Peripheral Nerve Injury Rehabilitation Programme

A patient’s guide to the
What do nerves do?
They have 2 main functions:

- They pick up information from the outside world, such as temperature, pain and touch, and carry this information to the brain. These are called sensory nerves.
- They carry messages from the brain back to the muscles to make them move. These are called motor nerves.

Messages can travel at up to 120 metres per second.

**Brachial Plexus**
The brachial plexus is a group of five nerve roots that originate from the spinal cord and stem out through gaps between the neck bones (vertebrae). These nerves supply the muscles and register sensation from the upper limbs.

These five nerve roots: C5, C6, C7, C8 and T1, are named according to where they are located along the spine. They divide into smaller branches forming the following five peripheral nerves: musculocutaneous nerve (C5, C6), axillary nerve (C5, C6), radial nerve (C6, C7, C8), median nerve (C6, C7, C8, T1) and ulnar nerve (C7, C8, T1). Between them they provide movement and sensation (feeling) to the shoulder, elbow, wrist and hand.

In simple terms:
- C5, C6 & C7 contributes to the innervation of the shoulder
- C6, C7 & C8 contributes to the innervation of the elbow
- C6, C7, C8 & T1 contribute to the innervation of the wrist and hand
Damage to the Peripheral Nervous System

Nerves can be damaged in a number of ways, such as a direct blow to the neck or a traction injury, which are often caused during a high impact road traffic accident.

There are several ways to describe damage to the brachial plexus, below is one way of explaining it:

Normal

Neuropraxia – this is when a nerve has been bruised and the messages are temporarily blocked. Usually the nerve recovers in approximately 6 weeks and does not deteriorate.

Axonotmesis – the outer covering of the nerve (sheath) remains intact, but the axon has been ruptured. The nerve starts to degenerate, but also attempts to regenerate following the injury. Surgery may be required to repair the nerve.

Neurotmesis (rupture) – both the axon and the sheath are damaged. Surgery is required for the nerve to repair. The axon usually regenerates approximately 1mm per day. This is the more severe nerve injury and the outcome is variable.

Avulsion – the nerve root is pulled out at the level of the spinal cord. This is the most severe nerve injury.
Pain is broadly divided into two types - nociceptive pain and neuropathic pain.

**Nociceptive pain**
This is the type of pain that all people have had at some point. It is caused by actual, or potential, damage to tissues. For example, a cut, a burn, or fracture can all cause nociceptive pain. The reason we feel pain in these situations is because tiny nerve endings become activated or damaged by the injury, and this sends pain messages to the brain via nerves.

Nociceptive pain tends to be sharp or aching. It also tends to be eased well by traditional painkillers such as Paracetamol, anti-inflammatory painkillers, Codeine and Morphine.

**Neuropathic pain**
This type of pain is caused by a problem with one or more nerves themselves. The function of the nerve is affected in a way that it sends pain messages to the brain. Neuropathic pain is often described as burning, stabbing, shooting, aching, or like an electric shock.

Neuropathic pain is less likely than nociceptive pain to be helped by traditional painkillers. However, other types of medicines often work well to ease the pain.

People often describe their neuropathic pain as ‘burning’ or ‘electric’, or may experience numbness or sensitivity of the skin, tingling, itching, aching or tightness. These symptoms may be different depending on the time of day (it is often worse at night) or what you are doing at the time.

Related to the pain there may also be:

**Allodynia**
This means that the pain comes on, or gets worse, with a touch or stimulus that would not normally cause pain. For example, a slight touch on the arm may trigger pain.

**Hyperalgesia.**
This means that you get severe pain from a stimulus or touch that would normally cause only slight discomfort. For example, a mild prod on your limb may cause intense pain.

**Paraesthesia**
This means that you get unpleasant or painful feelings even when there is nothing
touching you, and no stimulus. For example, you may have painful pins and needles, or electric shock-like sensations.

In addition to the pain itself, the impact that the pain has on your life may be just as important. For example, the pain may lead to disturbed sleep, anxiety and depression.

