The following information is reproduced from the Handbook of Spinal Cord Injuries, 2nd Edition, produced by the Queensland Spinal Cord Injuries Service, Princess Alexandra Hospital District Health Service, Brisbane, Queensland, Australia. This edition was published in 2001.

The aim of this handbook is to provide you with as much information as possible on Spinal Cord Injury (SCI) and the rehabilitation associated with it.

As no two spinal cord injuries are the same, some of the information may not apply to you and there will probably be some sections that you will find unnecessary to read.

By its very nature, this handbook can only be a general overview, and should only be used a guide. The information is provided solely on the basis that readers will be responsible for making their own assessment of the material presented. The information does not constitute professional advice and should not be relied upon as such.

If you have particular questions about problems or issues relating specifically to you, please contact your doctor, health professional or one of the staff of the Queensland Spinal Cord Injuries Service.

Material contained herein may be reproduced in its entirety and distributed free of charge to interested parties.

© 2002 Queensland Spinal Cord Injuries Service
The aim of this handbook is to provide you with as much information as possible on Spinal Cord Injury (SCI) and the rehabilitation associated with it.

As no two spinal cord injuries are the same, some of the information may not apply to you and there will probably be some sections that you will find unnecessary to read.

There are also sections that apply when you are first injured and some that will not apply until much later, when you leave the Spinal Injuries Unit - again do not feel that you need to read all the sections in one sitting.

We have tried to keep medical "jargon" to a minimum and where medical terms have been used they are explained in easy to understand language as well.

There are many other associated organisations, services, resources and contacts that we think may be useful for you to know about. These are listed in various parts of this handbook. To make it easier, we have put the contact numbers of all of these into one place in Chapter Five.

By its very nature, this handbook can only be a general overview. If you have particular questions about problems relating specifically to you, please contact your doctor, health professional or one of the staff of the Queensland Spinal Cord Injuries Service.
INTRODUCTION TO SECOND EDITION

This second edition of the “Handbook of Spinal Cord Injuries” has been produced by the Queensland Spinal Cord Injury Service (QSCIS) to help you to understand the changes that have occurred in your body because of the spinal cord injury and to help you stay healthy after your injury.

The handbook has been completely reviewed to give you the most up to date information available. Many of the sections from the last edition have been kept and some new parts have been added. We have attempted to make it easier to read and more user friendly. We would be happy to hear what you think and the ways that you think it could be improved even more.

In recent years in Queensland, along with the Spinal Injuries Unit we have been lucky enough to have two new programs to improve the help that we can give to people after they have had a spinal cord injury. These programs are called the Transitional Rehabilitation Program (TRP) and the Spinal Outreach Team (SPOT). They assist people once they leave hospital so the transition between hospital and home is easier and so that people have more help and support if they have any problems. We are very proud of these programs and we hope that you find them helpful if you need to use them. There is more information on the programs later in the manual.

I would like to thank everyone who has been involved in helping to make this second edition possible especially the members of the “Handbook Committee” and those people who are not directly related to QSCIS who have given their time and expertise to contribute to various parts of the manual.

I would also like to thank PBF Australia for their assistance with the printing of this second edition.

On behalf of all of the staff of the QSCIS, I hope that you find this manual informative and helpful.

Dr Tim Geraghty MBBS FAFRM(RACP)
Director of Rehabilitation (Spinal Injuries)
Queensland Spinal Cord Injuries Service
Princess Alexandra Hospital
It is worth remembering that prior to the end of the Second World War, those who received a spinal cord injury were virtually handed a death sentence. Thanks to the pioneering work of Sir Ludwig Guttmann at Stoke Mandeville Hospital, we are now able to apply a much more positive approach to this devastating injury. All over the world there are Spinal Injuries Units, and Australia is fortunate in having Units in all States, except Tasmania and the Northern Territory. These units are regarded as some of the best in the world. The Spinal Injuries Unit at Princess Alexandra Hospital in Brisbane services the whole of Queensland, and the area north of Coffs Harbour in New South Wales. We also receive referrals from the Northern Territory, and sometimes even from Papua New Guinea.

Unfortunately there is no cure as yet for spinal cord injury. However, much can be done in the way of teaching people to cope with the function they have remaining. The purpose of this handbook is to explain, in simple language, the main problems that are associated with an injury to the spinal cord. Since no two people sustain identical injuries, at best this can only be a book that contains general information. We hope that it will help patients and their relatives and friends to understand more about the problems, and we would welcome any suggestions that you feel may make it more readable or more easily understood.

Vernon HILL, MBBS., BPhty, FACRM, FAFRM(RACP)
Director
Spinal Injuries Unit
# Table of Contents

## Chapter One: The Basics

A. Anatomy of the Vertebral Column and Spinal Cord ........................................... 7
B. The Autonomic Nervous System ........................................................................... 13
C. Definitions ........................................................................................................... 14
D. How Do Injuries to the Spinal Cord Happen? .................................................. 15
E. Effects of SCI on the Body ................................................................................... 16
F. Treatment of the Acute Injury and Prevention of Early Complications .......... 17
G. What About Improvement and Recovery? ...................................................... 21

## Chapter Two: Effects of the Injury

A. Skin and sensation
   • Skin care in bed .............................................................................................. 22
   • Skin care in sitting ......................................................................................... 27
   • Skin care and equipment ............................................................................... 33
   • Skin care and clothing .................................................................................. 39
   • Skin care and travel ....................................................................................... 41
B. The Urinary System .............................................................................................. 45
C. The Digestive System .......................................................................................... 62
D. Circulation ........................................................................................................... 75
E. Temperature Control ......................................................................................... 76
F. Autonomic Dysreflexia ...................................................................................... 77
G. Respiration ......................................................................................................... 79
H. Healthy Eating .................................................................................................... 92
I. Sex and Sexual Function .................................................................................... 97
J. Fertility and Pregnancy ....................................................................................... 106
K. Spasm ................................................................................................................ 113
L. Posture ................................................................................................................ 118
M. Contractures ....................................................................................................... 120
N. Splinting ............................................................................................................... 122
O. Tendon Transfers ................................................................................................ 124
P. Pain ....................................................................................................................... 126
Q. Age and Ageing .................................................................................................. 129
### CHAPTER THREE: ADJUSTING TO A SPINAL CORD INJURY

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>A. Psychological and Emotional Issues</td>
<td>131</td>
</tr>
<tr>
<td>B. Relationships</td>
<td>134</td>
</tr>
<tr>
<td>C. Sexuality</td>
<td>136</td>
</tr>
<tr>
<td>D. Parenting</td>
<td>138</td>
</tr>
<tr>
<td>E. Stress Management</td>
<td>140</td>
</tr>
</tbody>
</table>

### CHAPTER FOUR: RETURNING TO THE COMMUNITY

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>A. Transitional Rehabilitation Program</td>
<td>144</td>
</tr>
<tr>
<td>B. Accommodation</td>
<td>146</td>
</tr>
<tr>
<td>C. Finance and Compensation</td>
<td>150</td>
</tr>
<tr>
<td>D. Return to Work</td>
<td>154</td>
</tr>
<tr>
<td>E. Driving and Transportation</td>
<td>157</td>
</tr>
<tr>
<td>F. Leisure, Sport and Fitness</td>
<td>161</td>
</tr>
<tr>
<td>G. Guidelines for Travel</td>
<td>168</td>
</tr>
<tr>
<td>H. Equipment and Suppliers</td>
<td>174</td>
</tr>
<tr>
<td>I. Spinal Outreach Team</td>
<td>179</td>
</tr>
<tr>
<td>J. Community Services</td>
<td>180</td>
</tr>
<tr>
<td>K. Paraplegic Benefit Fund</td>
<td>188</td>
</tr>
</tbody>
</table>

### CHAPTER FIVE: WHO TO CONTACT AND HOW TO CONTACT THEM

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>A. The Queensland Spinal Cord Injuries Service (QSCIS)</td>
<td>189</td>
</tr>
<tr>
<td>• Spinal Injuries Unit (SIU)</td>
<td></td>
</tr>
<tr>
<td>• Transitional Rehabilitation Program (TRP)</td>
<td></td>
</tr>
<tr>
<td>• Spinal Outreach Team (SPOT)</td>
<td></td>
</tr>
<tr>
<td>B. Centrelink</td>
<td>190</td>
</tr>
<tr>
<td>C. Community Health Centres</td>
<td>190</td>
</tr>
<tr>
<td>D. CRS Australia (CRS)</td>
<td>190</td>
</tr>
<tr>
<td>E. Disability Services Queensland</td>
<td>190</td>
</tr>
<tr>
<td>F. Home and Community Care (HACC)</td>
<td>190</td>
</tr>
<tr>
<td>G. Housing Queensland</td>
<td>191</td>
</tr>
<tr>
<td>H. Independent Living Centre</td>
<td>191</td>
</tr>
<tr>
<td>I. Mackay and District Spinal Injuries Association</td>
<td>191</td>
</tr>
<tr>
<td>J. Medical Aids Subsidy Scheme (MASS)</td>
<td>191</td>
</tr>
<tr>
<td>K. Nursing and Personal Care Services</td>
<td>191</td>
</tr>
<tr>
<td>L. Paraplegic and Quadriplegic Ass. of Q. (PQAQ)</td>
<td>192</td>
</tr>
<tr>
<td>M. Paraplegic Benefit Fund (PBF) Australia</td>
<td>192</td>
</tr>
<tr>
<td>N. Queensland Advocacy Incorporated</td>
<td>193</td>
</tr>
<tr>
<td>O. Queensland Council of Carers</td>
<td>193</td>
</tr>
<tr>
<td>P. Queensland Housing Coalition</td>
<td>193</td>
</tr>
<tr>
<td>Q. Queensland Transport</td>
<td>193</td>
</tr>
</tbody>
</table>
### DIAGRAMS, ILLUSTRATIONS AND TABLES

<table>
<thead>
<tr>
<th>Title</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>The Vertebral Column and Spinal Cord</td>
<td>8</td>
</tr>
<tr>
<td>Vertebral Bones and Spinal Cord Segments</td>
<td>10</td>
</tr>
<tr>
<td>Dermatomes</td>
<td>12</td>
</tr>
<tr>
<td>Skin Care in Bed</td>
<td>22</td>
</tr>
<tr>
<td>Assessing Your Own Skin</td>
<td>23</td>
</tr>
<tr>
<td>Positioning in Bed</td>
<td>24</td>
</tr>
<tr>
<td>Pressure Points while Sitting</td>
<td>28</td>
</tr>
<tr>
<td>Performing a Pressure Lift</td>
<td>31</td>
</tr>
<tr>
<td>Problems Related to Splints</td>
<td>37</td>
</tr>
<tr>
<td>Skin Damage from Heat</td>
<td>38</td>
</tr>
<tr>
<td>Protecting Your Feet</td>
<td>40</td>
</tr>
<tr>
<td>The Urinary System</td>
<td>45</td>
</tr>
<tr>
<td>Medications for Your Bladder</td>
<td>55</td>
</tr>
<tr>
<td>The Digestive System</td>
<td>62</td>
</tr>
<tr>
<td>Medications for Your Bowel</td>
<td>65</td>
</tr>
<tr>
<td>The Lower Bowel</td>
<td>69</td>
</tr>
<tr>
<td>Foods that Effect Your Bowel</td>
<td>70</td>
</tr>
<tr>
<td>The Respiratory System</td>
<td>79</td>
</tr>
<tr>
<td>Muscles Used for Breathing</td>
<td>80</td>
</tr>
<tr>
<td>Assisted Coughing</td>
<td>83/84</td>
</tr>
<tr>
<td>Positions for Postural Drainage of the Lungs</td>
<td>88</td>
</tr>
<tr>
<td>Chest Percussion</td>
<td>89</td>
</tr>
<tr>
<td>Medications for the Respiratory System</td>
<td>90</td>
</tr>
<tr>
<td>How to Gain Weight</td>
<td>94</td>
</tr>
<tr>
<td>How to Eat Less Fat</td>
<td>95</td>
</tr>
<tr>
<td>How to Prevent Constipation</td>
<td>95</td>
</tr>
<tr>
<td>Male Sexual Organs</td>
<td>97</td>
</tr>
<tr>
<td>Female Sexual Organs</td>
<td>98</td>
</tr>
<tr>
<td>Correct Sitting Posture</td>
<td>118</td>
</tr>
<tr>
<td>Scoliosis</td>
<td>118</td>
</tr>
<tr>
<td>Kyphosis</td>
<td>119</td>
</tr>
<tr>
<td>Problems Related to Splints</td>
<td>122</td>
</tr>
<tr>
<td>Types of Splints</td>
<td>123</td>
</tr>
<tr>
<td>Recreational and Sporting Activities</td>
<td>162-165</td>
</tr>
</tbody>
</table>
A. ANATOMY of the VERTEBRAL COLUMN AND SPINAL CORD

The Bony Vertebral Column (Spinal Column)
- Supports the head and encloses the spinal cord.
- There are 33 bones or vertebrae in the spine:
  - 7 cervical vertebrae in the neck
  - 12 thoracic vertebrae in the upper back corresponding to each pair of ribs
  - 5 lumbar vertebrae in the lower back
  - 5 sacral vertebrae are fused together to form 1 bone called the sacrum
  - and 4 coccygeal vertebrae that are also fused to form the coccyx or tailbone.
- We refer to the vertebrae by their name and number so that the cervical vertebrae are C1, C2, C3.........C7 where “C” stands for “cervical” and the number is the position of the vertebrae counting down from the head.
  - Therefore the thoracic vertebrae become T1 - T12
  - The lumbar are L1 - L5
  - And the sacrum and coccyx do not have numbers and each is thought of as one bone.

