

Above Knee Amputation: Your New Journey



National Rehabilitation
University Hospital

An tOspidéal Náisiúnta Athshlánúcháin



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This booklet has been designed by the Prosthetic, Orthotic and Limb Absence Rehabilitation (POLAR) team at the NRH, for you and with you in mind - a person who just had an amputation. Every amputee's experience and journey will be very different but we encourage you to use this book as a guide to help you move forward by giving you information on a wide range of topics and practical tips to help you go through the first few months after amputation.

In this booklet, your leg where the amputation surgery was performed will be referred to as the "Residual Limb" or "Residuum".

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First 12 months after an above knee amputation

A few weeks after your surgery, your sutures and staples will be removed. You will then transition to wound care and pain management.

What to expect in the first three months:

First two weeks

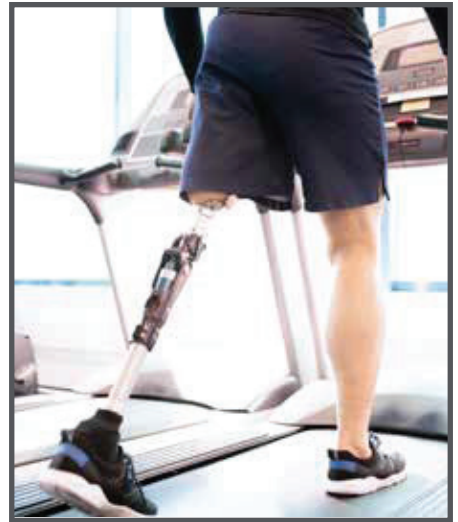
- Swelling
- Mild to moderate pain
- First physiotherapy sessions
- Assessment and provision of wheelchair by the Occupational Therapist



Two to four weeks

- Swelling subsides
- Suture lines showing signs of healing

- Might start using a shrinker sock depending on the wound healing stage



Four to twelve weeks

- Start to use a shrinker sock, wound healing permitting
- Assessment in the NRH prosthetic clinic

How can I look after my residual Limb?

Care of your residuum

While your wound is still healing the hospital staff and or public health nurse in your local community area should review your wound weekly. When your wound has healed it is important that you look after your residuum. Use a mirror to check the skin at the bottom and back of your residuum.

| | Scar Management *only complete when wound is closed | Skin care *only complete if skin is dry or cracking and peeling | Volume Management |
|----------------|---|--|---|
| Why | Massage your scar to reduce or prevent scar from sticking to soft tissues and bone underneath skin | Dry or cracked skin can be a source of irritation and a potential port for infection | After amputation swelling may build up in your amputated leg |
| How | 10 minutes 5 times daily making a cross sign with your thumb along the scar line | Use a perfume free moisturiser to moisturise your skin daily | Wear your shrinker sock as directed by your health team |
| Caution | If your scar shows any sign of break down or deterioration, stop the massage and talk to your nurse or doctor. Always consult with your health team before starting scar massage. | Make sure your skin is dry before putting your shrinker sock on | Your shrinker sock should be tight but not enough to restrict blood flow. Ensure there are no rolls in the shrinker and it is smooth and not too loose. |

How do you make your Residual Limb less sensitive?

After the amputation, you may have swelling and experience pain in your amputated limb. You may also feel that the limb is sensitive due to the operation. A desensitising programme will help and has the following benefits: Reduces pain, swelling, spasms, muscle stiffness, improves circulation and makes a sensitive area more comfortable to touch.

What can you do?

| 1. Massage | 2. Tapping and cupping | 3. Shaking and vibration | 4. Desensitise using different textures |
|---|---|--|--|
| <p>Apply a small amount of non-perfumed base lotion or any lotion recommended by your health care professionals.</p> <p>Gently stroke over the skin using the palms and heels of your hands. Massage from the bottom of your residual limb up towards the groin region.</p> | <p>Start by gently tapping on your residual limb with 2 fingers. Also, gently tap on the bottom of your residual limb with a cupped hand.</p> | <p>Gently use your relaxed hands to shake or vibrate the muscles of your residual limb</p> | <p>Gently rub cotton wool over the skin. As the residual limb becomes less sensitive, use tissue, then bath towel or ball of sock.</p> |

How long do I need to desensitise my residual limb?

