

A STEP AHEAD

WINTER EDITION



Amputees & Families
Support Group Qld Inc.

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

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FROM THE OFFICE



Welcome to the Winter Edition of A Step Ahead.

I hope that you are all safe and well in these uncertain times!

As restrictions are easing we still need to do our best to social distance, wash and sanitise our hands regularly and ultimately look after each other as best we can.

We have had to make changes to the way we operate our face to face peer support in late March due to restrictions brought into place by both the Queensland and Federal governments. All peer supports were being conducted via telephone, messenger or other alternate means during this time. In the last several weeks we have slowly started our face to face peer support visits by request only and in special circumstances where a visit is necessary.

All our peer support volunteers who are attending face to face peer support utilise personal protective equipment (PPE) such as face masks, gloves and hand sanitiser.

If you would like to know more about COVID-19, social distancing or need some support I have included further details on page 8 and 9. Restrictions are easing but we still need to ensure we follow social distancing and the recommendations from Queensland Health as well as the State and Federal governments.

As you may be aware from previous newsletters we have been having discussions with Queensland Artificial Limb Services (QALS) and Queensland Health in relation to the way that QALS has been operating. It has been very difficult to get through to QALS for approvals on repairs or consumables etc for months but recently QALS have added several staff who are working to catch up on the back log. If you have any issues or concerns please contact me. It is through the members that we are able to follow up on these issues and help ensure that people are getting the assistance that they need.

At this stage we have cancelled all of our functions, catch ups and workshops until further notice. We will continue to monitor and follow recommendations from the State government. We are looking forward to catching up again when possible.

Stay safe and well!

Lynda Foulis | State Coordinator

The Amputees and Families Support Group Qld Inc is partially funded by Queensland Health.



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What better time than now to practice random acts of kindness! Did you know that one of the best ways to be kind to yourself is to be kind to others?

Studies have shown that when you do a kind deed, it actually delivers a bigger **happiness boost to you than the person you're helping**. You can unlock this happiness boost with either an act of giving, like volunteering or helping a neighbour, or an act of gratitude, like sending a thank you note or just writing down something you are grateful for each day.

Why?

Research tells us that performing an act of kindness triggers the release of a chemical called oxytocin. This stimulates the area of your brain associated with social connection and trust, which makes you feel good.

Showing gratitude can improve your self-esteem, enhance empathy, reduce aggression and even help you sleep better. Acts of gratitude create strong positive emotions, and practising them regularly will also help build your mental resilience. Looking for ideas:

Try complimenting someone: Aim to give at least one genuine compliment every day. You'll feel good, and so will they.

Offer support: Reach out to a friend or relative who may need support or company. A little human kindness can go a long way.

Say thank you: Say "thank you" to someone for something they've done for you. It could be in the moment, or for a kind deed in the past.

Do something nice: Try performing a random act of kindness for someone and notice how that makes you feel.

Smile at a stranger: Try smiling at a stranger as you pass by - you never know how much it could brighten their day!

For more ideas visit: <https://mentalwellbeing.initiatives.qld.gov.au/>

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Coronavirus (COVID-19)

In these unprecedented times there are things that we can do to stop the spread and protect ourselves and those around us.



How can you help to stop the spread?

There are 5 ways we can all help stop the spread of viruses.

- **Stay home if you're sick. If you have COVID-19 symptoms get tested.**
- Clean your hands regularly with soap and water or alcohol-based hand sanitisers.
- Cover your nose and mouth with a tissue or bent elbow when coughing or sneezing.
- Avoid touching your face, nose and mouth. Avoid shaking hands.
- Keep 1.5 metres away from others as much as you can — think two big steps

There is a lot of information on COVID-19 and it may not all be reliable, the Queensland governments website <https://www.covid19.qld.gov.au/> has information relevant to Queenslanders, for information relevant to your state please visit <https://www.australia.gov.au/> and click on the link to your State or Territory.

If you require information in relation to carer wellbeing, mental health supports or assistance with medications and food deliveries please see the information below:

Health advice

For health advice, including an over-the-phone nurse assessment of your symptoms call 13 43 25 84 or contact your local GP.

Practical support

If you are self quarantined and need food or other essential supplies, please call the Community Recovery Hotline on 1800 173 349.

Seniors enquiry line is a Statewide information and referral service for Queensland seniors, families, friends, grandparents and carers. Call 1300 135 500.

Helplines

Short-term counselling psychological support services for carers and their families.

Carers Australia: 1800 242 636.

Carers Gateway: 1800 422 737 <https://www.carergateway.gov.au/>

Carers Qld: 1800 242 636 <https://carersqld.com.au/>

Little Dreamers: 1800 717 515 <https://www.littledreamers.org.au/>

Wellways: 1300 111 400 - <https://www.wellways.org/carers>



Telephone counselling services

For mental health support, call 1300 MH CALL (1300 64 22 55)

Beyondblue: Information and referral for depression and anxiety. Phone 1300 224 636

Kids Helpline: Telephone and online counselling for young people aged 5-25.