The Spinal Cord
- Is an extension of the brain that runs down the back and is surrounded and protected by the bony vertebral column.
- It is surrounded by fluid that acts as a buffer to protect the delicate nerve tissues.
- It consists of millions of nerve fibres that transmit information to and from the limbs, trunk and organs of the body.
- Nerves called the spinal nerves or nerve roots come off the spinal cord and pass out between the bones to carry the information from the spinal cord to the rest of the body:
- **cervical nerves** (nerves in the neck) supply movement and feeling to the arms, neck and upper trunk
- **thoracic nerves** (nerves in the upper back) supply the trunk and abdomen
- **lumbar and sacral nerves** (from the lower back) supply the legs, the bladder, bowel and sexual organs.

The spinal nerves carry information from different levels (segments) in the spinal cord. Both the nerves and the segments in the spinal cord are numbered in the same way as the bones:
- So the cervical nerves and spinal cord segments are called C1-C8, the thoracic are T1-T12, lumbar are L1-L5 and sacral are S1-S5.
How do the vertebrae relate to the spinal cord?

- The level of the spinal cord segments do not relate exactly to the level of the vertebral bodies i.e. damage to the bone at a particular level e.g. L5 vertebrae does not necessarily mean damage to the spinal cord at the same level.
- This is because there are:
  - 7 cervical vertebrae but 8 cervical nerve roots leaving the cord
  - the thoracic spinal cord segments are compressed into the level between the T1-T10 vertebrae
  - the lumbar and sacral segments are at the level of the T11 and T12 vertebrae
  - the spinal cord ends around the level of the disc between T12 and L1 vertebrae
  - below this level is an extension of the spinal cord called the cauda equina (which means “horses tail” in Latin). The cauda equina consists of some of the spinal nerves that are continuing down before they pass out between the vertebrae.
• Cervical spinal cord roots C1-C7 correspond to upper aspects of vertebral bodies.

• C8 & lower spinal roots leave below appropriate vertebral body.

Bone notch at base of neck is back of C7

Sensation of C7 nerve is middle finger

Sensation of T4 nerve is approximately level with nipple line

Sensation of T6 nerve approximately level with bottom of sternum

Sensation of T10 nerve approximately level with “belly button

Sensation of T12 is approximately over pubic bone

Sensation of S3, S4 & S5 nerves is perineal (genital) area

• Sensations of lumbar nerves are over the legs

• Sacral segments (S1-S5 “cauda equina”) are level with T12-L1 vertebrae

T12 cord segment is level with T9 vertebra

Spinal cord ends approximately between L1 & L2 vertebral bodies

Sacral vertebrae are fused and help to make up the sacrum

Coccygeal vertebrae are fused → “Tail bone”

Sensation of T12 is approximately over pubic bone

Ribs attach to T1-T12

C5 vertebra & cord segment are associated

Spinal Cord Segments

Vertebral Bodies

Relationship between spinal cord segments and vertebral bodies
What are the myotomes?

- Each muscle in the body is supplied by a particular level or segment of the spinal cord and by its corresponding spinal nerve. The muscle, and its nerve make up a **myotome**.
- This is approximately the same for every person:
  - C3,4 and 5 supply the diaphragm (the large muscle between the chest and the belly that we use to breathe)
  - C5 also supplies the shoulder muscles and the muscle that we use to bend our elbow
  - C6 is for bending the wrist back
  - C7 is for straightening the elbow
  - C8 bends the fingers
  - T1 spreads the fingers
  - T1 - T12 supplies the chest wall and abdominal muscles
  - L2 bends the hip
  - L3 straightens the knee
  - L4 pulls the foot up
  - L5 wiggles the toes
  - S1 pulls the foot down
  - S3,4 and 5 supply the bladder, bowel and sex organs and the anal and other pelvic muscles

What are the dermatomes?

- Each part of the skin is supplied by a particular segment of the spinal cord and its corresponding spinal nerve.
- This is approximately the same for every person.
The Dermatomes (areas of the skin supplied by each segment of the spinal cord and the corresponding spinal nerve)
B. THE AUTONOMIC NERVOUS SYSTEM

The human nervous system has two parts – the somatic nervous system and the autonomic nervous system.

- The somatic (voluntary) nervous system is responsible for:
  - The movements of our arms and legs and other muscles and joints
  - The feeling in our skin

- The autonomic (involuntary or automatic) nervous system is responsible for the activities that happen automatically in our bodies:
  - The blood vessels and the way the blood moves around the body (circulation)
  - Breathing
  - Some aspects of Bladder, Bowel and Sexual function
  - Sweating and Temperature Control

The two components are not totally separate and both may be damaged when the spinal cord is injured.

One of the most important problems that can happen when the autonomic nervous system is damaged following spinal cord injury (SCI) is autonomic dysreflexia. This problem will be discussed in detail later in this handbook (see page 72).
C. DEFINITIONS

- **Tetraplegia / Quadriplegia**
  - Injury to the spinal cord in the neck causes a condition known as tetraplegia or quadriplegia. These terms mean exactly the same thing, one is a Greek term and the other is Latin.
  - There is injury to the spinal cord between the spinal cord segments C1 and T1.
  - This causes paralysis and loss of feeling involving all 4 limbs as well as the bladder, bowel and sexual organs.

- **Paraplegia**
  - Injury to the spinal cord below the neck causes paraplegia.
  - There is injury to the spinal cord below the T1 cord segment.
  - This causes weakness and loss of feeling in the trunk, legs and bladder, bowel and sex organs.
  - But the arms and hands are normal.

- **Level of injury**
  - We describe the level of the injury by referring to the last spinal cord segment where the movement and feeling are normal.
  - For example, if your injury is called “C5” this means that you would be able to bend your elbow normally and would have normal feeling to around the level of your elbow but below that the movement and feeling would be reduced.

- **What do the terms Complete and Incomplete mean?**
  - **Incomplete**
    - An incomplete injury is one in which there is some movement or feeling below the level of the injury or in the genital region.
    - This implies that the damage in the spinal cord does not involve the whole spinal cord and that some messages are getting past the area of damage.
    - The chances of improvement and recovery are better if the injury is incomplete.
Complete
- A complete injury is one in which there is no movement or feeling in the genital region.
- This means that the damage in the spinal cord involves the whole spinal cord and that no messages are getting past the area of damage.
- The chance of improvement and recovery if the injury is complete is much lower.

D. HOW DO INJURIES TO THE SPINAL CORD HAPPEN

Spinal Cord Injury occurs:

- if pressure is applied to the spinal cord or
- if the blood supply (which brings the oxygen to the cord) is cut off for more than about 15 minutes.
- In most cases, the spinal cord damage is probably due to a combination of both these factors.

During the accident that causes the spinal cord injury, the bony vertebral column is usually violently bent forwards or backwards:

- this causes the bones to dislocate (move out of their usual position) or fracture (break).
- broken fragments of bone may press on the spinal cord or
- the spinal cord may be stretched across dislocated bones.
E. EFFECTS OF SCI ON THE BODY

• Spinal Shock
  - At the time of the accident all individuals with significant cord injury have "spinal shock" present.
  - This is like a "blackout effect" and happens because the injury causes total loss of function in the spinal cord at or near the level of injury.
  - It may last for several days only or up to several weeks.
  - It may be difficult to determine the exact extent of the injury during spinal shock.

• Effects of SCI on the Body

Injury to the spinal cord may cause:
  - paralysis (loss of movement) below the level of the injury
  - loss of feeling below the level including the ability to:
    - feel touch on the skin
    - feel painful sensations
    - tell the difference between hot and cold
    - know what body parts are doing and what position they are in without looking at them (called proprioception)
  - bladder and bowel function to be altered
  - sexual function to be altered
  - fertility may be affected (in males)

Depending on the level of injury:
  - temperature control and sweating may be altered
  - breathing may be effected
  - blood pressure and circulation may be altered
  - autonomic dysreflexia may occur.
F. TREATMENT OF THE ACUTE INJURY AND PREVENTION OF EARLY COMPLICATIONS

- Treatment to reduce the severity of SCI

  - Methylprednisolone (High Dose Steroids)
    - This medication is given early after the injury in an attempt to try to reduce the severity of the injury in the spinal cord and therefore increase the chance of recovery.
    - It must be given within 8 hours of the injury to be effective.
    - It is still somewhat controversial and is not used universally around the world.
    - It may also occasionally have side-effects such as stomach ulcers.
    - There are no guarantees that this therapy will be successful and it is not a miracle cure.

- Treatment of the Vertebral Fracture or Dislocation

  Treatment of the fractured or dislocated bones can be done by surgery or by conservative methods i.e. bed rest.

  - Surgical Treatment
    - Depending on the type of fracture, an operation may be required to stabilise (hold the bones in a good position) and help the bones to heal.
    - There is no strong evidence that performing an operation of this sort helps the nerves to repair themselves and recover.
    - It does allow you to sit up, get out of bed and commence rehabilitation earlier.
    - If you require an operation, this will be discussed with you in detail by the surgeon performing the operation and you will need to give your consent.

  - Conservative Treatment
    - Not all fractures need to be or can be operated on. Sometimes a period of bed rest is the only effective treatment.
    - Fractures of any part of the body need at least 6 weeks to heal and usually at least this long is required in bed. Sometimes a longer time is needed.
• **General Points**

Spinal Cord Injury not only causes major trauma to your neck and spinal cord but also effects the way the whole body functions. Other injuries can also complicate the problems.

- Because of this, the acute period soon after the injury is very important and there are many things that must be done in the first few weeks after the injury to ensure that you do not have other complications.
- Some of these include:
  - **Regular blood tests** to check your blood count and blood chemistry.
  - **X-rays** of the fracture, chest and other injuries.
  - **Special x-rays called Computerized Tomography (CT) or Magnetic Resonance Imaging (MRI) scans** may be required.
  - **Other specialists** may come to see you if you have special medical problems.
- Some of these things will become frustrating or be uncomfortable but please try to be patient and remember that tests are never done unless they are absolutely necessary to keep you as healthy as possible.

• **Care of the Stomach**

- After any major trauma and after SCI, the stomach stops working temporarily and you will not be able to eat or drink anything for a few days, sometimes longer.
- During this time you will be given all the fluid you need by **intravenous drip**.
- Sometimes a thin plastic tube called a **Nasogastric Tube** must be put down your nose into your stomach so that gastric juices can be removed to prevent vomiting.
  - This is uncomfortable but it will be removed as soon as it is safe to do so - usually a couple of days.
- You are also at risk of developing stomach ulcers so you will be placed on a special medication to prevent this. This medication (usually Ranitidine) continues for several months.
- Once the stomach begins to work again, food and fluids will be slowly restarted.

• **Care of the Skin**

- Special care must be taken of the skin because of loss of feeling, especially when you are in bed.
The skin is checked regularly and a special bed is used that enables you to be turned from one side to another at regular times. The aim of all these things is to prevent pressure sores from developing because you have stayed in the same position for too long.

• Care of Paralysed Limbs

- Prevention of stiffness and contractures
  - If you are not able to move your limbs they can become stiff and eventually would freeze in one position (a contracture).
  - The physiotherapist and occupational therapist move your joints regularly to prevent this from happening.
  - You may also be provided with special splints to wear on your hands and legs that help to reduce swelling, prevent deformity and maintain your joints in a good position.

- Prevention of Blood Clots
  - Inability to move your limbs also means that the blood does not circulate as well as usual.
  - This can lead to blood clots in the legs called Deep Vein Thrombosis or DVT. This can cause swelling and discomfort in the leg.
  - Occasionally part of this blood clot can break off and travel in the circulation to the lungs. This is called a Pulmonary Embolus or PE. If this happens it can effect your breathing and this can be dangerous.
  - To prevent both these things:
    - the physiotherapist will move your legs regularly.
    - you will also be given special stockings (called TED stockings) to wear and sometimes, special electrically inflated stockings that intermittently fill with air and then empty to help the blood to circulate better.
    - You will also be put on a medication called Heparin that helps to thin the blood and prevent clots from forming. This is given several times a day by injection under the skin.

• Care of Chest and Breathing Problems

- The ability to breathe may also be effected after spinal cord injuries.
- This applies to all people with injuries above T12 due to paralysis of the abdominal (stomach) and intercostal (between the ribs) muscles.
The higher the injury above T12 the more severe the breathing difficulty will be.
Your ability to cough well may also be effected.
These problems will be worse if you have other injuries to your chest or lungs.
The breathing and coughing difficulty can lead to chest infections and problems with coughing up secretions from the lungs.
To prevent this:
- The physiotherapist and nurses will assist you with breathing exercises and coughing.
- You may need to have oxygen given by a mask over your mouth and nose.
- Regular x-rays of your chest and blood tests may be needed.
- Antibiotics in tablet form or through an intravenous drip may be required.
Occasionally due to infections or other injuries, breathing may temporarily fail and a mechanical ventilator (respirator) may be needed to help you to breathe until your lungs recover. If this is needed it will be done in the intensive care unit in the main hospital.