It is recommended to desensitise your residual limb for 10-15 minutes, 3 times daily using any of the above.

Precaution

- Consult with your treating team before starting your desensitisation programme.
- Take extra precautions if you have wounds on your residual limb. Avoid the wound when doing your desensitising programme.
- Always check the skin after the desensitising programme, especially if you have an area of skin that has reduced sensation.



Exercises

It is important that you carry out exercises each day after your amputation. These are essential to keep full movement in your hips and remaining knee, and to maintain your strength and fitness.

Doing exercises each day will also make it easier to use a Prosthesis.

Do not exercise through pain; please talk to your Therapist if you are in doubt. Here are the most important exercises to carry out - please speak with your Therapist who can provide you with more exercises to further increase your flexibility and strength. Complete these exercises 3 times each day.

Hip Stretching

- Lie on your back with your sound knee bent up.
- Push your residual limb down into the bed.
- Hold for 30- 60 seconds.
- Repeat 5 times.



Bridging

- Lie on your back with rolled towels or pillow under your thighs.
- Push your thighs down.
- Lift up the buttocks off the bed.
- Hold for 3 seconds. Repeat 10 times.



Leg lifts on your Tummy

- Lie on your tummy.
- Lift your residual limb up off the bed.
- Don't let your pelvis lift up.
- Hold for 3 seconds.
- Repeat 10 times, then repeat with your sound leg.



Leg lifts on your side

- Lying on your sound side as shown.
- Make sure your residual limb is in a straight line with your body.
- Lift your residual limb up towards the ceiling.
- Don't let the leg veer forward.
- Hold for 3 seconds.
- Repeat 10 times, then repeat with your sound leg while lying on your other side.



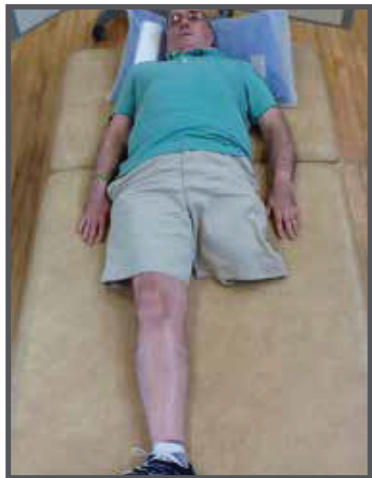
Straight Leg Raise

- Lying on your back as shown, straighten your sound knee by pushing the back of the knee into the bed.
- Keep your knee straight and your back flat.
- Lift your sound leg 10 inches off the bed.
- Hold for 3 seconds. Repeat 10 times.



Hip Hitching

- Lying on your back. Keep both legs flat on bed.
- Pull up residual limb as if you are trying to shorten it.
- At the same time, push the sound leg towards the end of bed.
- Feel the stretch in your waist.
- Repeat 10 times.



Positioning Advice after Your Amputation

After your amputation it is important that you place your residuum and your remaining leg in the best ways so that your joints don't get stiff. If you are using a prosthesis in the future, it is important to have good flexibility in your joints. These exercises will help you maintain your flexibility. Please discuss positioning options with your Therapist to make sure it is safe for you to complete them.

Lying on your stomach

- This helps to stretch your hips and stomach.
- Build up from 5 minutes to 30 minutes at a time, for 3 times each day.
- Place a pillow under your thighs to help stretch your hip more.
- Place a pillow under your tummy if your back is sore.



Lying on your back

- Keep your residual leg close to your body and your hip down.
- Don't put a pillow under your hip or knee.
- Don't let your residual limb hang over the side of the bed.
- Don't place a pillow between your thighs.