Phone 1800 551 800

Lifeline: Counselling services for anyone at anytime. Phone 13 11 14

Parentline: Support, counselling and education for parents. Phone 1300 301 300

SANE helpline: Information, advice and referral for mental illness. Phone 1800 187 263

The resources above are not an exhaustive list by any means but they may be of assistance if you or somebody you know needs help.

As at 21 May 2020 some restrictions have been lifted in Queensland allowing more travel, activities, and larger gatherings.

Permitted activities include:

- Up to five people can visit your home from separate households for day visits
- Up to 10 people can gather for non-contact outdoor activities
- You can travel up to 150km radius from your home (or 500km if you live in Outback Queensland) for recreational activities
- Up to 10 people (or up to 20 people for Outback Queensland local residents) can dine in at restaurants, cafes, pubs, registered and licensed clubs and RSL clubs provided the business is following a COVID SAFE checklist

For more information on what is allowed under Stage 1 of the roadmap to easing restrictions, visit www.covid19.qld.gov.au.

If you are feeling anxious about the reduction in restrictions or are concerned you do have the option of downloading the COVIDsafe app. The app helps health officials to quickly contact people who may have been exposed to COVID-19. The COVIDSafe app speeds up the current manual process of finding people who have been in close contact with someone with COVID-19. This means you'll be contacted more quickly if you are at risk and it may help alleviate anxiety.



Management of Residual Limb Pain

What is residual limb pain (RLP)? This is the pain that originates in the remaining part of your limb. It can be caused by a variety of conditions related to your surgery or it can be caused by conditions you had prior to your amputation. You and your healthcare team will want to work together carefully to understand the origin and cause of your pain in order to treat it successfully.



Possible causes of residual limb pain include:

- Underlying disease process such as skin problems and infection and nerve pain (neuropathy), especially if you have diabetes or circulatory problems
- Surgical trauma, including decreased blood supply to your limb or poor tissue coverage at the end of the bone
- Neuroma formation
- Entrapment of nerves in scar tissue.

Underlying Disease Processes

Key to managing symptoms of pain that have to do with a pre-existing condition like diabetes is to make sure that the condition is managed as well as possible.

For example, if you have diabetes, keep your blood sugar under good control. If you have **poor circulation, follow your physician's instructions for diet, exercise and medications.**

Managing pre-existing conditions after surgery is as important as ever.

Surgical Trauma

Poor tissue coverage can be caused by the bone at the end of your residual limb not being properly trimmed at the time of surgery, and this can cause pain when you wear your prosthesis. If padding and other methods are not successful, surgery may be required to revise your residual limb so as to decrease your pain and allow you to wear your prosthesis.

Neuromas

A neuroma is a collection, or bundle, of nerve endings that forms under the skin of your residual limb. Think of it like a tangle of hair. It can become very sensitive, especially if the tangle is pressing against your prosthesis.



Because neuromas are made up of nerve endings, possible treatments include medications that help with nerve pain, such as:

- Non-steroidal anti-inflammatory medications
- Specific antidepressants and anticonvulsants that have been found to be effective for nerve pain
- Steroid injections.

Non-medication options include:

- Ultrasound, which is essentially a machine that uses sound waves to generate heat within a body part; it can help increase blood flow so that inflammation and swelling can be decreased
- Massage, which also helps decrease inflammation and helps desensitize your residual limb to touch
- Vibration, which creates a mild shaking to contract muscles, to decrease inflammation and pain
- Percussion/finger tapping at the point of pain, which also helps desensitize your residual limb
- Acupuncture, manipulating thin, solid needles that have been inserted into specific acupuncture points in the skin
- **TENS (transcutaneous electrical nerve stimulation), which produces a mild “pins and needles” sensation, overriding some of the pain that your body is producing.**
- Modifying the prosthesis socket to prevent rubbing at the sensitive part of your limb may also be helpful.

Unfortunately, surgery to remove neuromas is not usually successful, because they often simply reform.

Heterotopic Bone

Occasionally, excess bone forms abnormally around the end of the amputated limb; this is **sometimes called a “bone spur.” The “extra” bone may cause pressure points that interfere** with the fit of your prosthesis; this occurs more frequently in children than adults. If the problem cannot be solved with changes to the prosthesis, surgery can remove the excess bone. For children, this is best done after the bone stops growing.

Entrapment of Nerves in Scar Tissue

As your incision begins to heal, your doctor will let you know when you can start massaging **your residual limb. This will help to prevent nerves from being “caught” in scar tissue.** 

You will also be taught how to wrap your limb using elastic wraps. This not only helps to prevent scarring but also helps with prosthesis fit.

Normal Postoperative Pain

After surgery, your postoperative pain will diminish over the first few weeks. After you are discharged from the hospital, you may still be taking pain pills, but should be able to decrease the number of pills fairly quickly.