**Care of the Paralysed Bladder**

- All activity in the bladder stops during the "spinal shock" phase of SCI and the bladder will not empty by itself.
- To allow the bladder to drain an **Indwelling Catheter (IDC)** is put into the bladder.
- This will remain in place until further investigation of the bladder can occur when you are out of bed.

**Care of the Paralysed Bowel**

- The activity in the lower bowel and rectum may also be effected immediately after the injury.
- This means that you will not be able to empty your bowel by yourself.
- Once you are able to start eating and drinking again, you will need tablets and also enemas or suppositories (these are placed in your anus) to help your bowel work.
- Because initially you will be restricted to bed, bowel care will need to be done in bed. The nurses will help you with this.
WHAT ABOUT IMPROVEMENT AND RECOVERY?

- Initially it may be difficult for your doctors to tell you exactly how severe the injury is and therefore, what the chances of improvement and recovery are. This is particularly true if the SCI is incomplete.

- **Remember:**
  - All spinal cord injuries are different and what happens with one person does not necessarily happen with another.

- The nerves in the spinal cord are very delicate and when they are injured they are sometimes not very good at repairing themselves.

- At present, there are few things that doctors can do to help the nerves in the spinal cord to repair themselves (except for the methylprednisolone described above). Recovery depends on how seriously the spinal cord has been damaged and whether the nerves can recover.

- Unfortunately total recovery from SCI is very rare.
  - Complete spinal cord injuries are more severe and the more time that passes after the injury the less chance there is of significant recovery.
  - People with incomplete injuries generally get more recovery than those with complete injuries but it is impossible to know exactly how much recovery there will be or how long it will take to happen. It is usually said that after 2 years there is little chance of further improvement.

  - Unfortunately, at present there is no cure for spinal cord injury but there are many doctors and researchers around the world looking for ways to help the nerves to heal themselves and recover.
CHAPTER TWO:
EFFECTS OF THE INJURY

A. SKIN AND SENSATION

SKIN CARE IN BED

Care of your skin when lying down is extremely important. When you are lying down, pressure is placed over several bony points, and these will change depending on the position you are lying in. The most common pressure points are marked on the diagrams below.

Lying on your Back

- Heels
- Tailbone
- Elbows
- Shoulder blades
- Back of head

Lying on your Side

- Between ankles
- Between knees
- Outer ankles
- Outer knees
- Hip bones
- Ears
- Shoulders
SKIN TOLERANCE

- Skin tolerance is the amount of time that you can spend in one position without getting a red mark or pressure sore due to too much pressure on your skin.
- It can vary from person to person.
- Some people can lie for hours in one position without their skin becoming marked while some will find their skin becomes red after only a short time.
- There are many factors that contribute to your ability to tolerate pressure. These can include:
  - how bony you are
  - how easily you can move yourself around
  - your general health.

Skin Tolerance - Assessing Your Own Skin

You should assess your own skin tolerance over a period of time.

- This means you need to spend time lying on your back and sides in order to assess your skin tolerance in all these positions.
  - For example, when you start assessing your skin tolerance you may first lie on one side for four hours, then the other side for four hours, then your back for four hours with skin checks immediately on each turn.
  - If your skin is free of marks or swollen areas, the following night you could increase the time spent in each position by half an hour.
However, if you do find a pink, red or swollen area, you will need to stay off the area until the mark has gone.

You should also reduce your turn times by at least one hour and begin the half hour increase per night again.

Once you are able to lie in one position for quite a few hours it will not be necessary to lie in each of these positions in one night.

In this situation, you could alternate your positions from one night to the next.

Most people will tolerate pressure better in one position than in others. For example, you may be able to spend longer on your back than on either of your sides.

Most of us have a preferred sleeping position, but it is very useful to alternate your position to allow your skin to remain healthy.

The reason for this is that if you do develop a pressure area, you will be able to lie in one or more of the other positions until your pressure area has healed.

Some people are also able to lie prone (on their stomach). This will depend on your level of injury. The benefits of lying prone are that it provides an alternative position when lying in bed and it can help reduce spasms and hip joint contractures. If you are able to lie prone you must gradually increase your skin tolerance as with lying in other positions.

Sitting up in bed is not recommended as pressure areas created by shearing forces can develop.

Shearing forces occur when the skin moves one way while the underlying bones move the other way.
- When you sit up in bed you tend to slide down the bed causing shearing forces to the flesh on your buttocks, sacrum, tailbone and heels.

- Although this process of assessing your skin’s tolerance may sound like a lengthy one, the results can have great benefits:
  - The gradual increase in time will result in greater confidence that your skin will remain healthy
  - You may be able to lie in one position for up to ten hours - that may mean ten hours of uninterrupted sleep
  - If your partner or carer assists you with your turns they will also be grateful for a night of uninterrupted sleep

**Skin Tolerance - Weight Loss**

- If you notice you have lost weight, or the muscles in your legs have wasted further, you will need to pay more attention to the care of your skin.
- When you lose weight or muscle bulk, the bones of your pelvis can become more prominent as more of your body’s natural padding is lost. You may need to turn in bed more frequently as your skin may have a reduced tolerance for pressure.
- If your weight loss has been severe and you are developing red areas, you will need to greatly decrease the time between your turns and gradually re-assess your skin tolerance again as described earlier.
- You may need to look at acquiring a pressure-relieving mattress if you are still having problems with your skin marking.
- Lying on a sheepskin can also be effective.
- Some people will continue to have some muscle wasting for one to two years after injury, however if you are uncertain of the cause of your weight loss it would be advisable to contact your doctor.
- Examination of your diet is also advisable as good skin tolerance depends on good nutrition.

**Skin Tolerance - Illness**

- If you are unwell for any reason e.g. urinary tract infection, chest infection, your skin tolerance will be effected.
- You should decrease the time between your turns whilst in bed and be vigilant with checking your skin.
- Once you have recovered from your illness you will not be able to go straight back to lying in one position for an extended period.
- You will need to gradually re-assess your skin tolerance.
MATTRESSES

• Many factors can influence the type of mattress that you require for a good night’s sleep while preventing pressure related problems.

• Some of these factors can include:
  - the tolerance of your skin to pressure
  - your ability to move yourself around in bed
  - how you transfer
  - and pain, to mention a few.

• Some people will manage with a normal mattress, while others may require additional protection such as sheepskin overlays, pressure relieving mattress overlays or pressure relieving mattresses that replace your existing mattress.

• If you go on holiday or sleep somewhere other than on your usual mattress you should not assume your skin tolerance will be the same.
  - You should reduce the time spent in one position and thoroughly check your skin after each turn, increasing the times gradually if no reddened areas are found.
  - If possible it is a good idea to take your mattress with you when staying away from home.

• If you obtain a new mattress or a new bed, you should re-assess your skin tolerance.

Questions

• How do you assess your skin tolerance for lying in bed?
• How would finding a pink, red or hardened area affect your turning times when in bed?
• What are the benefits of assessing your skin tolerance when in bed?
• How does weight loss affect your skin tolerance?
• Do you need to rotate from your preferred position of sleeping each night?
• Why is not sitting up in bed recommended?
• What is a shearing force?
• How does illness affect your skin tolerance?
• What should you do if you are not sleeping on your usual mattress?
SKIN CARE WHEN SITTING

Why is my skin at risk when I am sitting?

- If you watch a group of people who are sitting down, you will notice that nobody sits perfectly still for very long.
  - We constantly readjust our position because we get uncomfortable if we sit in the same position for too long.
  - Nerves normally transmit messages of pain or discomfort to our brains, causing us to move.
  - We remove pressure from one area of our buttocks and shift it to another without even thinking about it. We do this by crossing or uncrossing our legs, leaning forward or backward, leaning from side to side, or even by standing up!
- People who have had a spinal cord injury can completely or partially lose their ability to feel this discomfort, and may have more difficulty moving to relieve pressure.
  - For these reasons, you may be at risk of developing skin problems when sitting for long periods of time.
- There are many factors that can increase your risk of developing pressure sores. For example, if you are bony or thin, have frequent bowel or bladder accidents, perspire a lot or are unwell, the risk of developing problems may be greater.

- There are many ways of relieving pressure and minimising the risk of developing pressure sores.
- Determining what is best for you will depend on a number of factors and will require some experimentation. Some of the areas that you and your physiotherapist will discuss include equipment (wheelchair and cushion), posture, and different methods of shifting your weight to relieve pressure.

Why are cushions so important?

- Everybody who uses a wheelchair should sit on a cushion.
- When we are sitting, we sit on two bones (that are part of our pelvis) called the ischial tuberosities.
  - It is very important that you know where these are (where to look with a mirror) and what they normally feel like.
- Sitting may also put pressure on our coccyx (tailbone).
- If you sit with poor posture (e.g. slide your bottom forward on the cushion), there may even be pressure over your sacrum (the flat bone at the base of the spine).
Cushions provide pressure relief because they spread your body weight over a larger surface area. Instead of all the pressure being taken over the ischial tuberosities, as you sink into the cushion, the pressure is distributed more evenly over the buttocks and thighs.

- Different cushions provide different degrees of pressure relief, depending on their design, and the material from which they are manufactured.
- Because everyone is different, you should discuss your needs in this area with your physiotherapist.

In deciding which cushion is best for you, you and your physiotherapist should consider:

- Whether you have normal feeling(sensation) over your buttocks
- The design of your wheelchair
- How your wheelchair is adjusted (e.g. whether it is set up correctly for you)
- Your posture
- Your ability to relieve pressure (e.g. lift, lean, shift, stand)
- How you transfer in and out of your wheelchair
- Any pain you may experience while you are sitting
- Any history of pressure sores or other skin problems

- You should be given the opportunity to trial a number of pressure relieving cushions to determine which is best for you.
- Your cushion and wheelchair should be considered together, as they function as a unit for pressure relief and postural support.
• As a general rule, every new cushion should be trialled for at least a week, unless problems arise. This can be a lengthy process for some people, but is extremely important.
• **Pressure sores are an extremely serious complication of spinal cord injury.**
  - If you develop any red areas or skin breakdown from sitting, it is important that you try to determine the cause as soon as possible.
  - Most importantly, **you should never continue to sit on red or broken skin, or if hardening or swelling is present beneath the skin.**
  - Any pressure applied to these areas will prevent healing from taking place, and will most likely make things considerably worse.
  - Sitting on a pressure relieving cushion is **not** adequate protection if you have a pressure sore.

**Why is good posture so important?**

• **Good posture** usually means having your bottom back as far as it will go on the seat, with your pelvis level, and your spine reasonably straight (actually a gentle ‘S’ shape when viewed from the side, and straight when looking from the front). Good posture allows the pressure to be distributed over the areas that are able to tolerate it most effectively (ischial tuberosities, buttocks and thighs)
• **Poor posture** usually results in your spine taking on a ‘C’ shape. This can occur if your bottom slides forward on the seat, placing greater pressure over the coccyx and sacrum.
• The skin over the coccyx and sacrum is thin, with very little padding. It does not tolerate pressure or shearing forces well, and will break down more easily.

**How can I minimise the risk of developing a pressure sore from sitting?**

• **Check your skin regularly** (at least twice a day), particularly immediately after you have been sitting.
  - If you develop red marks, take note of their location, whether they blanche or not, and how long they take to fade.
  - If they last longer than 20 to 30 minutes, or the skin does not blanche when gently pressed, this means that skin damage has probably occurred.
  - You should determine the cause of the problem as soon as possible – this may mean enlisting the help of your physiotherapist or experienced health professional.
• **Check your posture regularly**, particularly when you first get into your wheelchair. If you are concerned that your posture is not as good as it used to be, seek the advice of your physiotherapist.

• **Check that your thighs are well supported.**
  - This may mean checking the height of your footplates.
  - Well-supported thighs will assist in distributing the pressure over the largest possible surface area.

• **Make sure that your wheelchair cushion and seat are long enough to support your thighs adequately, without putting pressure over the back of your calves.**

• **Relieve pressure as often as you can.**
  - If you are sitting on a foam cushion, you may need to relieve pressure as often as every 15 to 20 minutes.
  - On a recognised pressure-relieving cushion such as a Roho or Jay, you should relieve pressure at least once an hour.

• **Ensure that your cushion and wheelchair are both in good condition.**
  - Foam cushions should generally be replaced every 6 to 12 months.
  - Your therapist will be able to show you how to check that your special pressure-relieving cushion is functioning correctly.

• **NEVER** sit on red marks, broken skin, or areas where swelling or hardening are present beneath the skin, even if you use a special pressure relieving cushion.