**Commonly used traditional painkillers**
You may have already tried traditional painkillers such as Paracetamol or anti-inflammatory painkillers such as Ibuprofen that you can buy from pharmacies. However, these are unlikely to ease neuropathic pain very much in most cases.

**Tricyclic antidepressant medicines**
An antidepressant medicine in the tricyclic group is a common treatment for neuropathic pain. It is not used here to treat depression. Tricyclic antidepressants ease neuropathic pain separate to their action on depression. It is thought that they work by interfering with the way nerve impulses are transmitted. There are several tricyclic antidepressants, but Amitriptyline is the one most commonly used for neuropathic pain.

A tricyclic antidepressant may ease the pain within a few days, but it may take 2-3 weeks. It can take several weeks before you get maximum benefit. Some people give up on their treatment too early. It is best to persevere for at least 4-6 weeks to see how well the antidepressant is working.

Tricyclic antidepressants sometimes cause drowsiness as a side-effect. This often eases in time. To try to avoid drowsiness, a low dose is usually started at first, and then built up gradually if needed. Also, the full daily dose is often taken at night because of the drowsiness side-effect. A dry mouth is another common side-effect. Frequent sips of water may help with a dry mouth. See the leaflet that comes with the medicine packet for a full list of possible side-effects.
Other antidepressant medicines
An antidepressant called Duloxetine has also been shown in research trials to be good at easing neuropathic pain. Duloxetine is not classed as a tricyclic antidepressant but as a serotonin and norepinephrine reuptake inhibitor (SNRI). It may be tried for other types of neuropathic pain if a tricyclic antidepressant has not worked so well, or has caused problematic side-effects. The range of possible side-effects caused by Duloxetine is different to those caused by tricyclic antidepressants.

Anti-epileptic medicines (anticonvulsants)
An anti-epileptic medicine is an alternative to an antidepressant. For example, Gabapentin or Pregabalin. These medicines are commonly used to treat epilepsy but they have also been found to ease nerve pain. An anti-epileptic medicine can stop nerve impulses causing pains separate to its action on preventing epileptic seizures. As with antidepressants, a low dose is usually started at first and built up gradually, if needed. It may take several weeks for maximum effect as the dose is gradually increased.

Opiate painkillers
Opiate painkillers are the stronger traditional painkillers. For example, Codeine, Morphine and related drugs. As a general rule, they are not used first-line for neuropathic pain. This is partly because there is a risk of problems of drug dependence, impaired mental functioning and other side-effects with the long-term use of opiates.

Tramadol is a painkiller that is similar to opiates but has a distinct method of action that is different to other opiate painkillers. Tramadol can be used for short-term treatment of neuropathic pain.
Combinations of medicines
Sometimes both an antidepressant and an anti-epileptic medicine are taken if either alone does not work very well. Sometimes Tramadol is combined with an antidepressant or an anti-epileptic medicine. As they work in different ways, they may complement each other and have an additive effect on easing pain better than either alone.

Side-effects and titrating dosages of medicines
For most of the medicines listed above it is common practice to start at a low dose at first. This may be sufficient to ease the pain but often the dose needs to be increased if the effect is not satisfactory. This is usually done gradually and is called titrating the dose. Any increase in dose may be started after a certain number of days or weeks - depending on the medicine. Your doctor will advise how and when to increase the dose if required, and the maximum dose that can be taken for each particular medicine.

The aim is to find the lowest dose required to ease the pain. This is because a lower dose has less likelihood of troublesome side-effects. A full list of possible side-effects can be found with information in the medicine packet. Some people don’t get any side-effects, some people are only mildly troubled by side-effects that are OK to live with, but some people are troubled quite badly by side-effects. Tell your doctor if you develop any troublesome side-effects. A switch to a different medicine may be an option if this occurs.

If your pain remains difficult to manage, you may be referred to a specialist pain clinic to try and help you manage your pain in different ways.
Whenever we go through a significant change as individuals we can experience a loss of some kind. This appears obvious in such cases as bereavement, but a significant loss can be also felt when someone loses their ability to live as they once did. This type of loss can be just as devastating as it often encompasses the loss of work, relationships, social life, etc. We call this; a loss of identity.

