these theories may be that phantom limb pain springs from more than one source, which could explain why healthcare professionals pursue so many different methods of treating it.

#### Striking Back at the Phantom

The list of potential medical treatments for phantom limb pain is lengthy, spanning noninvasive methods to deeply invasive ones. These include:

- + Antidepressants
- ✤ Anticonvulsants
- ✤ Brain stimulation
- ✤ Narcotics
- ✤ Nerve blocks
- ✤ NMDA (N-methyl-D-aspartate) receptor antagonists
- ✤ Painkiller injections
- Neurectomy (surgery to sever nerves)
- + Spinal cord stimulation
- ✤ Residual limb revision
- + TENS (transcutaneous electrical nerve stimulation) therapy
- Virtual reality therapy

Your physician can explain each of these treatments and outline their potential benefits, risks, pitfalls, and side effects. However, Miknevich points out two important caveats to consider before you search out treatments for phantom limb pain. First, you and your physician must determine that what you are experiencing is phantom limb pain, because psychological factors may be in play that mimic its presentation.



"One of the toughest things is to separate the emotional part of what is going on from the physical pain," Miknevich explains. "When you are under stress or tension, all types of pain seems to be worse. If you're already in pain, then your tolerance for anything is less; it's like being tortured on a continual basis."

Therefore, a discussion with your healthcare professional about all your symptoms and other potential contributors to your condition is imperative before seeking remedies for your pain.

Second, Miknevich cautions that patients for whom phantom limb pain has been nonexistent or minimal should be aware that, if it suddenly occurs or worsens, a physiological cause might be the culprit. Some of her patients have had abnormal pressure on their residual limbs, which presented as phantom limb pain, because of poorly fitting or misaligned prosthetic sockets. Others have had additional circulatory blockage causing ischemic pain, which increased the severity of their phantom limb pain.

"I recently had a patient who suddenly developed phantom limb pain, and he had developed a very large neuroma in his residual limb," she says. "It's important if you notice a change in your phantom pain to alert your physician and your limb maker."

A number of psychological and alternative therapies are options to medical interventions:

- Guided imagery therapy helps amputees focus on soothing mental images to alleviate their phantom limb pain, and other relaxation techniques, such as controlled breathing, offer similar approaches.
- Hypnosis may soothe some people's pain, and distraction therapy may take their mind off it.
- Biofeedback teaches patients to control bodily processes that are normally involuntary, which may help them suppress phantom limb sensations.
- Acupuncture, which stimulates pressure points on the body with needles, has been successfully used by some amputees for relief.
- Mirror-box therapy, which shows patients a mirror image of their sound limb so they can practice "controlling" their missing limb, has also benefited some.



There are still other avenues to explore before pursuing medical treatment, including lifestyle remedies. These methods do not require a medical professional's involvement. They include keeping phantom journal of pain а help This can occurrences. amputees identify triggers for the pain and avoid them in the future.



For some, simply rubbing, massaging, or applying a shrinker to the residual limb reduces the sensation. For others, a full-body massage helps. Cold packs, heating pads, exercise, diet, and lifestyle changes (such as quitting smoking or drinking) may also reduce the frequency or intensity of the pain. Some people use more unexpected measures:

Miknevich recalls a patient in one of her support groups who talked to his pain.

#### "He would say, 'Go away! You are not there!' and that works for him," she says.

### Beware the Phantom's Fellow Fiends

As noted in the earlier example conversation, some phantom limb pain sufferers try herbal supplements. Miknevich counsels that people with limb loss should consult with **their physicians before taking any dietary supplements to ensure that the products don't** interfere with or have adverse interactions with prescribed medications they are taking.

Clearly, there are almost as many ways to attempt solving phantom limb pain as there are people suffering from it. However, while herbal supplements may not be hazardous to your health (as long as you consult with your physician about their use), other dangers lurk on the fringes of acceptable medical treatments. "There are unscrupulous people out there who are looking to take advantage of people and make money on them," Miknevich says.

She warns about promises of miracle cures for phantom limb pain. Consider that if your agony makes you desperate for relief, that desperation can make you easy prey for con artists.

Ultimately, there exists no cookie-cutter cure for phantom limb pain. It may take a combination of treatments and strategies to achieve some measure of relief. So, the best course of action is to discuss methods of addressing your phantom limb pain with others who also grapple with the condition and to consult with your physician to devise a comprehensive approach to cope with it.

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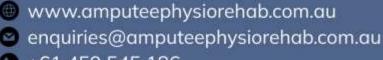
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# Foot Care

Come join us and Judi from Solemate Podiatry for more information on foot care and the importance to your health, ways to manage your feet at home and the benefits of early podiatry intervention.

Foot Care is a **Healthy Ageing Hub** event, supporting improved health outcomes for older people.

Date:	Wednesday, 4th December 2024			
Where:	Ben Matthews Playground Community Centre 47-55 Ellen Street, Logan Central			
Time:	10:00 am followed by morning tea.			
RSVP:	Please contact Lynda on 3290 4293 or email admin@afsg.org.au for catering purposes.			





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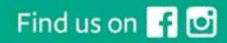
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