**Why should I relieve pressure?**

• Sitting in one position for a long period of time reduces the blood supply to areas of skin that are under pressure from underlying bones.
• This reduces the amount of oxygen and nutrients to skin cells, and leads to the accumulation of cellular waste products that can also be harmful.
• If cells are deprived of oxygen and nutrients for prolonged periods of time, localised cell death can occur.
• If sufficient cells in any one area die, a pressure sore, or skin breakdown will result.
• Continuing to sit on an area such as this can result in a rapid increase in the severity of the sore.
• Relieving pressure allows the circulation to temporarily return to these areas, providing the cells with oxygen and nutrients, and removing waste products. This will allow skin cells to remain healthy.

How can I relieve pressure?

• There are a number of ways to relieve the pressure from your buttocks while you are sitting.
• If you have weakness in your upper limbs, you may need assistance to perform a pressure relieving manoeuvre.

The most common methods are:

➢ The pressure 'lift' - using your arms, lift your bottom off the cushion and hold it up for 15 to 20 seconds. If you are not strong enough to lift your bottom completely off the seat, you may still be able to partially relieve the pressure.

➢ The pressure 'lean'
  ▪ You can shift your weight to one side by leaning, thereby removing pressure from the opposite buttock. Once again, you should hold this position for 15 to 20 seconds, and then repeat in the opposite direction. If you are unable to do this by yourself, someone can assist you to perform the manoeuvre.
  ▪ Alternatively, leaning completely forward, until your chest sits on your knees, will also relieve pressure from your buttocks.
Once again, if you cannot get up and down yourself, you may require some assistance.

- Some powerdrive and manual wheelchairs offer a ‘tilt-in space’ feature.
  - This allows the whole seat and backrest to be tilted backwards.
  - In the ‘tilted backwards’ position, pressure is reduced over the buttocks and is transferred to other areas.
  - If you use a chair that has this feature, you should develop a habit of regularly tilting to relieve pressure, at least once every hour or two.
  - ‘Tilting’ is preferable to ‘reclining’. In a ‘reclining’ chair, the backrest reclines, but the seat stays in the same position (in a ‘tilting’ chair, both the seat and backrest tilt backwards). Reclining the backrest of a wheelchair tends to cause the person to slide forwards, placing pressure and causing shearing forces over the tailbone and sacrum.

- If you are able, standing up is another good way of relieving pressure.
- Spending some time in bed in the middle of the day may be a useful method of relieving pressure for some people.

Questions

- What cushion are you using?
- How often should you relieve pressure on this cushion?
- How do you know if your cushion is not working?
- What do you do if your cushion is not working?
- What maintenance does your cushion require?
- How often should your cushion be replaced?
- Can you describe the different ways to relieve pressure?
- In what situations would the risk of pressure areas increase in sitting?
SKIN CARE AND EQUIPMENT

When using any of your equipment items it is important to consider skin care precautions. The following section outlines precautions that should be applied with the basic self care and mobility equipment items.

**Shower Commode Chairs**

As with wheelchairs, shower commode chairs should be prescribed to maintain correct posture and positioning while providing for maximal independence. Skin care and the prevention of any possible pressure areas are also important considerations.

- For people with a spinal cord injury **padded seats** on the shower commodes are recommended.
- A padded seat assists in reducing the risk of possible pressure areas and these seats are available in different sizes and with the opening at different positions (e.g. front, back, right, left, no opening).
- If required, additional padding can also be attached to the shower commode seat (e.g. tie on padded foam cushion, tie on Roho commode cushion).

However even with the padding it is still important to be aware of skin care precautions and to ensure that the equipment is in good working order. For example:

**Precautions:**

- **Tears in the padding** can cause possible trauma to the skin. If the padding does have a tear in it, it should be replaced.
- Similarly, **prominent or open seams** should be noted and repaired.
- **With age and continual use**, the padding can tend to flatten down and may no longer be providing adequate pressure relief. It is important to **monitor your skin after use of the shower commode** and to have **the padded seat replaced** if it is no longer providing adequate pressure relief.
- The foam **does not provide for full pressure relief** and prolonged sitting on the shower commode without some form of pressure lift should be avoided. As with the above point it is important to monitor your skin carefully after use.
- **Care needs to be taken if transferring onto the shower chair** (e.g. you need to avoid scraping or rubbing against the edge of the seat, the wheel, brake lever or any other part of the shower chair). It is possible to get different wheel or seat heights and this will be considered during the initial prescription of the commode. Remember,
if a poor transfer is performed when your skin and the shower commode is wet, a scrape or tear in your skin is more likely to occur.

The following aspects should also be considered with positioning in the shower commode chair:

• Footrests should be at the correct height

• Armrests should be supportive. Gutter armrests are available if required.

• The backrest should also be of a suitable height and type.

• Reclining chairs or tilt-in-space options are available if required.

It is also important to ensure that the equipment is suitable for you over time (e.g. sometimes if there is any significant change in weight or body shape, etc. the chair may need to be reviewed).

General maintenance of the chair also needs to be conducted regularly to ensure that it is in correct working order.

**Padded Toilet Seats and Bath Boards**

If you use a padded toilet seat or padded bathboard the same precautions as listed above should be followed.

**Hoists and Slings**

Appropriate use of your hoist and sling is very important to ensure that skin care precautions are adhered to. It is very important that both you and your carer have a good understanding of the factors involved.

For example:

• Size of the Sling:
  - The sling needs to provide adequate support and positioning.

• Shape of the Sling:
  - While the sling needs to provide adequate support during hoisting, adequate clearance of fragile skin areas may need to be considered.

• Type of Sling Material:
  - Slings are available in mesh or canvas type materials with or without
padding. A variety of slings will be trialled and the one most suitable for you will be recommended.

• Application of the Sling:
  - Ensure that your carer rolls you correctly so that the sling can be put in place or removed easily.
  - Make sure that the sling is not pulled through under the skin, i.e. the carer needs to lift your legs so that the sling can be put in place or removed easily without rubbing on the skin. Particularly, tearing of the skin is more likely to occur if the skin or the sling is wet.
  - Avoid twists in the straps and ensure that the section underneath the legs is not bunched up. This is important to reduce shearing effects when being lifted.
  - Do not continue to sit on the sling once positioned, but have the hoist sling removed.

• Hygiene/Care of the Sling:
  - If the sling is soiled or wet it is important that it is laundered correctly. Ideally the sling should not be used when wet or soiled and if possible a back up sling should be obtained.

• When Hoisting:
  - Ensure that your carer raises the hoist adequately so that your bottom clears the bed or chair.

It is also important to ensure that the equipment is suitable for you over time (e.g. sometimes if there is any significant change in weight or body shape, etc. the sling may need to be reviewed).

**Electric Beds**

Appropriate use of your electric bed is very important to ensure that skin care precautions are adhered to. It is very important that both you and your carer have a good understanding of the factors involved.

For example:

• Correct positioning in bed (use of pillows, etc.) is essential.

• If you or your carer are controlling the head raise and lower feature of the bed it is important to be aware of not sitting too long in a semi reclined position (definitely less than 30 minutes).
In this position, you will tend to slide down the bed and this can increase pressure and shearing forces, particularly over the sacrum and coccyx area.
Consequently, reddened areas would likely develop here.

- You need to ensure that the pressure relieving mattress that you have is appropriate for use with an electric bed (i.e. that the mattress will still have pressure relieving qualities when the head or foot of the bed is raised).
- If you are in doubt as to whether your pressure-relieving mattress is suitable for you or the bed consult your Occupational Therapist or Nurse.

**Mattresses**
- Whilst you are in the Spinal Injuries Unit it will be necessary to decide on whether you require a special pressure relieving mattress.
- This will depend on a number of issues e.g. sensation, skin tolerance, ability to change position as needed etc.
- Different mattresses will provide differing amounts of pressure relief in side lying and supine for an individual, so your Therapists and Nurse will assist you with your selection.
- You need to trial a variety of pressure relieving mattresses over an appropriate period of time. It is a lengthy process as with any equipment selection.
- Be aware that using fitted or tight sheets will reduce the pressure relief provided by the mattress, so it will be important to consider linen carefully.
- It will also be important to discuss the appropriate use of sheepskins and pillows for positioning with your Therapists or Nurse.

**Skin Care and Splints**

Any device applied to your body has the potential to cause skin problems. If you wear splints during the day or night you should:

- Regularly check your skin and monitor the fit and application of the splint.
- Ensure that straps are firm but not tight.
- Be particularly aware that reddened areas are most likely to develop over bony prominences.
- Report any problems with excessive sweating as this may also contribute to skin breakdown or other problems.
• Be aware that if some muscle wasting occurs in your hands, your splints may become too loose which could cause rubbing. In this case your splints may need reviewing by an Occupational Therapist.

**Problems related to the use of Splints**

<table>
<thead>
<tr>
<th>PROBLEM</th>
<th>POSSIBLE CAUSES</th>
<th>WHAT TO DO</th>
</tr>
</thead>
</table>
| Skin irritation, red areas or blisters | - Pressure due to splint fitting incorrectly  
- Splint not applied correctly  
- Poor sensation | - Remove splint  
- Review HOW TO APPLY  
- Review WEARING REGIME |
| Increase in swelling             | - Strap fastened too tight  
- Incorrect position of arm/hand | - Loosen straps and review application  
- Keep arms supported |
| Pain                             | - Splint or straps may not be applied correctly | - Review wearing regime  
- Keep arms supported |

If any of these problems persist contact an Occupational Therapist.

**SKIN CARE AND SAFETY IN THE KITCHEN**

The following are some considerations for safety in the kitchen:

• It is important to have a good understanding of your sensation (e.g. are there areas on your body where you cannot feel hot or cold?). Being aware of these areas (as well as the areas where you may be able to accurately detect hot and cold) can help in preventing possible burns.

• When preparing food, be careful not to rest hands or arms on or near hot surfaces (e.g. edge of fry pan, hot plates). Remember that steam can burn also.

• When using cooking appliances, be aware that these surfaces may be very hot (e.g. sides/top of toasters, grill and kettle, etc.).

• When using the sink, be aware that the bottom of the sink and the water pipes can become very hot. Ideally these should be insulated.
- When carrying hot foods or drink, be careful not to rest them directly on your lap or between your legs. The use of a stable table or tray is a convenient way to carry items and prevent burns.

- If you have altered sensation in your hands be careful when eating hot finger foods as they can cause burns.

**Other precautions:**

- Be aware that there are some similar considerations when in the bathroom e.g. dripping taps, water pipes. It is also possible to lower the hot water temperature using a regulating thermostat.

- Be aware of not sitting too close to a bar heater or camp fire, etc.. Regularly check your legs to ensure that they are not getting too hot. Remember that the metal on your wheelchair will also heat up and could potentially cause burns.

QUESTIONS

**Padded Seats**

- Why is a padded seat on the toilet or other showering equipment (e.g. bath board, shower bench, shower commode) important?
- Padded seats should be checked regularly for signs of wear and tear. What should you look for?
• What aspects should be considered when positioning in the shower chair?

Hoists

• What skin care precautions should you be aware of when using a hoist and sling?
• What is the recommended time limit for sitting semi-reclined in bed?
• If you wear splints, what skin care precautions should you be aware of?

Safety in the Kitchen

• Why is it important to have a good understanding of your sensation?
• What safety precautions should you be aware of when in the kitchen?
• What other skin care precautions should you be aware of in regards to heating?

SKIN CARE AND CLOTHING

Clothing can increase the risk of developing a pressure area therefore it is very important to be aware of the type and positioning of your clothing.

Things to Avoid

• Clothes that are too tight
• Rough or thick seams
• Back pockets
• Back zips, buttons or studs
• Tight fitting underpants

Positioning Of Clothing

Checking the position of your clothing is just as important as being straight in the chair.
• Ensure there are as few wrinkles as possible underneath you
• If you are wearing trousers ensure the seam is positioned between your buttock cheeks
• Clothing can sometimes ride up when transferring so check for “wedgies”
**New Clothes**

When wearing a new style of clothing, check skin after ½ hour to see whether you have any marks. If no marks are present, increase the time of wearing those clothes as your skin tolerance allows.

**Important Things to Remember**

- Avoid keeping anything in your pockets e.g. coins in trouser pockets, as these may cause pressure areas.
- Metal holds heat so if you have clothing with metal zippers or studs e.g. jeans, and you are near a heater or fire, the metal parts on your clothing may burn your skin.
- Tight fitting belts may cause a pressure area.
- Avoid underwear that fits tightly around your waist and in particular your legs. The latter can cause a pressure area in your groin or bottom.
- Be careful not to catch your skin when doing up zips and buttons.
- Be careful of tight fitting clothes and the pressure they cause on catheters and leg bags.
- Ensure leg bags themselves are not worn too tight.