Lying on your side

- Pull your residual limb back as far as you can to stretch the front of your hip.
- Use a pillow in front of your residual limb to keep it pulled back.



Sitting down

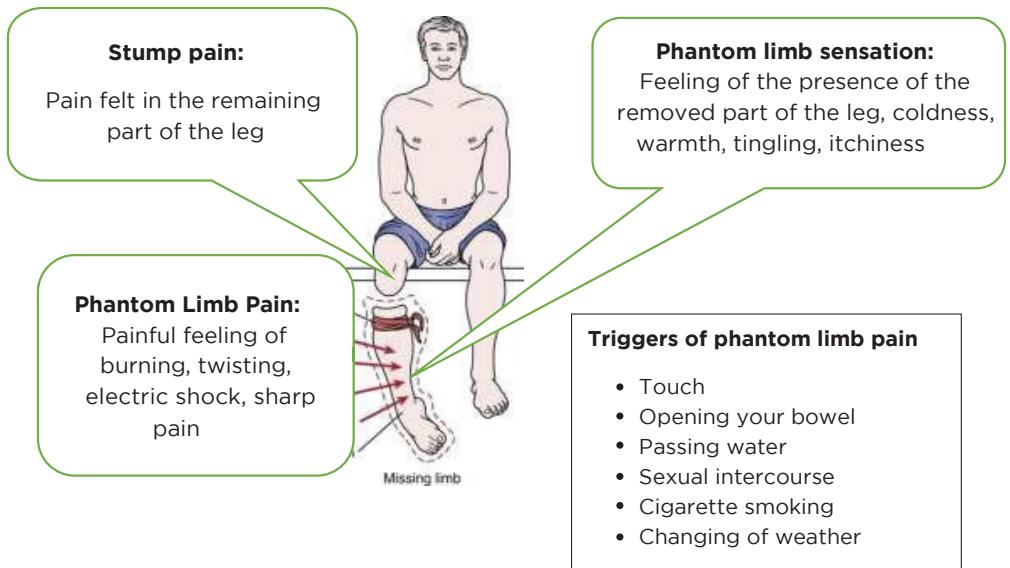
- Use a stump board to keep your residual limb supported.
- Keep your residual knee as straight as you can.
- Don't let your residual knee bend or point out to the side.



Pain after amputation:

1. Phantom limb pain or sensation

- Up to 8 out of 10 amputees experience this kind of pain or sensation.
- Commonly, it significantly improves within 3-6 months after your surgery.
- It may last from a few seconds, to minutes, to hours or to days at a time.
- You may also feel the phantom leg is fixed in a certain position or the missing toes and foot are getting closer to the remaining part of your amputated leg over time.
- The painful sensation you experience is real. Tell your health care team so that you are started on the right treatments.
- The exact cause of phantom limb pain and sensation is still unknown. It may be caused by the mixed messages from the brain and spinal cord due to the amputation.



You can easily do the following:

- Exercise
- Massaging the amputated leg
- Use of shrinker sock
- Distraction

Combination of different medications given by your doctor

Non Medication Approach

- Avoid your known triggers
- Work with your doctor and nurses to find the right type of medications that work for you with minimal side effects.
- Talk to your occupational therapist and physiotherapist for more advice on non-medication approach

You may need some guidance for the following:

- Mirror therapy

Phantom Limb Pain Treatment

Combination of medication and non-medication approach seems to be the most effective

You will need help for the following:

- Virtual reality therapy
- Acupuncture

Non medication approach explained further:

Mirror therapy

- Use a mirror to make it look like an amputated leg exists.
- Watch the intact limb move and imagine that your missing leg is moving.



TENS ‘Nerve stimulation’

A device that sends a weak electrical current via adhesive patches on the skin. This may interrupt or mask pain, preventing them from reaching your brain.