Methods to decrease swelling will also help reduce your pain, including elastic wraps and residual limb socks, light massage and finger tapping, and cold packs.

Residual limb pain is different from this normal post-op pain. For example, it commonly occurs after your postoperative pain has ended. It is frequently described as sharp, aching, throbbing or burning in nature. Your entire healthcare team, including your doctors, therapists and prosthetist, will work with you to determine the cause of this pain and decide what treatments might be most effective.

Pain Management Principles

No matter the cause of residual limb pain, the following methods can help you manage your pain.

- Begin exercises as soon as your surgeon allows it. Standing, walking and muscle stretching not only improve your general health, but also interrupt pain signals.
- Desensitize your residual limb, following the instructions of your physical or occupational therapist; this includes both massaging and wrapping your residual limb.
- Work with your prosthetist to maintain proper prosthetic alignment and to choose prosthetic components that are appropriate to your needs.
- Keep a pain journal. Keeping track of your symptoms and sharing them with your healthcare team will help you find the right treatments for you.

Practice relaxation. We know that tension and stress increase pain. It is estimated that 50 percent of pain can be reduced by relaxation.

Article is sourced from <https://www.amputee-coalition.org/>

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Every magazine we will include information on concessions that are available for you to access further if they are required. <https://www.qld.gov.au/community/cost-of-living-support/concessions>.

Spectacle Supply

The Spectacle Supply Scheme (SSS) assists eligible Queensland residents by providing a comprehensive range of free basic spectacles. As from 1 January 2008 Queensland Health administers SSS through the Medical Aids Subsidy Scheme (MASS) replacing the previous application process. MASS aims to benefit clients by streamlining the application process for spectacles through SSS.

Who is eligible?

To be eligible for SSS you must:

Be a permanent resident in Queensland; and

Hold, in your own name, one of the following concession cards continuously for a minimum period of six months immediately before you apply:

- Pensioner Concession Card
- Health Care Card
- Queensland Seniors Card; and
- Have a clinical need for spectacles based on changes to your eyesight as determined by your optometrist or ophthalmologist.

You will be required to complete a Medical Aids Subsidy Scheme (MASS) Client Consent - Proxy Access to Centrelink Information declaration to enable SSS to confirm administrative eligibility.

How often can I have new spectacles?

You are eligible to apply for new spectacles through SSS every two (2) years.

Further Information

If you have questions concerning any aspect of SSS, please telephone 13 HEALTH (13 43 25 84) or contact the SSS team on (07) 3136 3636.





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Care of your prosthesis

A prosthetic limb is custom made for each person. A small amount of daily maintenance and care will extend the life and comfort of your prosthetic limb and reduce the chance of problems occurring. Your prosthetic limb is an important part of your life so look after it and it will serve you well.⁽¹⁾

Think of your prosthetic limb as a car and treat it accordingly. A responsible driver will keep their car maintained and serviced so that it does not break down. They will also follow the limitations of the vehicle to avoid an accident or damage. Finally, they will maintain the car according to the manual and if a problem arises the car is taken to a trained mechanic. Treat your prosthetic limb in the same way by having it serviced, performing routine maintenance and using it within its limitations.

Special tools, equipment, and skills are required for work on a prosthetic limb. If a problem occurs, you should contact your prosthetist immediately. Do not try to fix it yourself as you may ruin the prosthesis completely risking serious injury if the prosthetic limb or a component fails. If you adjust the components it may affect your gait and cause pain. You will also void the warranties on any components that you have damaged.⁽¹⁾

Do not use your prosthetic limb in a manner it was not designed for and do not abuse it, for example by trying to use it as a lever or a hammer. It will not last very long if it is treated in this manner.⁽¹⁾

Cleaning a prosthetic limb

A prosthetic limb that is clean will give fewer problems than one that is neglected. A socket that is not clean will accumulate sweat resulting in strong odour and increased risks of skin problems. Each day when you remove your prosthesis clean the socket, liner and socks. Wipe out the socket and liner with a cloth and warm soapy water. Use a soap that will not irritate your skin. Do not immerse the prosthesis in water, as this can cause damage to the components. A soft toothbrush can be used

to gently clean in difficult to reach areas. If you are not sure how to clean a certain part ask your prosthetist for instructions.⁽¹⁻³⁾

After wiping out, ensure you dry all parts thoroughly. If you perspire a lot, you may need to clean your prosthesis more than once a day. Some knee components cannot be inverted so if you have a knee unit do not place the prosthetic limb upside down to dry.⁽¹⁻³⁾