**Footwear**

Shoes should be worn to protect your feet from damage and if possible at least one size bigger than your normal shoe size.
• The inside of your shoes should be free of rough seams or ridges.
• Check your shoes for foreign bodies before putting them on.
• If your shoes have a tongue ensure it is pulled out and not bunched up inside your shoe.
• Check that the laces are not caught up inside your shoes.
• Avoid socks that have a rough seam across the toes.
• Socks should not be tight around the toes, ankles or around the leg.
• While anti-embolic stockings (TEDS) or compression stockings are worn they should be free of creases at the back of knees and ankles.
• When wearing new shoes you must check your feet after wearing them for \( \frac{1}{2} \) hour. If you have any lumps or marks you may need to try a larger size after the marks have gone. If your feet are free from lumps or marks increase the time wearing your new shoes as your skin tolerance allows.
• Check the position of your toes and ensure they are not caught or folded over.
• Remember a firm soled shoe encourages good foot positioning.

**QUESTIONS**

• What features in clothing should you avoid?
• What should you check for when sitting in regards to your clothing?
• What things should you be aware of regarding footwear?
• When buying new shoes, what should you look for?
• What skin care precautions should you take with socks or TED stockings?

**SKIN CARE AND TRAVEL**

**Why is my skin at risk when I travel?**

• Travelling, either by car, plane, bus or train, poses a number of unique risks to your skin.
  - You may need to transfer in difficult or cramped situations, and will usually have to spend lengthy periods of time out of your wheelchair, depending on the length of your journey.
  - Knowing what to expect will help you to plan how you will manage these challenges, and minimise the risk of developing skin problems.
**Travel by Car**

- You should endeavour to **relieve pressure every 100km, or every hour**, whichever comes first. You will need to do this whether you are passenger or driver.
  - Pressure relief can be achieved by pressure lifts or by leaning from side to side to remove pressure from the ischial tuberosities.

- If possible, you should **use a pressure-relieving device** for added insurance.
  - A pressure-relieving cushion can be used, but many people find that this sits them up too high in the car.
  - If you use a Jay cushion, the fluid pad may be removed from the base and used alone to provide some protection.
  - A piece of Velcro the same width as the base can be used to help maintain the shape of the pad.
  - If you don't wish to use a cushion in the car, a sheepskin will also offer some protection.
  - **Cushions or sheepskins are not a substitute for regular pressure relief.**

- You should always wear **shoes and socks when in a car**.
  - The floors of some older cars can heat up, causing burns to feet.
  - If you are in the car for a long period, you should reposition your feet from time to time.

- **Take care not to have your feet directly under heating vents** - hot air can also cause skin burns.

- **Be wary if the car has been sitting in the sun.**
  - Seat upholstery, belt buckles and other surfaces can hold a considerable amount of heat.
  - If these surfaces come into contact with your skin, burns can occur.

- If you are travelling long distances in hot conditions, make sure that you **drink plenty of fluids** (water is best).

**Air Travel**

Check in and transfers...

- When you are checking in your baggage, insist that you be allowed to remain in your wheelchair until boarding time.
This will allow you to go to the bathroom before boarding, and means you can stay sitting on your cushion for as long as possible.

• When checking in, also ask to be seated in an aisle where the armrest is removable - this will mean a safer, easier transfer when you are getting on and off the plane.

• You will be first on the plane and last off. This can mean an extra hour or more on the plane, in addition to the flight time, so it is usually advisable to visit the bathroom before boarding.

• Your wheelchair should be labelled with a 'gate check' tag as well as the regular luggage destination tag.
  ➢ This will ensure that it is brought to the door of the plane at your destination, instead of being unloaded with the rest of the baggage. Ask for this at check-in also. Your wheelchair will travel in the hold.

• At the door of the plane, you will have to transfer into an 'aisle chair'.
  ➢ This is a narrow chair designed to fit up the aisle of the plane.
  ➢ If you require assistance to transfer, airline staff will be available to assist you.
  ➢ Make airline staff aware if you have difficulty balancing - they may need to strap you in or have someone (maybe your travelling partner) stay close by as you move down the aisle.

• Always take your wheelchair cushion on board the plane with you, even if you don't intend to sit on it.
  ➢ Parts of your wheelchair that are easily detached can be easily lost.
  ➢ If unsure, remove it and take it on board too (quick release wheels excluded).

• Take care if you have to transfer or be lifted over the top of an armrest when getting into your seat. Skin damage can occur if you aren't careful.

• If you use a powerdrive wheelchair, airline staff may enquire as to the type of batteries the chair uses. For safe travel, all batteries must be a sealed variety. These are standard on most modern wheelchairs - if in doubt, check with the wheelchair supplier before you depart.
During the flight...

- If you use a pressure-relieving cushion, it may be advisable for you to sit on it if the flight is longer than a couple of hours.

- If you use a Jay cushion, you can sit on the cushion as it is, or remove the fluid pad as described in the Car Travel section.

- If you use a Roho cushion, be aware that even in a pressurised cabin, the inflation of your cushion will change with altitude.
  - As the plane ascends the cushion will seem to inflate and as you descend, the reverse will occur.
  - It is advisable to take your pump on board to make the necessary adjustments.
  - Wait until the plane has reached it’s cruising altitude before making any adjustments.
  - You will have to readjust when you land.

- On long flights, relieve pressure by lifting or leaning on a regular basis. Remember, leaning forwards is also a useful way of relieving pressure.

- Remember that your legs may swell during long flights.
  - This can cause pressure problems in shoes and under leg bag straps.
  - Check this regularly during the flight, and elevate your legs at regular intervals if at all possible.
  - Some people wear support stockings or use bandages to minimise swelling.

Questions

- When travelling by car etc, how can you relieve pressure and how often should you do this?
- What are some of the possible dangers related to heat to be aware of when travelling by car?
- How might a change in altitude affect your body and your equipment?
- What action might you take to avoid these?
The bladder acts as a reservoir and is able to hold up to 400mls without discomfort. The bladder’s task is to store the urine and expel it at a socially acceptable time. To assist with this task, a muscle at the bladder outlet (the sphincter) normally keeps the opening closed.

Usually when the bladder is full a message is sent to the brain via the spinal cord for a conscious decision (to pass urine) to be made. When it is convenient to pass urine the brain sends a message back down the spinal cord to the bladder. This initiates the bladder muscle to contract and the sphincter muscle around the top of the urethra to relax and open. Urine then flows down the urethra to the outside. In normal circumstances the bladder empties completely.

Your spinal cord injury causes these messages to be interrupted therefore some form of bladder management is necessary to result in safe and effective emptying of your bladder.

Failure to empty the bladder effectively can lead to problems. When urine left in the bladder after voiding (known as “residual urine”) is more than 80mls infection will most likely develop. As well as making you unwell, this infection can result in the formation of calculi/stones and curing an infection is extremely difficult in the presence of stones.
In nearly all cases of spinal cord injury, control over the bladder is initially lost. During the first few days the bladder is paralysed and a catheter is inserted to drain the urine from the bladder continuously. Although the bladder tone (ability to expel urine) gradually returns as the shock wears off, voluntary control over voiding is generally lost.

Realistically, this means that:

• When you are in casualty an indwelling catheter will be inserted.
• Urine measures will be taken hourly until the “spinal shock” wears off. This is done to ensure that your kidneys are functioning, and also to ensure that you are not getting too much fluid via your “drip” (intravenous therapy).
• After spinal shock has worn off, and you slowly commence eating and drinking more normally there will be a more relaxed attitude. The amount of urine you make will be measured over each 8 hour period.
• Your fluid intake and output will be monitored until staff members are assured that it is satisfactory.

After spinal cord injury your bladder will not act in the same way as previously, due to the damage to the spinal cord. Your level of injury will determine how your bladder will behave. The nerve supply to the bladder is at the sacral nerves 2,3,4.

• If there is damage below L1 the bladder will be flaccid with no reflex activity and will not contract (flaccid).
• If there is damage above L1 and the nerves below are intact the bladder may have high pressures due to reflex contractions of the bladder (tonic/spastic).

The purpose of all bladder management is to protect the kidneys from damage. The chosen method of bladder management is very individualised and personal.

The type of bladder management, which is most suitable for you will depend on many factors. Your lifestyle and your physical ability to manage your bladder, and how your bladder behaves, all have a bearing on the best form of bladder management for you.

To assess what is happening within the urinary system there are tests that will be recommended. These tests are to help with the early recognition of any abnormalities which could affect your health and lifestyle. For example, if the pressure within the bladder rises too high, there is a danger that the urine trying to pass into the bladder will not be
able to and may reflux back up in the wrong direction. Reflux of infected urine will ultimately lead to damage to the kidneys. This is usually permanent and in the past has been the cause of early death among people who have a spinal cord injury.

**Bladder Investigations**

Some of the investigations of your bladder that may be required include:

1. **Micro-Urine (MSU)**

   Once a week (while in hospital) a sample of urine is collected for microscopic examination. This sample will be tested for the presence of infection ('bugs”). If they are present there will be an indication of the degree of infection and, if necessary, the antibiotics required in counter-acting the infection. The results of these tests will be assessed and your doctor will start you on antibiotics if required.

   After discharge from hospital we recommend that you have your urine checked from 3 to 5 times a year (or whenever you think you may have a bladder infection) to detect any presence of infection. Your local doctor will be able to get this specimen tested for you.

2. **Urodynamics**

   (This test is not required regularly after discharge. However, if you experience changes of your voiding patterns, it may be recommended that you undergo it once again.)

   This test is usually performed in the urodynamics room located in the spinal unit. It is a test that will determine how your bladder is working.

   Whilst in urodynamics:

   - The nurse will empty your bladder with an intermittent catheter (if you have an IDC this will be removed).
   - You will then be re-catheterised with two lines being put into your bladder. One will measure the pressure in your bladder (detrusor muscle pressure) and the other line will fill your bladder with fluid.
   - You will also have a small balloon inserted into your rectum to measure abdominal pressure.
   - These lines will all be removed at the end of the procedure and you will be re-catheterised to drain your bladder.

   Urodynamics will show:

   - Bladder size or capacity - how much urine it can hold
   - Bladder shape
   - Sphincter activity or strength
   - Urine leaking from bladder or urethra during procedure.
Urodynamics may be performed under conditions that allow for them to be X-rayed. This is called **video-urodynamics**. They are usually done at the QE II hospital (if they are required while you are in hospital, the appointment and transportation will be organised by the ward staff).

- If you are allergic to fish or iodine please let the staff know, as the dye required for these films contain some portion of these.
- This procedure shows whether there is reflux of urine back to the kidneys. Urine flowing back up ureters from the bladder can lead to kidney problems eg. renal failure.

3. **Intravenous Pyelogram (IVP)**

This investigation shows how the urine is first concentrated by the kidneys, and then passed down the ureters into the bladder. A small amount of dye is injected into a vein, and then over a period of 45 minutes a series of X-rays are taken as the dye concentrates in the kidneys and passes down into the bladder. This is the most useful test that we have to check the kidney function, and therefore the test is often recommended in annual check-ups.

4. **Ultrasound**

Ultrasound of the kidneys can be used to check on the size of the kidneys and will pick up any enlargements of the kidneys, ureters or bladder. This is a simpler investigation because it does not involve injection of any dye. It is often recommended when you need to have a review of how the kidneys and bladder are functioning.

You may hear the term "KUB" used. 'KUB' (Kidneys, Ureters and Bladder) refers to a plain X-ray of the abdomen that is done at the same time as the ultrasound.

4. **Micturating Cysto-Urethrogram (MCG)**

(This test is not performed on a routine basis while in hospital or required on a regular basis after discharge from hospital)

In this investigation, dye is inserted into the bladder via a catheter. The prime aim is to detect whether any of the dye goes up the ureters towards the kidneys (reflux). 350mls of dye is usually used and after the initial X-rays have been taken, you will be asked to try and void (wee). X-rays taken at this point give an outline of the bladder, and may show the bladder neck opening and urine passing.
5. Cystoscopy
(This procedure is not required for everyone while they are in hospital or on a regular basis after discharge)

The Unit Urologist usually does this procedure under a general anaesthetic. The purpose is to look into the bladder with an instrument, which has a light on the end so enabling the surgeon to check for any abnormalities within the bladder (such as stones or tumour). They can also look at the bladder lining and ureteric outlets. (It is with this instrument that the external sphincterotomy is performed to allow the bladder neck free drainage of urine.)

Factors Effecting Bladder Care

- **Hand Function** - ability / inability to hold a catheter.
- **Level of Injury** - balance and ability to transfer.
- **Wearing Collar or Brace** - a collar may make it difficult to physically see to do intermittent catheters and thoraco-lumbar braces may make it difficult to get into a position suitable for self catheterisation.
- **Type of Bladder** (eg. flaccid or reflex) - determined by urodynamics
- **Previous History of Bladder Problems**
- **Age**
- **Personal Preference**
- **Lifestyle**

Aim of Bladder Management

It is very important that the urinary system is kept healthy so the kidneys can function properly. Ways of maintaining this are:

- **By emptying the bladder regularly** ensuring as little urine as possible is left in the bladder. This will reduce the risk of urinary tract infections.
- **Good personal hygiene and skin care** - plus washing your hands before and after dealing with your bladder care - will reduce cross infection (spread of germs).
- **Check the urine** colour, amount and clarity daily for signs of infection. Take a urine sample to your local doctor for testing if you suspect there is a problem.
- **Continue your bladder medication** as directed by your doctor.
Types of Bladder Management

Indwelling Catheter

No doubt, you are already familiar with this type of bladder management.