Shrinker

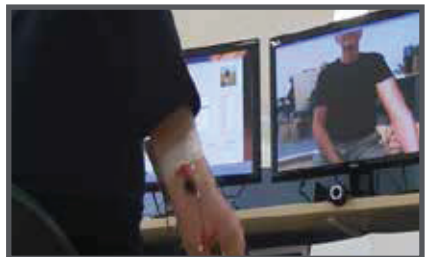
An elastic stocking that helps to shape your amputated leg down to conical shape. It reduces the swelling of your amputated leg after the operation. It may help reduce your phantom limb pain.



Virtual Reality

New technology that helps you to trick your brains into thinking that you have the control of the missing arm or leg.

Some researchers suggest it may help your phantom limb pain.



2. Pain in the residual limb

- Commonly referred to as “residual limb pain” or “stump pain”.
- Could be caused by different reasons including infection, inadequate blood supply.
- Should settle gradually after the operation. Talk to your surgeon if your pain is not settling.
- You need to work with your healthcare team closely to find out the cause of your pain.

Pain felt in your amputated leg:

- Sharp pain
- Throbbing
- Burning



Post-operative pain

Should improve within a few weeks.

Possible treatments

- medication
- Gentle cupping and tapping
- Use shrinker sock to reduce swelling

Entrapment of nerve in scar tissue

Possible treatment

- As soon as your wound is healing, your health care team will advise you when to start massaging the scar tissue of your residuum.

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

- Understand the possible causes of your pain.
- Look after your general well-being. Make sure you are sleeping and eating well.
- Stay active! Begin exercises as soon as your surgeon allows it. Standing, walking trial, stretching and strengthening will also improve your general health.
- Make your residual limb less sensitive by massaging and using shrinker sock. Follow the instructions of your healthcare professions.
- Keep a pain diary and show it to your healthcare team. Keeping track of your symptoms will help you find the right treatments.
- Practice relaxation. Tension and stress make pain worse.
- It is challenging to learn how to manage the loss of your limb as well as pain. You may find it helpful to talk to your counsellor or psychologist.
- Seek support. Talk to your family or friends. You may find it helpful to join a peer support group.



Emotions

Limb loss has a significant impact on you and your family. You may experience a range of emotions during the first 12 months after your amputation and maybe even longer.

Relationships

Limb loss can affect your body image, relationships and sexuality. Some individuals who have experienced an amputation avoid relationships or stay away from friends, relatives and strangers because of concerns regarding the reactions of others. These fears are most often unfounded. Remain involved with people you know, and share your feelings with them.

Body Image issues and intimacy

Body image is the way you feel about how you look. When you don't like the way you look or don't look the way you are expected to look, it might be hard to accept yourself or be accepted by others. A negative body image can also limit your intimacy and sexuality. Talk to your partner about your concerns. Talking about your feelings can help alleviate fears and prevent misunderstandings and hurt feelings.



Medical Card and the Financial Impact of Limb Loss

Many patients find that financial concerns are a source of stress. They may have reduced income as they are unable to work. They have additional costs for transport, house adaptations costs. They may have mortgages and childcare expenses placing many families under severe financial strain when there is a decrease in household income. At the same time they are facing increased medical costs. Whilst the cost of a first prosthesis is covered by the HSE, subsequent prostheses are not provided unless the patient has a medical card.

We are highlighting these concerns to emphasise the importance for you in applying for a medical card if you don't already have one. Some patients are reluctant to apply if their weekly income is above the weekly income limit set by the HSE - for example a couple's income is set at a certain amount per week. However, allowances are available for each child as well as childcare costs, mortgage or rent payments, home insurance and travel to work. If your income is still above the guidelines, you have the right to have your medical card application considered on a discretionary basis.

For this you need to present documentation to show that you are suffering 'undue hardship' without a medical card to pay for the additional costs of medication, equipment, G.P and other health professional fees. You can also appeal by letter or email if you are unhappy with a decision not to grant you a medical card.

Assistance with your medical card application or appeal process is available from your Social Worker (if available in your hospital or Community Primary Care Team) or from your local Citizen Information Centre.