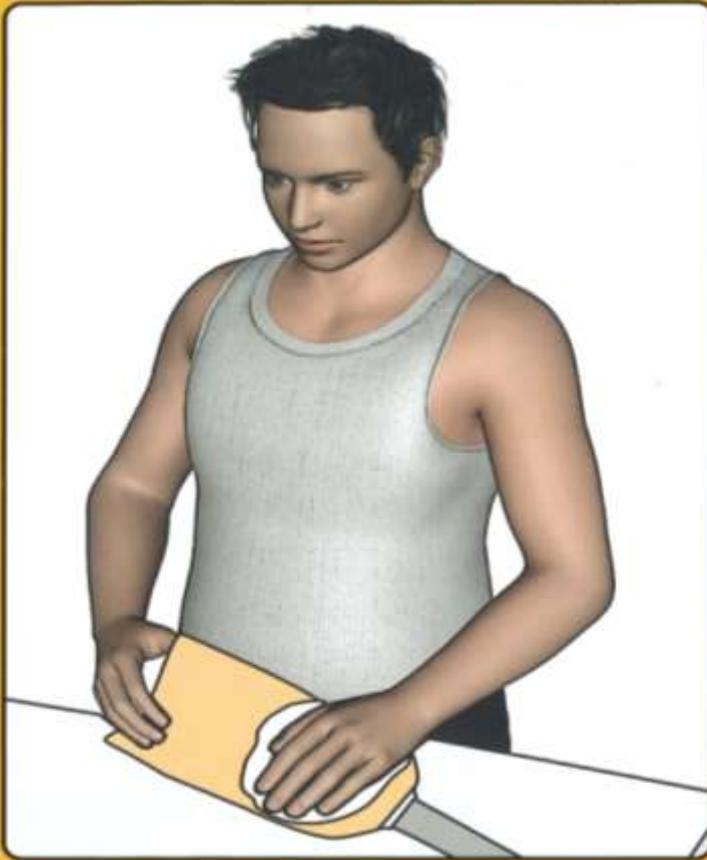
If your prosthesis has leather on it, avoid getting this wet and use a leather soap for cleaning. Use a leather conditioner to prevent the leather from splitting and wipe leather parts daily to avoid a build up of sweat. If your prosthesis has cosmetic stockings, these should be removed and washed to protect the foam cover.^(1,3)

Woollen socks, cotton socks, and prosthetic sheaths can all be hand washed in warm water with a gentle detergent or soap. Socks can be hung out to dry but it is best if strong sunlight is avoided. Care instructions are provided with each packet of socks or ask your prosthetist. Gel socks are best sponged with a damp washer and a mild soap and dried indoors. All socks should be left to dry in a way that does not let them become misshapen or creased.^(1,4)

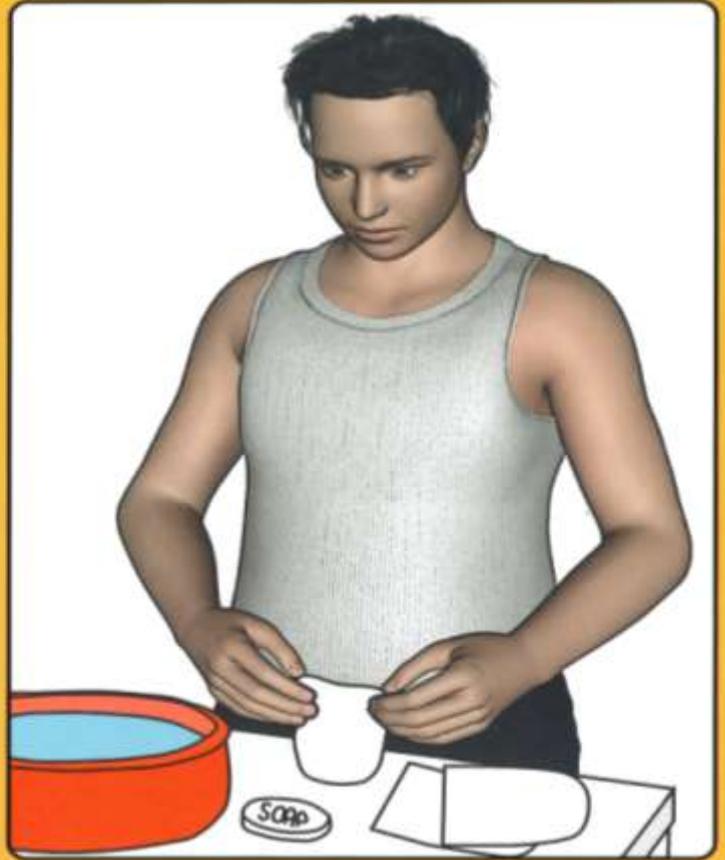
To clean your liners follow the instructions of the manufacturer. Suitable products for cleaning depend on what the liner is made from and the wrong product can cause damage. Liners made from silicone are easily stained by inks and dyes so never sit one on newspapers to dry.⁽⁶⁾ Gel liners must be dried right side out. Liners can be wiped with warm water and mild soap and then left to dry. Do not use a hair dryer or any other direct heat on your liner.⁽⁷⁾

It is advisable to carry a prosthetic limb kit with you. This kit should contain some clean stump socks, a packet of suitable wipes for cleaning your skin and socket; antiperspirant and a shrinker to wear if you must remove your prosthetic limb. Keep the kit in a handy location such as your car.⁽⁶⁾