All patients admitted with a spinal cord injury have an indwelling catheter initially. It is a hollow tube that is inserted into your bladder via your urethra and drains away all your urine as it is produced. It is changed fortnightly or monthly, depending on which type of catheter, you are using.

You may choose to use an indwelling catheter as your long-term bladder management. However, it is important to be aware of the complications that can occur from having an indwelling catheter in situ (long-term) e.g. infection (You can ask your doctor or nurse for details of these possible complications.)

Long-term care:

- The catheter needs to be changed regularly, either by you, your carer or one of the community services this ensures less likelihood of catheter blockage and infection.
- Care must be taken that the catheter is not pulled out if this happens, there is the chance you may bleed and form blood clots in your bladder (which can cause catheter blockage). Attachment to the abdomen or leg (by tape) may be beneficial and prevent this happening. If a catheter is removed, it should be replaced as soon as possible.
- Drinking plenty of water (approximately 2.5 - 3 litres) per day this helps to keep the urine free of debris.
- Wash around the catheter site twice a day with soap and water good hygiene decreases the risk of infection.
- Maintain a “closed” system (no breaking of seals/connections) as much as possible. This means keeping the number of times you have to disconnect the bag to an absolute minimum this will reduce your chance of getting infections.
- Ensure the drainage bag is below the level of your bladder to allow the urine to drain by gravity decreases the risk of infection.
- Ensure that clear yellow urine is flowing well this allows early detection of problems (eg. catheter blockage or urine infection).

① The tubing should feel warm to touch. If the tubing is cold, there may be a blockage. “Milking” the tube (by squeezing the tubing or applying pressure over the bladder) may be enough to dislodge the blockage. If this is unsuccessful, the catheter needs to be changed immediately.
A ‘routine’ bladder wash out may be recommended if there is a chronic problem with infection, sediment or debris. Individual/spontaneous assessment, as to whether to do a bladder wash out, can be made from the state of the drainage of urine.

**Suprapubic Catheter**

Suprapubic means → the area just above your pubic bone, above the level of your pubic hair.
Catheter means → a hollow tube that is inserted into your bladder to drain away your urine.
A suprapubic catheter means → that you have a urinary catheter inserted into your bladder through the abdominal wall.

**Reasons for having a suprapubic catheter:**
- If you are unable to perform self-catheterisation yourself due to limited hand function and you decide that you do not wish anybody else to perform the procedure.
- If your urethra (the tube joined to your bladder through which you pass urine) is damaged.
- Long term indwelling catheters (those that are inserted into your bladder via your urethra which are only removed when due for changing) can cause complications eg. urethral erosion, so you may decide on the alternative of a suprapubic catheter for your long term bladder management.
- It can be more convenient when having sexual relations with your partner than an indwelling catheter.

**Advantages of suprapubic catheterisation:**
- It is a more hygienic solution to long-term bladder drainage than an indwelling catheter. It is away from the genital area where infection has an easy passage to the bladder via an urethral catheter.
- There is less likelihood of contamination when being changed (especially with females).
- The catheter itself is easier to change and less embarrassing (due to exposure) for you and your carer.
- Less likelihood of ulceration (pressure areas) developing with long-term use.
- Sexual activity is less inhibited with the absence of a urethral catheter.
- Your independence may increase if you are able to change your own catheter (particularly for females).
Disadvantages of suprapubic catheterisation:

- **Any** tube going into your bladder can provide an entry for infection. Therefore the same precautions for care must be taken with SPC as for indwelling catheters.
- Your catheter **must** be replaced immediately if it falls out → as the opening may close over.
- You may not be comfortable with the idea of a tube going through your abdominal wall.
- Urine can still leak via the urethra. This happens particularly when the suprapubic catheter is blocked or kinked off.
- Ensure that **clear** yellow urine is flowing well → this allows early detection of problems (eg. catheter blockage or urine infection).
  1. The tubing should feel warm to touch. If the tubing is cold, there may be a blockage. “Milking” the tube (by squeezing the tubing or applying pressure over the bladder) may be enough to dislodge the blockage. If this is unsuccessful, the catheter needs to be changed immediately.
  2. A ‘routine’ bladder wash out may be recommended if there is a chronic problem with infection, sediment or debris. Individual/spontaneous assessment, as to whether to do a bladder wash out, can be made from the state of the drainage of urine.

Procedure for insertion:

When the decision has been made that a supra-pubic catheter is the bladder management of choice for you, the urology doctors will arrange for this to be done in the operating theatre under a light anaesthetic.

A supra-pubic catheter does not have to be permanent - it can be removed at any time if you decide to change your bladder management. However you must consult with your doctor.

Long-term Care:

- These are similar for those required by an indwelling catheter.
- Drinking plenty of water (approximately 2.5 - 3 litres) per day → this helps to keep the urine free of debris.
- The catheter needs to be changed regularly, either by you, your carer or one of the community services → this ensures less likelihood of catheter blockage.
- Check the catheter site daily for signs of infection or irritation (you are looking for redness, feel for heat at site and check for discharge). If you feel that there is a problem inform your local doctor.
• Thoroughly clean the catheter site daily in the shower.
• Avoid the use of talcum powder, sprays or deodorants around the site of the catheter.
• Have a spare catheter with you at all times in case of emergencies.

**Self Intermittent Catheters (SICs or ICSCs)**

You may also hear these being referred to as ICSCs (Intermittent Clean Self-Catheterisations) or IMCs (Intermittent catheterisations). The second term is what we call them when a staff member is doing the procedure.

This is a method, which empties the bladder 4-6 hourly and allows the bladder to fill up in between. It involves passing a catheter into the bladder and once the bladder has been emptied of urine the catheter is removed. This technique takes only minutes to perform. It does require fairly good hand function, however, and there are aids available to assist those who have a low cervical injury of C6 or C7.

**Technique:**
If you elect this method for management of your bladder emptying,
• You will be given literature to assist you to understand the technique
• Once you are totally prepared to commence ➔ an experienced staff member will demonstrate the technique.
• You will be supervised, whilst you do the procedure ➔ until you are happy that you are confident with the procedure. It is also very important that you are performing the technique cleanly and safely and not at risk of introducing infection into your bladder with the catheter. You will be supervised until you can do this by yourself.
• When your program for bladder management seems appropriate for you, and 'should' result in minimal infections, more independence (stopping of staff monitoring and urine measuring etc.) will evolve.
• Once you are independent with your bladder management program, please don’t hesitate to inform staff if you suspect a difference (in colour, clarity, volume or frequency).
• When it is closer to the time for you to go home, learning of the 'home technique’ is presented in the same way. Your ordering of equipment (present and future) will need to be made and will be assisted by nursing staff members.
Long-term Care:

- Your technique for passing your catheters will be assessed thoroughly. This is to try and prevent bladder infections caused by careless introduction of germs via the catheter.
- A strict regime of “no touch” must be adhered to.
- Wash hands before and after the procedure.
- Balance fluid intake with output. This will help prevent the pressure within your bladder getting so high that it causes reflux and infection.
- Catheterise every 4 hours. Depending on what the estimated urine volume will be → a 6 hour break overnight may be taken or the swelling in your legs may make it necessary to do an extra catheter a couple of hours after you lie down.
- A maximum time of 6 hours between catheters will decrease your risk of bladder infections significantly.
- Empty your bladder completely with each catheter. If there is urine left in the bladder, it will provide a breeding ground for infection.
- The care of your equipment will be discussed with you before your discharge.

Tapping and Expressing

Males have the option of wearing a uridome (an external drainage system that is applied to the outside of the penis), but this method of bladder emptying is only suitable for females who can transfer on to the toilet independently. Tapping on the suprapubic area (just above your pubic bone, above the level of your pubic hair) can make the bladder automatically empty itself.

When this method of bladder management is commenced you may need to have a catheter put into your bladder to check that you are emptying your bladder completely. Alternatively, your nurse may do an ultrasound of your bladder to check the amount of urine remaining. If the ultrasound shows a large amount of urine is still in your bladder you will need to have a catheter passed to drain this. At the beginning it is important to inform your nurse as soon as you have emptied your bladder so these procedures can be done accurately.

Long-term Care:

- The collection device is worn at all times and must be firmly in place. Those people who do not have a problem with significant spasm may elect to have a bottle at night to rest the skin of the penis.
- Change the uridome morning and night and check the skin for redness or breaks.
• Perform percussion (tapping) over the bladder every 2-4 hours, to ensure the bladder is emptying.
• Drink at least 3 litres of fluid a day.
• Care of your leg bag will be discussed with you before discharge from hospital.

Free Drainage

This method of bladder management is also suitable for males and involves wearing a uridome. Some people with spinal cord injury may find their bladder will drain automatically, however most will require a sphincterotomy (TURS) to ensure their bladder empties properly.

A sphincterotomy (TURS) is an operation that opens the sphincter (the muscle at the base of the bladder which relaxes during urination) to allow urine to drain freely down the urethra to the outside. Some people require more than one sphincterotomy (TURS). This procedure is not reversible.

Long-term Care:
• These care issues are the same as for those who tap and express.

MEDICATIONS THAT EFFECT YOUR BLADDER MANAGEMENT PROGRAM:

<table>
<thead>
<tr>
<th>DRUG</th>
<th>STRENGTH</th>
<th>ACTION</th>
<th>ADVERSE REACTIONS</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>ASSIST TO RETAIN URINE:</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Oxybutinin</td>
<td>Blue 5mg tablets</td>
<td>Relaxes the bladder muscle (an anti-spasmodic effect)</td>
<td>Dry mouth, drowsiness. Constipation.</td>
</tr>
<tr>
<td><strong>ASSIST TO VOID:</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Phenoxybenzamine</td>
<td>10mg red &amp; white capsules</td>
<td>Relaxes the bladder sphincter</td>
<td>Nasal congestion. Headaches, postural hypotension (fainting when you get up), blurred vision.</td>
</tr>
<tr>
<td>DRUG</td>
<td>STRENGTH</td>
<td>ACTION</td>
<td>ADVERSE REACTIONS</td>
</tr>
<tr>
<td>-----------------------------</td>
<td>---------------------------</td>
<td>------------------------------------------------------------------------</td>
<td>--------------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>HELP MAINTAIN STERILE URINE:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hiprex (hexamine hippurate)</td>
<td>White 1gm tablets (usually twice a day)</td>
<td>1. Urinary anti-septic in long term treatment of chronic or recurrent Urinary Tract Infections (as with a permanent IDC) 1. Acidifies urine → Halts the growth of bacteria.</td>
<td>Occasionally:  • Nausea  • Digestive disturbances (eg “Heartburn”)  • Rash  Note:  • Effects reduced when used with alkalinising agents &amp; sulphonamides  • Vitamin C (ascorbic acid) or ammonium chloride increase the acidity of urine</td>
</tr>
<tr>
<td>Hexamine Mandelate</td>
<td>Purple 1gm tablets (usually 4 times a day)</td>
<td>Same as above</td>
<td>Same as above</td>
</tr>
<tr>
<td>Cranberry</td>
<td>Available from chemist or some health food shops</td>
<td>Increases the acidity of urine Reduces the risk of infection</td>
<td>• Effects reduced when used with alkalinising agents &amp; sulphonamides  • Vitamin C (ascorbic acid) or ammonium chloride increase the acidity of urine</td>
</tr>
</tbody>
</table>

MEDICATIONS WHICH EFFECT BLADDER MANAGEMENT PROGRAM:

<table>
<thead>
<tr>
<th>Medication</th>
<th>Effect</th>
<th>Side Effect</th>
</tr>
</thead>
<tbody>
<tr>
<td>Amitryptyline</td>
<td>Given for nerve pain →</td>
<td>May cause urine retention</td>
</tr>
<tr>
<td>Depo-Provera (Progestosterone)</td>
<td>Give for contraception →</td>
<td>May cause urine retention</td>
</tr>
<tr>
<td>Dilantin</td>
<td>Given for epilepsy →</td>
<td>May cause urine retention</td>
</tr>
<tr>
<td>Probanthine</td>
<td>Given to reduce inappropriate sweating and control bladder spasm →</td>
<td>May cause difficulty in passing urine</td>
</tr>
<tr>
<td>Sudafed</td>
<td>Given to help stop fainting when you get up as well as help with nasal decongestion →</td>
<td>May cause urine retention</td>
</tr>
</tbody>
</table>
### Drugs Affecting Bladder Management

<table>
<thead>
<tr>
<th>DRUG</th>
<th>STRENGTH</th>
<th>ACTION</th>
<th>ADVERSE REACTIONS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ventolin</td>
<td><em>Given to help relieve asthma (also available in tablet form)</em></td>
<td>→</td>
<td>May cause urine retention</td>
</tr>
<tr>
<td>Propanalol</td>
<td><em>Cardiac medication</em></td>
<td>→</td>
<td>May cause urine incontinence</td>
</tr>
<tr>
<td>Largactil</td>
<td><em>A sedative and tranquilliser</em></td>
<td>→</td>
<td>May cause urine incontinence</td>
</tr>
</tbody>
</table>

### Urinary Tract Infection (UTI)

**Signs and Symptoms:**
- Fever/high temperature
- Feeling unwell
- Sweating/shivering
- Skin tolerance may be reduced/your skin may mark easily
- You may leak in-between SIC’s
- If you can feel you may experience some pain or discomfort when passing urine or doing your SIC
- You may get autonomic dysreflexia if your lesion is above T6
- Increased spasms

**Urine may be:**
- Offensive smelling
- It may be cloudy or debris may be present
- A small amount of blood may be present
- If you have sensation, urine may sting or burn as it is being passed

**What you should do if you suspect a urinary tract infection**

**Indwelling and Suprapubic catheters:**
- Increase fluid intake of clear fluids (e.g., water) to at least 3 litres per day.
- You will need to empty your drainage bag more frequently.
- Take a sample of urine (MSU) from the outlet of your catheter to give to your local doctor (GP). Results may take up to a week to be processed.
- You must turn more frequently when in bed and do more pressure lifts when up in chair. You must check your skin more regularly.