Our identity is essentially what we think makes us who we are and can be greatly threatened if due to injury we are unable to engage in the life that defined us. For example, through injury you may not enjoy a social life like you did in the past and feel relationships slipping away. Or perhaps you have had to leave your job and feel lost without job satisfaction or direction. These examples highlight how the things that we took for granted can leave a tremendous sense of loss and loneliness when they are taken from us.

It is important to understand that if we experience a loss of identity we go through a grieving process just like we would for a bereavement. The first thing to acknowledge is that part of the grieving process is to experience a range of challenging emotions such as anger, sadness and loneliness. These emotions can be hard to express and tolerate and therefore we often try to hide them from our loved ones. Alternatively we may act them out towards those we are closest to (we’ve all “flown off the handle” when we’ve been frustrated or distressed).

What is important to remember is that these emotions are normal. We often find them uncomfortable and say we should behave a certain way but it is imperative that we are more compassionate to our needs and respect that we are going through a challenging and necessary part of life.
However, it is equally important to also set goals on how to rebuild our lives if we have experienced a loss of identity. We need to be mindful of saying things like “I just want to go back to the way things were” or “I just want to be normal”. These phrases can keep us stuck as we are aiming to return to a place that is beyond reach. It is critical that we plan a future around what we are capable of doing instead. For example, rather than saying “I just want to go back to work” perhaps ask “what work can I do in the future?”

Essentially it is important to develop a level of acceptance around the new limitations of your body. It is much easier to say this than to actually do it but a balance of experiencing and expressing emotions constructively, with planning a new lifestyle based on your new circumstances is imperative.

Finally it is important to remain compassionate to your body. Again the temptation is to often dislike or resent our body for its new limitations. However, these emotions keep us stuck once again and we continue to ruminate and fight against our circumstances rather than go forward.

If you feel you would benefit from seeing a psychologist whilst on your rehabilitation programme, please speak to your Therapist or a member of the team.
Scars form as a result of the natural healing process of the skin.

Sometimes as a scar forms it becomes hard, red, raised and thick. It may adhere (stick) to underlying tissues and it may itch or be sensitive to the touch. Scars which run across or close to a joint may limit movement at that joint and thus restrict your function.

Everyone’s skin is different and some people are more prone to problems with their scars. The following massage techniques can help to soften the scar tissue and make it flatter, paler, cooler and smoother.

Massage can be commenced once all stitches are removed and the wound is closed.

Use an unperfumed moisturizing cream or lotion (e.g. E45, Nivea, Vaseline Intensive Care). Massage the scar and any tight/hard areas lying close to the scar for 5-10 minutes. For optimal results you should complete this 2 or 3 times per day. From about 6 weeks after the date of the surgery, if preferred, Bio-oil can be used instead of the cream or lotion. It may take several months to achieve a flat and moveable scar. A scar can take up to 18 months to mature fully.

**Massage Technique**

1. Start with small circles along the length of the scar either with your thumb or first two fingers. Use a firm even pressure.
2. Next, work horizontally across the scar to and fro in small movements.
3. Then, work vertically along the length of the scar.

If someone else is helping you with scar massage for steps two and three they can use both hands working in opposite directions.

If you have any concerns about your scars, or the massage technique, please speak to your therapist.
Oedema Management

Oedema (swelling) is clear fluid called lymph, which collects in one part of the body. Lymph usually flows through pathways much as blood does through veins and arteries.

As lymph flows through the channels it goes through lymph nodes that cleanse it of bacteria, viruses, debris and antibodies – so the lymphatic system forms an important part of your immunity and, when you have had surgery, infection control.

Blood is pumped around the body by the heart. Lymph is pumped by the action of our muscles, our breath and by the gentle stimulation provided by the arterial pulse.

There are a number of reasons why part of the body may be swollen:

- We may not be able to move it, so the action of muscles is no longer moving the lymph
- We may be finding it difficult to move in general, so the breath and pulse are quite shallow – again this doesn’t help if we want lymph to move
- If you have had surgery, the lymph nodes in that area may be full and working, so there is a back-log of lymph building up waiting for the ‘path to clear’!