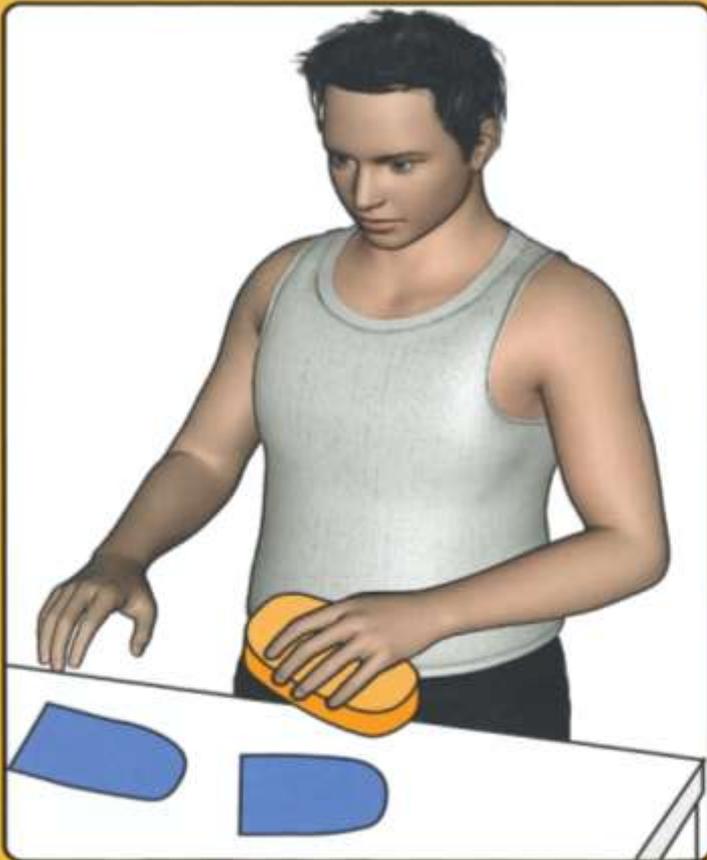
Cleaning your prosthetic limb



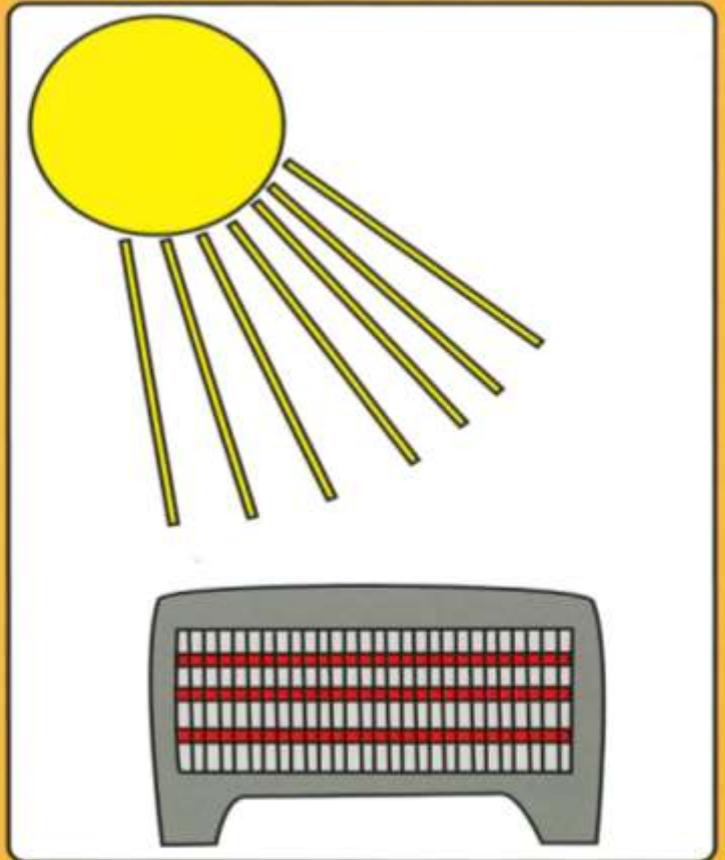
1. Wipe the prosthetic limb with a damp cloth and gentle soap.