Entitlements – Benefits

There are a number of benefits and entitlements for which you may qualify. For some entitlements you must have enough Pay Related Social Insurance (PRSI) contributions to qualify. Other payments have a means test and whether you qualify depends on your income. Most illness and disability payments stop when you reach the age of 66 at which time you become eligible for a state pension.



Illness Benefit

This is a short-term payment made to people who are unable to work due to illness and who have enough PRSI contributions.

Invalidity Pension

This is a PRSI based long-term payment for people who have been unable to work for a year due to illness or disability and who are expected to be unable to work for at least another year. If you are on either of these payments and wish to return to work you can apply for Partial Capacity Benefit.

Disability Allowance

This is a means-tested payment for people with a disability that substantially restricts their capacity to work. You may also get an extra amount for your adult dependent (your spouse or partner) and dependent children.

Household Benefits Package

If you are awarded Disability Allowance or Invalidity Pension you may be entitled to the Household Benefits Package to help you with your electricity or gas bills. If you qualify, you will also get a free television licence.

Free Travel Card

If you are 66 or over you are automatically entitled to a free travel pass. If you are under age 66 and you are awarded an Invalidity Pension, a Disability Allowance or a Blind Pension you are entitled to a free travel pass.

Occupational Injuries Benefit Scheme

This applies to people who have been injured due to an accident at work. The main benefits under this scheme are Injury Benefit which is a short term payment and Disablement Benefit which can be paid as a long-term pension or a once-off payment.

If your income is too low to meet your needs while you are waiting for a decision on your application for any of these entitlements, you may be entitled to a Supplementary Welfare Allowance (SWA) which is means tested. You are advised to check that you are availing of all your entitlements.

If you do not have a Social Work Service in your hospital and have any doubts about which entitlements to apply for, contact your local Citizen's Information Centre and or your local Social Welfare office for more information.

Appeals

If you are not satisfied with the decision made in your case (for example if you are not granted disability allowance) you have the right to appeal or request a review. If possible, submit additional reports and evidence to support your appeal. The Social Protection Appeals office operates independently of the Department of Social Protection to ensure that the appeals decisions are independent and fair.

EEA and Non EEA Nationals



Once your right to reside in Ireland has been established (with the appropriate immigration stamp on your passport) the following five factors are examined to find out if you are habitually resident in Ireland.

1. Length and continuity of residence in Ireland.
2. Length and purpose of any absence from Ireland.
3. Nature and pattern of employment.
4. Your main centre of interest.
5. Your future intentions to live in Ireland.

Once you satisfy these Habitual Residence Conditions you may apply for Social Welfare entitlements on the same basis as an Irish citizen.

Supporting your Carers

Family Carers are the backbone of our Health Services and must be acknowledged for their tremendous contribution to caring for and supporting their loved ones to remain at home.

If you require daily assistance with your personal care and activities of daily living you may have a family member, relative or close friend supporting you to manage daily life at home.

Caring can be both a fulfilling and stressful experience. However having information on entitlements and services that provide practical and emotional support can alleviate stress for all concerned. If you do not have access to supports for your family and carers in your hospital there is help available from a number of organisations that were set up to assist families and carers in coping with their changed roles and circumstances these include:

The Family Carers Association

(www.familycarers.ie) provides advice, guidance and advocacy in this area through its many centres across the country. It also offers a confidential and supportive helpline (phone: 1800240724) which is open from 9am to 8pm Monday to Friday and 9am to 12 noon on Saturdays.

Age Action (www.ageaction.ie) provides an advocacy and information service to older people and their families. They also have a service called **Care and Repair** which provides a befriending service and also carries out minor repairs free of charge for older people to improve comfort, security and wellbeing at home. It is a nationwide service and to find your nearest Care and Repair provider you can log onto the website or phone 01 4756989.

Carers Entitlements and Benefits

Carers are entitled to a range of allowances and benefits to suit people on low incomes and also those working fulltime who wish to take carer's leave.