**Self Intermittent Catheters:**
- Increase fluid intake to at least 2.5-3 litres per day.
- Increase the number and frequency of catheters you do.
• Take a sample of urine (MSU) mid flow as you do your SIC to give to your local doctor (G.P). Results may take up to one week to be processed.
• Males may wish to wear a drainage bag and uridome in-between your SIC’s in case of urine leakage (a symptom of UTI).
• Female patients who are still leaking urine after increasing SIC’s, may wish to insert an indwelling catheter (IDC) for a few days. If you have been commenced on antibiotics remove the IDC on the 4th day and restart SIC’s. The antibiotics should have started working by the 4th day but you must complete the entire course of antibiotics.
• You must turn more frequently when in bed and do extra pressure lifts when up in chair. You must check your skin more regularly.

Tapping and expressing:
• Increase fluid intake to at least 3 litres per day
• Increase the frequency of tapping and expressing
• You will need to empty your drainage bag more frequently
• Take a sample of urine midstream as you are expressing to give to your local doctor (GP). Results may take up to a week to be processed.
• You must turn more frequently when in bed and do extra pressure lifts when up in chair. You must check your skin more regularly.

Free Drainage:
• Increase fluid intake to at least 3 litres per day
• You will need to empty your drainage bag more frequently
• Try to collect a midstream sample of urine (MSU) to give to your local doctor (GP). Results may take up to a week to be processed.
• You must turn more frequently when in bed and do extra pressure lifts when up in chair. You must check your skin more regularly.

Antibiotics
• If the infection is severe you may need antibiotics to treat it. Your doctor will be able to advise you whether antibiotics are required.

Skin Tolerance
• Having a UTI will decrease your skin tolerance therefore you are more susceptible to getting pressure areas. It is extremely important to check your skin more regularly, turn more frequently when in bed, and increase your pressure lifts when up in your chair.
Preventing Recurrence of UTI

- Ensure you thoroughly wash your hands (or ask your carers to wash their hands) before and after dealing with your bladder care.
- Reassess your technique of changing your catheter or passing your SIC.
- If your bladder management is SIC’s, thoroughly wash your groin area before each procedure.
- If your bladder management is SPC or IDC ensure the area around your catheter is thoroughly cleaned at least twice a day.
- If you wear a uridome ensure your penis and groin area is thoroughly washed and dried before applying your uridome.
- You may find that drinking cranberry juice (available from your supermarket) or taking cranberry juice tablets (available from chemists and health food stores) will help reduce the number of UTIs. Also Vitamin C can help prevent recurrent infections.

Trouble Shooting

1. Catheter NOT draining:
   - Check for kinks in your tubing.
   - Check that your catheter drainage bag is below your bladder (pelvis).
   - Adjust your position to see if that helps the drainage.
   - Prepare to change the catheter if you are trained to do so or make arrangements for someone else to do so.

   Do not take the catheter out unless another one is going to be reinserted immediately!

   ➔ With a SPC, do not remove the blocked catheter. You can drain the bladder urethrally by inserting a urethral catheter (an IDC - as well as the SPC) or uridome, if appropriate. This should give you enough leeway to get to a casualty department (or local GP) and have your SPC changed. Don't forget to take your emergency catheter along, so the one inserted is of the right size and type.

2. Cloudy urine or debris present:
   - The cause could be a urinary tract infection ➔ take a urine sample to be tested.
   - If problems with drainage occur ➔ have your catheter changed as soon as possible.
   - Take cranberry tablets or juice ➔ this can help reduce the amount of sediment in your urine.
   - Increase the amount of fluid you drink to at least three litres per day.
If you are self-catheterising, this may mean that you need to do an extra catheter or two. You should consult your local health care professional if you are not improving.

Having a catheter in your bladder puts you at a greater risk of developing bladder stones. Bladder stones can be the cause of recurrent urinary tract infections, and may cause drainage problems. If grit or stones cause problems with the drainage of your catheter, please inform your doctor.

3. Bleeding:

**After a catheter change:**
- When a catheter (IDC or SPC) is changed there can be a small amount of trauma, which will cause bleeding → sometimes this is unavoidable. If the occasional very small blood clots are passed (via your tubing), this is usual and to be expected. However, if the blood-clots get large, more frequent and the colour of your urine changes suddenly (very dark or 'pinkish') or gets progressively darker → consult with your local GP or Casualty Department.
- Ensure your catheter is still draining urine and increase your oral fluid intake → to dilute and flush out the blood.
- If the bleeding has not stopped in 24 hours or causes your catheter to block, seek a catheter change, immediately.

4. The catheter balloon will NOT INflate;
- If you are unable to inflate the balloon, check that the catheter is inserted far enough into the bladder. If the catheter is NOT inserted far enough → you may be trying to inflate the balloon in the urethra. Try to insert the catheter further before you try to inflate the balloon again.
- If you have persistent trouble, please seek advice from your local GP or hospital.

5. The catheter balloon will NOT DEflate;
- Are you pushing the syringe tightly enough into the balloon port as you draw back on the syringe (to remove the fluid)?
- For Suprapubic Catheter: If you are unable to get the balloon down and the catheter needs to be changed quickly (emergency) → insert an IDC and seek help from your closest Casualty Department as soon as possible!
- For Indwelling Catheter: Your IDC may be blocked or the end may have calculi around it → try a bladder washout to clear
debris. Whether this is successful or not, and seek help from your closest Casualty Department as soon as possible!

6. **Autonomic Dysreflexia**

Please see Chapter TWO, Section F for information on Autonomic Dysreflexia.
The Effect of Spinal Cord Injury on the Digestive System

Following a spinal cord injury your bowel evacuation may not happen in the same way as before your injury. This is due to the pathway from your bowel through your spinal cord to your brain being damaged either completely or incompletely. As the nerves supplying the rectum leave the spinal cord very low down (Sacral nerves 2,3 &4), nearly all people suffering from a spinal injury have effected bowel function. Therefore, your bowel needs to be trained to empty completely on demand.

Immediately after the injury, it is normal to have a paralytic ileus - that is loss of all movement of the stomach and ‘gut’. This is initially treated by passing a naso-gastric tube through your nose down into your stomach. This tube is used to drain any fluid that remains or which is produced by the stomach whilst the gut is immobile. You will also have intravenous therapy ("drip") inserted into a vein in your arm to maintain your body fluids while your gut is not working.

The digestive system comprises:
- Everything in your mouth, which allows you to chew and swallow your food.
- Oesophagus, which is the tube that goes from your mouth to your stomach.
- Stomach, which adds special fluid to help break down your food into fluid that can be absorbed by your body.
- The fluid then passes into the small intestine, which is very long and has various sections called: Duodenum, Ileum, Jejunum.
- From the small intestine the now semi-solid passes into the large intestine; past your appendix, into the caecum, ascending colon, transverse colon and descending colon.
- The stool then travels through your sigmoid colon, rectum and out through your anus.
Bowel therapy commences once the paralytic ileus wears off, you will be asked to let a nurse or doctor know when you start passing wind ('flatus'). They will listen to your stomach hoping to hear your stomach moving. Once this is happening the tube will be removed and you will slowly begin eating and drinking more normally. This usually happens about the third day after your admission to hospital.

While you are in bed, you will be started on tablets and suppositories (these are medications put into your rectum) that will assist your bowel to empty. You will be given these at the same time each day.

When you start getting up and commence your Physiotherapy and Occupational Therapy suitable times for your bowel therapy will be established.

The aim of a good bowel management program: is to achieve complete emptying of the rectum at predictable regular times and so preventing bowel accidents in between.

For successful management you will need:

1. Right consistency: (to prevent constipation or diarrhoea)
   - adequate fluid intake
   - high fibre diet
   - use of additional softening agents (if necessary)

2. Right Place: (to promote social continence)
   - a regular habit, i.e. the same time each day
   - use of gastro-colic reflex
     - this a reflex that everyone one has.
     - When you eat or drink something, this reflex tends to make your bowel want to empty.
     - You can use this reflex to your advantage by having some food or a hot drink about 30 minutes before you want your bowel to empty.
   - use of medications that stimulate your bowel to open.

3. Right Time: (to promote social continence)
   - fit the bowel program into your lifestyle (including that of your family, significant others and care giver).
   - pre-injury habits
   - facilitate timing of evacuation after a meal or warm drink by using the gastro-colic reflex.
4. **A Trigger:** (to promote complete emptying of the rectum)
   - The lower bowel can be assisted to empty by using its in-built ‘reflex’. This reflex method can be triggered by increased pressure in the rectum and can be initiated by:
     - straining
     - pressure
     - stimulation - chemical
     - digital.

The method of bowel evacuation that will be most effective for you will depend largely on your level of injury.
- Those with a high level of injury usually find that a ‘reflex’ method of bowel evacuation works well (see above).
- People with a low level of injury may require the use of abdominal pressure or straining to assist with bowel evacuation.

Almost all persons with a spinal injury require medications in addition to these methods.

**An effective routine will be established for you before your discharge from hospital.**

**Bowel Training Revolves Around:**

1. **Diet:**
   - Well balanced, high fibre diet,
   - Adequate fluid intake.

2. **Medications:**
   - **Oral** - usually taken 10-12 hours before suppositories are given to be most effective.
   - **Rectal** - the time taken for suppositories or enemas to work varies with each individual → the time that these are given will be established whilst you are in hospital.
      - The use of enemas, which consist of large amounts of fluid, is not recommended, as they decrease the normal bowel muscle tone.

**Common medications**

There are a number of different types of medications that may be used to assist you to maintain a healthy bowel management program.
They are:

(a) Bulk Producing agents:
- Normacol granules
- Methylcellulose tablets
- Unprocessed bran

(b) Lubricants:
- Agarol
- Glycerine suppositories

(c) Faecal softening agents:
- Pear juice
- Coloxyl
- Duphalac/Lactulose

(d) Stimulants:
- Senekot tablets or granules
- Nulax
- Agarol
- Durolax/Biscodyl suppositories or tablets.

The following table explains these medications in more detail:

<table>
<thead>
<tr>
<th>DRUG</th>
<th>STRENGTH</th>
<th>ACTION</th>
<th>ADVERSE REACTIONS</th>
</tr>
</thead>
<tbody>
<tr>
<td>BULK PRODUCING AGENTS</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pear Juice</td>
<td>1 glass per day</td>
<td>Fibre/bulk producing agent.</td>
<td>Not to be taken if faecal impaction or gut obstruction suspected</td>
</tr>
<tr>
<td>Metamucil (We recommend that you try pear juice first)</td>
<td>Orange powder → Usually 1 teaspoon mixed into a glass of water, after meals or before bed.</td>
<td>Fibre/bulk producing agent.</td>
<td>Not to be taken if faecal impaction or gut obstruction suspected</td>
</tr>
<tr>
<td>Normacol:</td>
<td>Granules → usually 1-2 heaped teaspoons once/twice a day after main meals or before sleep.</td>
<td>Intestinal evacuant bulk former.</td>
<td>Not to be taken if faecal impaction or gut obstruction suspected</td>
</tr>
<tr>
<td></td>
<td>Granules are placed dry on tongue and swallowed whole with plenty of water.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
| **Cellulone or Methylcellulose tablets:** | Large off-white tablets → 3-4 tablets after meals with 2 glasses of water. | These agents increase the bulk of colon contents so as to:  
• Restore natural bowel function  
• Relieve constipation |
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>LUBRICANTS</strong></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
| Agarol | Thick white liquid | Acts as:  
• lubricant in the colon.  
• Stimulant of bowel movement. |
| Glycerol suppositories: | Suppositories | Acts locally. They have an irritant effect on the large bowel. |
| **FAECAL SOFTENING AGENTS** |  |
| Pear juice | Fruit juice (available from a supermarket) | Stool softener & bowel regulator |
| Coloxyl | Tablets:  
• 50 mg (yellow)  
• 120 mg (peach)  
Drops:  
• 15 drops 3 times a day | Stool softener designed to prevent/relieve constipation  
Best taken with at least one glass of water. Should be used in conjunction with:  
• increasing bulk or high fibre diet  
• increased exercise  
Minimum of one litre of water daily  
Not to be taken if you have stomach pain, nausea or vomiting.  
Can cause abdominal cramps. |
| Duphalac or Lactulose | Thick, clear syrup | Stool softener by increasing the water content of bowel contents.  
Can cause excessive gas/flatus. |
<table>
<thead>
<tr>
<th>STIMULANTS</th>
<th>Tablets or granules</th>
<th>Doseage: One that gives comfortable, softly formed stool. Usually: • 2-4 tablets daily • 1-2 teaspoons of granules 2-3 times daily</th>
<th>• Restores gut motility and stimulates reflex emptying of your bowel • stimulates the colon, restoring normal rhythmic activity</th>
<th>Abdominal discomfort, loose stools.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Senekot:</td>
<td></td>
<td>• Action lasts 8 - 10 hours • Best given with meal, approximately 10 - 12 hours prior to suppositories • Taken with full glass of water.</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Coloaryl with senna</td>
<td>Brown enteric coated tablets</td>
<td>Stool softener and colonic stimulant</td>
<td>Diarrhoea, abdominal discomfort.</td>
<td></td>
</tr>
<tr>
<td>Nulax</td>
<td>Pieces of dried fruit and ground senna, that is presented in block form. Doseage; a piece the size of a walnut, 10-12 hours prior to evacuation.</td>
<td>Acts as peristaltic stimulant to the bowel.</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Biscodyl, Durolax or Bisalax</td>
<td>Tablets • 5 mg (yellow) Dosage: • 1-3 tablets daily as necessary • 10-12 hours prior to evacuation Suppositories; • 10 mg Contact stimulant (10-20 minutes) Enema; • 5 ml solution</td>
<td>Peristaltic stimulant acting on contact with bowel mucosa.</td>
<td>Abdominal cramps, rectal irritation, flatulence (wind), imbalance of fluids.</td>
<td></td>
</tr>
</tbody>
</table>
Granacol | Sugar coated granules. Dosage: 1-2 teaspoons twice daily after meals • swallowed whole with water or fruit juice. | • Bowel regulating agent • Swells in the small intestine stimulating peristalsis. |
Microlax enema | 5 ml solution given rectally. Dosage: 1-2 enemas | Contact irritant. Bowel evacuation usually occurs 5-10 minutes later. |