2. Hand wash your cotton/wool socks in warm soapy water. Rinse well.

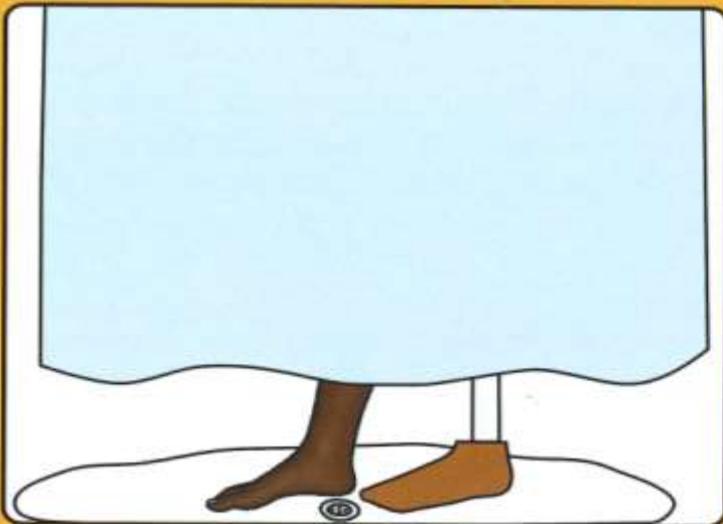


3. Clean your liner and gel socks with a damp sponge. Turn right side out to dry.



4. Dry the socks and liner away from direct heat and sunlight.

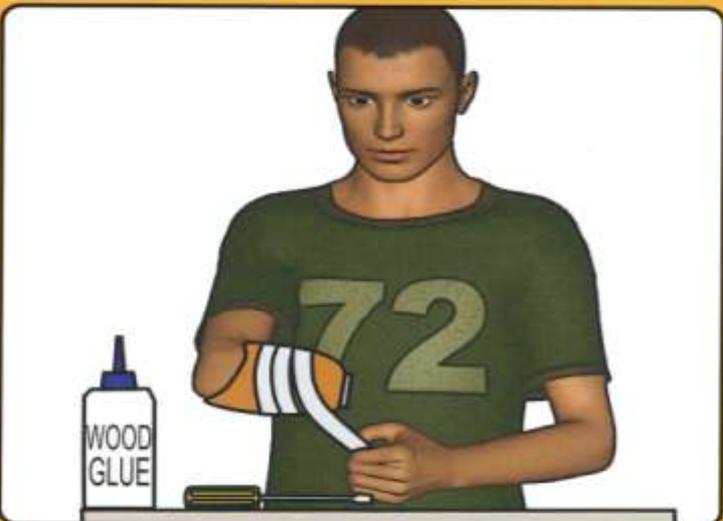
Keeping your prosthesis in good shape



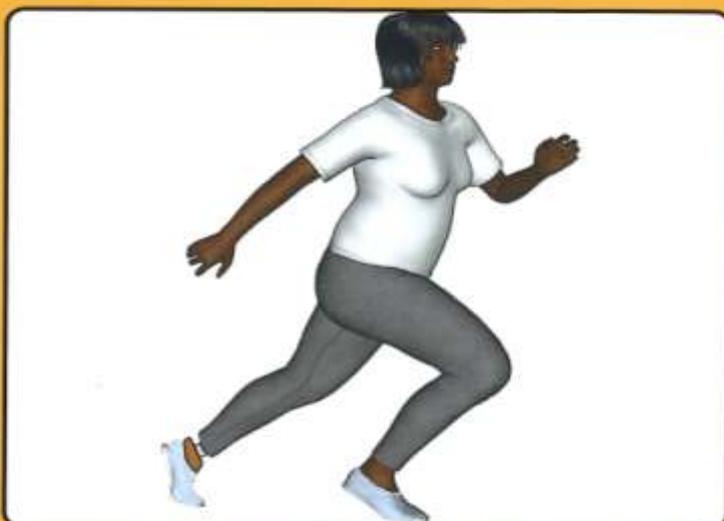
X Don't swim or shower in the prosthesis without a xerosock⁽³⁾



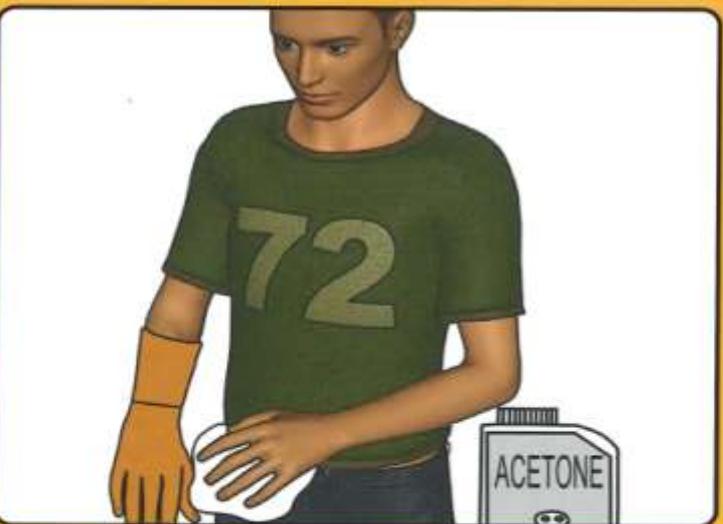
X Don't carry heavy loads above the prosthesis' weight limit.⁽³⁾