Carer's Allowance is a means tested payment. If a carer qualifies for this, free travel pass is also provided.

Half-rate Carer's Allowance is payable with certain other social welfare payments provided other qualifying conditions are met.

Carer's Benefit is a social insurance payment made to someone who takes time off work to provide and carry out the responsibilities of a Carer. The Carer can also work part time up to a maximum of 15 hours per week. It is based on the employees PRSI contributions and provides job protection for up to 104 weeks.

Carer's Leave is unpaid leave where the employee has insufficient PRSI contributions but has job protection guaranteed during leave to care (up to 104 weeks) once there has been a record of 12 months continuous work.

Carer's Support Grant is an additional payment is made automatically to Carers in receipt of Carer's Allowance.

Carer's Benefit and Domiciliary Care Allowance. This is paid annually in June each year. If someone is caring for more than one person a grant is paid for each of them.

Carer's Support Grant is also paid to Carers who do not qualify for Carer's Allowance, Carer's Benefit or Carer's Leave. To receive the grant your Carer must be providing 6 months continuous care to include the first Tuesday in June.

For further information on the qualifying conditions and rules for these payments it is best to visit a Citizens Information Centre or local Social Protection Office.

Home Modifications after Amputation



It is important that you can independently access and get around your own home if you are using a wheelchair or are a potential prosthetic user. This may require you to make some minor or major modifications to your existing house. It's important that you link in with your Occupational Therapist in the Hospital or your in community, to support you in knowing what changes are needed. Some changes may include;

- Installing a temporary or permanent ramp to allow you to enter and exit your home
- Installing grab rails in the bathroom and around the toilet
- Re-configuring your bathroom to make it wheelchair accessible
- Remove trip hazards by re-positioning furniture and removing mats
- Consider use of assistive aids such as a shower chair, raised toilet seat

Some major changes may include:

- Consider downstairs living
- Permanent ramp and rails to access points
- An extension to accommodate a downstairs wheelchair accessible toilet and wheelchair accessible shower.
- Wider hallways and doors

If you are considering purchasing or renting a new home or renovating your existing property, please ensure you link in with your Community Occupational Therapist. They will support you in ensuring wheelchair accessibility and universal design guidelines are met.

Links:

AOTI housing guidelines:

Universal design guidelines for homes in Ireland

www.universaldesign.ie



Driving

It is possible to return to driving following an amputation. If you wish to explore returning to driving this can be arranged through driving sessions with an Irish Wheelchair Association (IWA) driving instructor in your community area. It is not possible to use a prosthetic limb for driving. You may be required to make adjustments to your vehicle such as switching to an automatic car, switching to a left foot accelerator, installing hand controls.

For further information please see www.iwa.ie



Vehicle Entitlements

Following an amputation you may be entitled to the Primary Medical Certificate (PMC). The PMC is part of the Disabled Drivers and Disabled Passengers Scheme.

This scheme provides a range of tax reliefs linked to the purchase and use of specially constructed or adapted vehicles by drivers and passengers with a disability. Under the terms of the scheme, you

can claim remission or repayment of vehicle registration tax (VRT), repayment of value-added tax (VAT) on the purchase of a vehicle and repayment of VAT on the cost of adapting a vehicle.

In addition, if you qualify under the scheme, your vehicle may be exempt from the payment of annual motor tax on application to a Motor Tax Office. Applications for the PMC can be made through your local health office.

Parking Permit

Following an amputation you can apply for a parking card from the Irish Wheelchair Association (IWA) - 'Disabled Person's Parking Permit'. This permit is issued by the IWA and applications are sent to them directly. For further information please see www.iwa.ie

Returning to Work

Returning to work after an amputation is possible. It may require you to change the way that you do some of your work or how your work space is set up. Should you wish to explore returning to work you can be referred to the Vocational Assessment Service at the National Rehabilitation Hospital, who can provide advice and guidance as well as a work place site visit if deemed appropriate.