Things you can do to help yourself:

1. Deep breathing – before and during movement, it will make exercise sessions work for you! Ask a qualified therapist to show you diaphragmatic breathing
2. Movement programme as advised by your therapist
3. Gentle general exercise can help and Tai Chi or Qi gong and Yoga may be beneficial too.
Important Legislation

Disability Discrimination Act 2005
The Disability Discrimination Act (DDA) 1995 aims to end the discrimination that many people with disabilities face. This Act has been significantly extended to include the Disability Discrimination Order 2006 (DDO). It now gives people with disabilities rights to:

- Employment
- Education
- Buying or renting land or property, including making it easier for people with disabilities to rent property and for tenants to make disability-related adaptations
- Functions of public bodies, for example issuing of licences

Equality Act 2010

- Supports people with disabilities in employment
- You are disabled under the Equality Act 2010 if you have a physical or mental impairment that has a ‘substantial’ and ‘long-term’ negative effect on your ability to do normal daily activities.
- Ensures protection against discrimination
- Places a duty on employers to make ‘reasonable adjustments’ to accommodate your needs

Advisory Services

- Your Occupational Health services
- Access to Work – government initiative
- Disability Employment Adviser (DEA) – your local Jobcentre Plus office
- Consider community rehabilitation team to facilitate return to work
Access to Work:  
www.gov.uk/access-to-work/overview

There is no set amount for an Access to Work grant. How much you get depends on your circumstances. The money can pay for things like:

- Special equipment
- Fares to work if you can’t use public transport
- A support worker or job coach to help you in your workplace
- Disability awareness training for your colleagues
- The cost of moving your equipment if you change location or job

Options
If previous employment is not appropriate or desired, options include:

- Contact jobcentre plus at www.gov.uk/contact-jobcentre-plus
- Liaise with Access to Work re alternatives
- Liaise with careers advisor at your local job centre
- www.nationalcareersservice.direct.gov.uk
- www.startability.org.uk (self-employment)
- www.scope.org.uk/support/services/employment
- Association of disabled professionals: www.adp.org.uk (self-employment)
- For 18 -30 year olds the princes enterprise trust for help with starting a business www.princes-trust.org.uk/help-for-young-people/support-starting-business

Volunteering
- www.do-it.org
- www.ncvo.org.uk/ncvo-volunteering
- www.vinspired.com/ (14-25 year olds)

Your Occupational Therapist will be happy to discuss returning to work with you. Please highlight this need to them during your assessment.
Legal responsibility
You must tell DVLA if you have a driving licence and:

- You develop a ‘notifiable’ medical condition or disability
- A condition or disability has got worse since you got your licence

You could be fined up to £1,000 if you don’t tell DVLA about a condition that might affect your ability to drive safely. You could also be prosecuted if you have an accident.

G1 form online should be used for reporting medical conditions such as:

- Arthritis
- Brachial plexus injury
- Cancer
- Learning difficulties
- Limb disability
- Paraplegia
- Spinal problems
- Any persisting issues which can affect movement (including impact of medication on fitness to drive)

You can access the G1 form at:
www.gov.uk/government/publications/g1-online-confidential-medical-information

Please be advised that your therapist is legally obligated to inform the DVLA if a driver is known to be unsafe and disregarding recommendations to stop driving.

What happens after you tell DVLA
You’ll usually get a decision within 6 weeks. You’ll get a letter from DVLA if it takes longer.

DVLA might:

- Contact your doctor or consultant
- Arrange for you to be examined
- Ask you to take a driving assessment, or an eyesight or driving test
What DVLA will decide
DVLA will assess your medical condition or disability and decide if:

- You need to get a new driving licence
- You can have a shorter licence - for 1, 2 or 3 years - with a review at the end of that period, should you wish to reapply
- Adapting your vehicle by fitting special controls (see below)
- You must stop driving and give up your licence

Adapting your vehicle:
If you’ve been told that you must adapt your car, you get an independent assessment of your adaptation needs. Please check the following website for your local Mobility Centre: [www.mobility-centres.org.uk/find_a_centre](http://www.mobility-centres.org.uk/find_a_centre)

Find out more about adapting your vehicle and where to get special controls fitted through the Ricability charity.