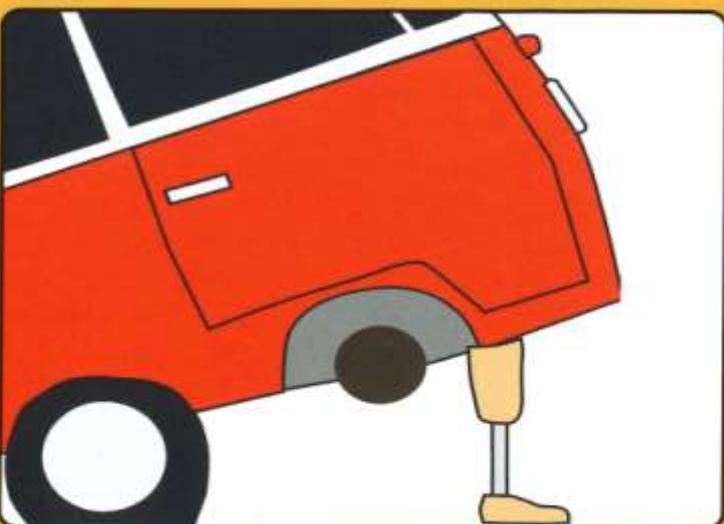
X Don't repair the limb or pack the socket yourself.^(1,3)



X Don't engage in high impact activities with your prosthesis.⁽³⁾



X Don't expose the prosthesis to solvents and chemicals.⁽⁵⁾



X Don't use the prosthesis for anything it was not made for.⁽¹⁾

Component maintenance

A prosthetic limb needs to be maintained to function well. Your prosthetist will service your limb regularly and you can perform some basic maintenance and inspection to detect problems before they become serious.

Sockets

As well as cleaning the socket daily inspect it for cracks. A small crack can expand causing the whole socket to fail. Cracks should always be repaired as soon as possible.⁽²⁾

If you have a pin lock suspension and it is not making a good connection the lock may need cleaning or replacement. The pin should attach to the lock with a 'click' sound. If the pin continues to click as you walk the pin or lock are most likely worn. If you cannot remove the pin from the lock easily there is probably rust or dirt in the lock.⁽⁷⁾

Suspension

If your suspension or socket does not fit properly the stump may move up and down in the socket: this is called pistoning. You may also feel like the prosthetic limb is slipping on the stump causing it to lag behind your body making walking laborious.^(7,8)

Knees

Knees are quite complex and are not designed for home repair. If your knee requires oiling or cleaning your prosthetist will show you how to do it correctly.

Your knee should move smoothly if you find it is jamming or floppy it needs adjustments or replacement. If your knee is hydraulic it should work silently, if it is making noises such as gurgling it is in need of repair.⁽⁷⁾

Feet

Feet are made to be somewhat water resistant but should not be submerged in water or worn in the shower. SACH type feet will deteriorate if exposed to water and not dried thoroughly. Feet need to be protected by always wearing shoes. The rubber bumpers in some feet need regular

replacement. To care for silicone feet see the section on silicone care.⁽⁷⁾

Upper limb harnesses and wires

Harnesses need to be cleaned frequently to avoid sweat staining. Wires can wear and fray so inspect them regularly for damage.⁽⁹⁾

Terminal devices

Terminal devices should not be immersed into dish washing water as the detergent will dissolve the device's lubricant. Replace the rubber bands on hooks regularly. To care for silicone covers and hands read the following section on silicone care.⁽⁹⁾

Silicone care

Silicone is a common material in prosthetic limbs. It can be found in liners, socks, cosmeses, hands and feet. Silicone requires special care to keep it in good shape and avoid stains.

Silicone is very absorbent; avoid contact with perfumes and strong soaps as they may be absorbed and released onto the stump skin. Silicone liners can absorb sweat and body odours. If you smoke the silicone will absorb the smoke odour. Always wash silicone liners daily and practice good stump hygiene. If you put lotion on your stump wait at least 30 minutes before donning a silicone liner or prosthesis.^(5,10)

Silicone should be cleaned with warm water and mild soap. If it is not dried properly mould can grow and destroy it. To avoid mould after washing spray silicone with medical alcohol to displace excess water.^(5,10)

Inks and dyes must be avoided as they stain silicone. Take care if using items like markers, food dyes, hair dye, printer inks, copier toners and wood stains near silicone. Wash new clothes, especially denim, before wearing to remove excess dye.^(5,10)

Silicone must never touch solvents or oils such as nail polish remover and Vaseline as both damage silicone. If you accidentally cut into silicone your prosthetist can use a special glue to repair it; do not glue it yourself as many glues contain solvents.^(5,10)

Socket fit

Sockets are designed to distribute weight over the entire stump, taking pressure off of the distal end. The socket should be a snug fit and not require too many socks. A socket does not last forever and stumps change shape so it is important to watch for signs of a socket fitting poorly.