Next steps:

Assessment in the prosthetic clinic in the NRH

Once your surgeon, hospital team or GP has referred you to the NRH, you will receive an appointment to attend the assessment clinic with the multidisciplinary team.

You will meet a member of the medical team along with the Physiotherapist, Occupational Therapist and Prosthetist to assess your suitability for prosthetic rehabilitation. Not everyone will be safe using a prosthesis after an amputation.

If the team finds that you are safe to use a prosthesis, depending on your own goals and your fitness levels, a prescription will be raised and funding will be sought. If you had your amputation in a public hospital, your first prosthesis will be paid for by the hospital where the surgery took place.

On receipt of the funding, which can take several weeks up to several months, the manufacture of the prosthesis can start followed then by prosthetic rehabilitation.

What is rehabilitation?

Rehabilitation is a learning process. A range of rehabilitation specialists (your rehabilitation team) will work together with you and your family to help you adjust to your injury or illness and learn the skills needed to help you become as independent as possible.

Rehabilitation is an educational and therapeutic process through which you will learn and develop skills designed to:

- Help you achieve your personal rehabilitation goals
- Reach your safest level of independence
- Help you to participate in your personal, family and community life

Did you know?

A prosthesis requires a lot more energy to walk with.

Some people are only safe using a prosthesis under supervision.

10 tips for avoiding a fall:

Amputees are at higher risks of having a fall due to altered sense of balance. It is more challenging for you to regain balance if you have a slip or a trip.

1. No hopping on one leg without walking aid. Talk to your Physiotherapist or Surgeon about your suitability of hopping with a walking aid.
2. Always put on the brakes and remove footrests when getting in and out of a wheelchair. Don't over-reach.
3. If you have phantom sensation, take your time and think carefully before you move, for example from bed to wheelchair. Having your walking aid or wheelchair right beside the bed at night can help remind you before you move out of the bed.
4. Remain active to improve your balance and coordination.
5. Make sure you have the right type of wheelchair that suits you, such as anti-tippers. You also need to have the right skills to operate your wheelchair safely especially when going up and down the ramp.
6. Your mobility aid must be of good working condition. Check that your wheelchair brakes are working and the plastic ferrule at the bottom of your crutches or sticks is NOT worn out.
7. Work with your Occupational Therapist closely to have the right equipment at home. Remove any tripping and slipping hazards at home, for example:
 - Wiping up spills promptly
 - Rearranging furniture to make the room clutter-free
 - Avoiding mats that could slide out underneath you
 - Securing carpet
 - Fixing loose cord on skirting board
 - Keeping outdoor equipment put away or hung up
8. Consider having a bedside lamp, sensor or night light in hallways, entrances, and bathroom.
9. Good fitting and comfortable footwear with non-slip soles.
10. If you have any vision problem, dizziness, issues with toileting (rushing to the toilets, increased urgency), talk to your nurse and doctor. Ask your doctor to review your medication list regularly.

TIP:

Always tell your health care professionals if you have falls and or notice any change to your health. Please keep an updated list of the contact details of your doctor, nurse, occupational therapist and physiotherapist.

Resources and websites:

Information about the Irish Amputee football Association

<http://www.irishamputeefootballassociation.com>

American Amputee Coalition: lots of fact sheets and ideas to make life easier:

<http://www.amputee-coalition.org>

Limbless Association

<https://www.limbless-association.org>

Irish Citizens information page on advocacy

<https://www.citizensinformationboard.ie/en/services/advocacy/>

Assist Ireland page on transport

[http://assistireland.ie/eng/Information/Transport/useful contacts, resources and Websites/](http://assistireland.ie/eng/Information/Transport/useful%20contacts,%20resources%20and%20Websites/)

**Contact details for:
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The **National Rehabilitation Hospital** is accredited by CARF (Commission for Accreditation of Rehabilitation Facilities) for a range of services, confirming they meet recognized international standard.



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