You must stop driving
You’ll be given a medical reason why you must stop driving, and be told if and when you can reapply for your licence. You’ll also be told how you can appeal against the decision.

Motability scheme
If you’re disabled and receive mobility allowance you may be able to use the motability scheme to lease a vehicle. Contact Motability to find out more about the scheme.
Telephone: 0300 456 4566

DVLA details
Drivers Medical Enquiries
Monday to Friday - 8am to 5:30pm, Saturday - 8am to 1pm
Telephone: 0300 790 6806
Fax: 0845 850 0095

Website: [www.gov.uk/driving-medical-conditions](http://www.gov.uk/driving-medical-conditions)

Or write to: Drivers Medical Enquiries, DVLA, Swansea SA99 1TU

All information is subject to change so patients are advised to review individual Websites for the most current information.
To support the work you have done during your rehabilitation, please discuss the following with your therapist:

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<th>Goal/ Recommendation</th>
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## Useful Contacts

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<tr>
<th>Description</th>
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<tr>
<td><strong>Support Groups</strong></td>
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<tr>
<td>Traumatic Brachial Plexus Injury Group (TBPI)</td>
<td>07956 525752</td>
<td><a href="http://www.tbpi-group.org">www.tbpi-group.org</a></td>
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<tr>
<td>Disability Living Foundation</td>
<td>0845 1309177</td>
<td><a href="http://www.dlf.org.uk">www.dlf.org.uk</a></td>
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<tr>
<td>National Association for Bikers with a Disability</td>
<td>0870 759063</td>
<td><a href="http://www.nabd.org.uk">www.nabd.org.uk</a></td>
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<td><strong>Driving</strong></td>
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<tr>
<td>DVLA</td>
<td>0300 1230784</td>
<td><a href="http://www.dvla.gov.uk">www.dvla.gov.uk</a></td>
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<tr>
<td>Mobility Centres</td>
<td>0800 5593636</td>
<td><a href="http://www.mobility-centres.org.uk">www.mobility-centres.org.uk</a></td>
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<tr>
<td><strong>Equipment</strong></td>
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<tr>
<td>Ricability – Consumer research and advice for disabled people</td>
<td>0207 427 2460</td>
<td><a href="http://www.ricability.org.uk">www.ricability.org.uk</a></td>
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<tr>
<td>Homecraft</td>
<td>0844 4124330</td>
<td><a href="http://www.homecraft-rolyan.com">www.homecraft-rolyan.com</a></td>
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<tr>
<td>Promedics Ltd</td>
<td>01475 746400</td>
<td><a href="http://www.promedics.co.uk">www.promedics.co.uk</a></td>
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<tr>
<td>Plexfit sling – sling for active users</td>
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<td><a href="http://www.avalanche.com.sg">www.avalanche.com.sg</a></td>
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<tr>
<td>Not Broken – offering solutions/equipment for mountain biking</td>
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<td><a href="http://www.gov.uk">www.gov.uk</a></td>
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<td><a href="http://www.jobcentreplus.gov.uk">www.jobcentreplus.gov.uk</a></td>
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<tr>
<td>Shawtrust</td>
<td>0345 234 9675</td>
<td><a href="http://www.shaw-trust.org.uk">www.shaw-trust.org.uk</a></td>
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<tr>
<td><strong>The Disability Foundation</strong></td>
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<tr>
<td>Offers low cost complementary therapies/treatments</td>
<td>0208 954 7373</td>
<td><a href="http://www.tdf.org.uk">www.tdf.org.uk</a></td>
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### Useful reading

- One Handed in a Two Handed World – Tommy K. Mayer
- Living Well with Pain and Illness – V Burch
- The Chimp Paradox – Prof Steve Peters
- Phantoms in the Brain – V.S. Ramachandran
If you would like this leaflet translated into another language/large print, please contact the Quality Team on 020 8909 5439.