Signs a socket is too loose:

- The leg moves up and down in the socket: This is called pistoning and may be caused by a loose socket.
- Air 'burps' out of the top of the socket.
- The prosthesis is slipping on the stump causing it to lag behind your body and it feels heavy.
- You feel comfortable except for pressure around the knee because you have too many socks on.
- The prosthetic limb turns on your stump making the foot protrude to the side.
- There is pressure from the socket on the groin area and your 'sit bones' (ischial bones)
- The limb feels too short.^(7,8)

Signs a socket is too tight

- Ulcers and pressure points are often caused by a socket that is too tight.
- Throbbing pains and redness: These are caused by a tight socket or wearing too many socks.
- The bottom of the stump is hard and swollen. This is caused by the stump end not making contact with the base of the socket because the socket is too small. Fluid accumulates in the distal end of the stump due to the vacuum created.
- The limb feels too tall.
- Painful pressure on the back of the knee.^(7,8)

Never pad the socket

If part of the socket is causing pressure or pain it may be tempting to pad the area with items such as gauze, foam rubber or cotton wool while you wait to see your prosthetist. It is very important that you do not pad pressure points yourself because:

- The item used to pad can move up and down in the socket and cause skin abrasions or affect the suction fit.

- Padding areas of a socket will make that part of the socket even tighter and create greater pressure on the stump area. This can limit blood supply to the area and make the wound worse.
- Making a doughnut shaped pad to protect a wound or ulcer can cause tissue swelling inside the 'hole' of the doughnut.⁽¹¹⁾

If you are experiencing pain see your prosthetist as soon as possible and do not wear the prosthesis: use a backup mobility device. If you have a 'boney' stump special pads are available from your prosthetist.

Fit issues caused by shoes

A prosthetic leg is designed for a flat soled shoe with a low heel. Shoes need to be replaced and most of us have shoes for different occasions and activities e.g dress shoes, work shoes, gum boots, sneakers, and summer sandals. When new shoes are worn there may be issues caused by a change in heel height.⁽⁷⁾

If your heel is too high you will feel as if you were leaning forward or walking downhill. There can be excess pressure on the shin area and kneecap. If you use a prosthetic knee it may flex differently to what you are used to and buckle when moved forward.⁽⁷⁾

Your heel height is too low if you feel like you are leaning backward or walking uphill. You may feel pressure on the back of the knee and the tendons on the kneecap. If you use a prosthetic knee it may flex differently to what you are used to.⁽⁷⁾

When having your prosthetic limb fitted bring the pair of shoes that you wear most often as the prosthetic limb will be adjusted to the heel height. As this is difficult to change you will need to have shoes for other occasions with the same heel height. If you are not sure what type of shoes to choose sneakers are the preferred choice as they are light, comfortable and have good grip. If you would like to wear a variety of heel heights there are adjustable prosthetic ankles and feet for this purpose.^(7,12)

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This Article was taken from "Information for People Living with Amputation" by Queensland Health. If you would like a copy of this book please contact the Amputees & Families Support Group Queensland Inc on 07 3290 4293 or via email admin@afsg.org.au and we will arrange for a copy to be sent to you.

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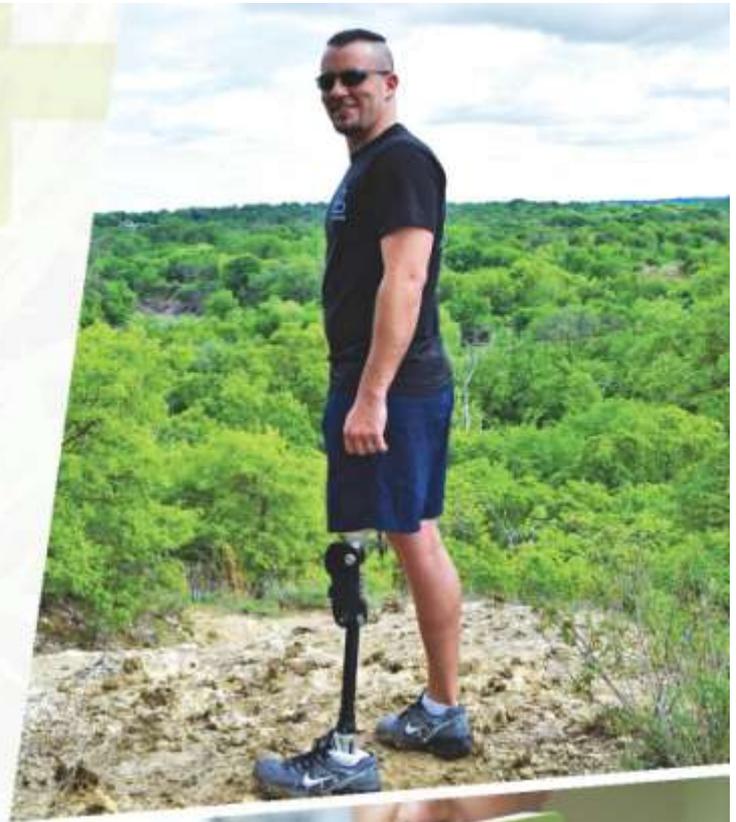
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