OTHER MEDICATIONS WHICH CAN EFFECT YOUR BOWEL MANAGEMENT PROGRAM:

Cisapride | Given to help prevent gastric reflux ➔ it also increases gut motility. | Abdominal cramps, diarrhoea. |
Oxybutinin | Given to assist with your bladder management program ➔ can slow down peristalsis | Constipation. |
Pro-banthine | Given to help reduce inappropriate sweating ➔ can slow down peristalsis | Constipation. |
Narcotics; (eg MS Contin, Endone, Morphine) | Given to relieve pain ➔ can slow down peristalsis | Constipation. |
Analgaesia; (eg Panadeine, Codeine) | Given to relieve pain ➔ can slow down peristalsis | Constipation. |

3. Time and routine:

- Past experience has shown that if you have your bowel therapy at the same time each day there is less likelihood of 'accidents' due to incomplete emptying.
- Routine will vary with individuals but should be well established before discharge. If not, you will be given a bowel management plan to follow when discharged.
- If your routine, time and frequency - eg. 3 times a week in the morning is changed, it will take 2-3 weeks for your bowel to re-establish a habit. There may be bowel accidents within this time.
- The change in your routine cannot be evaluated for effectiveness until the 2-3 weeks has passed.
Tips for Effective Bowel Evacuation:

1. **Diet:**
   - Meal beforehand (if possible) → stimulates peristalsis (gut movement) to empty your rectum.
   - Hot drink beforehand (every time) → stimulates peristalsis (gut movement) to empty your rectum.

2. **Suppositories:**
   - Sit over toilet or in shower chair (approximately 30-45 minutes) → gravity helps with emptying.

3. **Massage and Straining:**
   - Massage abdomen → right to left (under your ribs) and down the left side,
   - Deep breathing and straining,

4. **Digital stimulation:**
   - Digital stimulation of the anus (when suppositories are inserted is a good time) will often hasten the process → by inserting a well-lubricated gloved finger or adaptive device into your rectum, and with a circular motion, massage the anal muscle until it relaxes (15-60 seconds).
   - You may need to do digital stimulation every 5-10 minutes → allowing stool to pass through the anal muscle.

   - Insert suppositories immediately after warm drink
   - Suppositories should be well-lubricated and inserted high up into your rectum with a gloved finger or adaptive device.
   - They should be placed right next to the intestinal wall.
   - Remove any stool in rectum first if it is in the way of placing the suppository.

**The Female Pelvic Organs**
5. Check results:
- Do a final check with lubricated, gloved finger or adaptive device to determine if rectum is empty.
- Once your rectum is completely empty, showering can be completed.

Things That Can Affect Your Bowel Management Program:
- Some medications that you are using for other purposes can effect your bowel.
- Emotional stress may cause either diarrhoea or constipation.
- Exercise may stimulate your bowel to move. Range of motion exercises can be done after inserting the suppositories and before digital stimulation. Passive exercises twice a day will not only prevent muscle contractures, but will also aid your bowel evacuation program.
- A change in the timing of your bowel program may lead to bowel accidents.
- Your diet can harden or soften your stool (See table below). How did different foods eg Spicy foods, stone fruit, effect you previously? Does alcohol give you diarrhoea? It will be of great benefit if you are aware of these things.

<table>
<thead>
<tr>
<th>Food Group</th>
<th>Foods That Can Harden Stools</th>
<th>Foods That Can Soften Stools</th>
</tr>
</thead>
<tbody>
<tr>
<td>Milk</td>
<td>Milk, yogurt made without fruit, cheese, cottage cheese, ice cream</td>
<td>Yogurt with seeds or fruit</td>
</tr>
<tr>
<td>Bread &amp; Cereal</td>
<td>Enriched white bread or rolls, saltine crackers, refined cereals, pancakes, waffles, bagels, biscuits, white rice, enriched noodles</td>
<td>Whole grain breads and cereals</td>
</tr>
<tr>
<td>Fruit &amp; Vegetables</td>
<td>Strained fruit juice, apple sauce, potatoes without the skins</td>
<td>All vegetables (except potatoes without the skin), whole fruit</td>
</tr>
<tr>
<td>Meats</td>
<td>Any meat, fish or poultry</td>
<td>Alternatives – Nuts, dried beans, peas, seeds, lentils, chunky peanut butter</td>
</tr>
<tr>
<td>Fats</td>
<td>None</td>
<td>Any</td>
</tr>
<tr>
<td>Desserts &amp; Sweets</td>
<td>Any without seeds or fruit</td>
<td>Any made with cracked wheat, seeds or fruit</td>
</tr>
<tr>
<td>Soups</td>
<td>Any creamed or broth-based soups without vegetables, beans or lentils</td>
<td>Soups with vegetables beans or lentils</td>
</tr>
</tbody>
</table>
Tips for Solving Problems related to your Bowel

Diarrhoea
Diarrhoea is an unformed, loose stool, which may cause unplanned bowel movements or 'accidents'.

Causes:
- Spicy foods or foods/drinks containing caffeine eg. coffee, tea, cocoa or cola drinks.
- Antibiotics
- Overuse of bowel motion softeners/laxatives
- Flu or intestinal infection ('gastro' or 'the trots')
- Psychological stress.

Solutions (for true diarrhoea):
- Eat the recommended foods for hardening stools (see table).
- Stop any laxatives until diarrhoea clears up → (unless severe constipation is thought to be the cause).
- Stop any stool softeners (coloxyl, pear juice) temporarily, then begin again when the diarrhoea is over, adjusting dose to get the stool consistency you want → unless severe constipation is thought to be the cause.
- After the diarrhoea clears up, re-evaluate your bowel regime, use of stool softeners, diet, etc.
- If your diarrhoea lasts more than 24 hours, please contact your local G.P. or other health care professional.

Is it 'overflow' diarrhoea? When you are assessing status of your bowel management program, recent bowel motions must be taken into consideration. Because severe constipation (faecal impaction) can present itself like diarrhoea → this is due to the fact that the only thing getting around the hard stool will be very thin faecal fluid. Therefore, if the only bowel action has been a thin fluid with no fibre or solid substance, then this problem must be considered when you calculate a solution.

Therefore you need to evaluate whether there is a chance that you have an impaction or severe constipation:- no stools, hard stools or small, hard bowel movements within the last week.

Some solutions for constipation are given below. However, if the condition persists → you need to contact your local GP or other health care professional.
Constipation

Constipation is a condition of hard, infrequent stools.

Causes:
- Lack of a regularly scheduled bowel program.
- Incomplete emptying with your bowel regime → the longer the stool remains within your intestines the more water is drawn out of it.
- A diet which is low in fibre.
- Bedrest or low - physical activity levels.
- Medications: Narcotics, iron, Amphogel.

Solutions:
- Eat foods to soften your stools to help prevent constipation (see table).
- Increase activity and range of motion exercises.
- Drinking pear juice may help.
- Drink plenty of fluids within the boundaries of your bladder management regime.

Rectal Bleeding

Rectal bleeding is seen as bright red blood on your stool, toilet paper or glove.

Causes:
- Haemorrhoids.
- Hard stools (constipation).
- Rectal fissures (small breaks in the skin).
- Trauma caused by digital stimulation of the anus eg. Long fingernails damaging the rectum.

Solutions:
- Soften stools with foods (see table) and/or pear juice and water.
- Be more gentle with digital stimulation, so trauma is less likely to occur.
- If the bleeding is excessive or continues for two or three days contact your local GP.

BOWEL THERAPY and AUTONOMIC DYSREFLEXIA

For signs and symptoms of Autonomic Dysreflexia refer to the appropriate chapter within this handbook.

Causes:
- Haemorrhoids or small tears in the skin or anything that can cause pain.
• Full or over distended bowel (constipation, missed bowel therapy, impaction).
• Rough digital stimulation.
• Over stimulation of the anal sphincter.

Solutions:
• Regular bowel therapy, with complete emptying of the rectum. You may have to adjust the frequency of your bowel therapy particularly with your change of diet after discharge from hospital.
• Comfortable positioning during bowel therapy.
• Anaesthetic ointment applied to anal area 5-10 minutes before suppository insertion and digital stimulation.

No Bowel Movements for 2-3 Days of Bowel Therapy

Causes:
• Constipation.
• Impaction.
• Not eating.

Solutions:
• Try to determine the cause and resolve see section on constipation.
• Contact your local health care professional.

Excessive Gas

Causes:
• Gas forming foods.

GAS FORMING FOODS

<table>
<thead>
<tr>
<th>VEGETABLES</th>
<th>FRUIT</th>
</tr>
</thead>
<tbody>
<tr>
<td>Beans (kidney, lima or navy)</td>
<td>Kohlrabi</td>
</tr>
<tr>
<td>Broccoli</td>
<td>Leeks</td>
</tr>
<tr>
<td>Brussels sprouts</td>
<td>Lentils</td>
</tr>
<tr>
<td>Cabbage</td>
<td>Onions</td>
</tr>
<tr>
<td>Cauliflower</td>
<td>Peas (split or black-eyed)</td>
</tr>
<tr>
<td>Corn</td>
<td>Peppers</td>
</tr>
<tr>
<td>Cucumbers</td>
<td>Pimentos</td>
</tr>
</tbody>
</table>

• Constipation.
• Swallowing air whilst drinking or eating.
• More than normal bacterial breakdown of bowel contents.
Solutions:

- Eat your food slowly, chewing with your mouth closed → avoid gulping down food.
- Certain foods will give you gas. Try omitting these foods one at a time → to enable you to establish which, if any, cause the problem.
- Adjust your bowel therapy, if necessary.
- Try eating yoghurt or drinking vaalia.

Remember!

- Administer your bowel therapy at the same time each day! Your bowel is a creature of habit and can be trained.
- Re-assess your bowel management each day. Look at your bowel motion or ask your carer what it looks like:
  - If it is a formed stool → continue with your regular laxatives.
  - If it is soft → you may decide not to take any laxatives or reduce the amount you usually take
  - If it is hard or you have no result → you may decide to increase your usual laxative intake.

In time and with some trial and error you will know exactly what bowel therapy works for you.
D. CIRCULATION

It is rare for people with SCI to suffer problems with poor blood supply to their limbs or from the complications of high blood pressure (hypertension).

The reason for this is that the autonomic nervous system tends to be reset at a lower level and it is usual for the blood pressure of a person with tetraplegia to be lower than before the injury:

- Normally Blood Pressure is ~ 120/80 mmHg
- In Tetraplegia it may be as low as 90/60 mmHg

This lower blood pressure protects the heart and blood vessels from the effects of hypertension.

Some problems that may be caused by the changed circulation and lower blood pressure may be:

- Fainting (also called Postural Hypotension)
  - This is a common problem especially when you first start getting up out of bed after a long period of bed rest.
  - If you get up too quickly you may faint because the body can not adapt to the upright posture as quickly as it should.
  - Things that you can do to help with this include:
    - Get up more slowly i.e. make sure that you sit up in bed for 30 minutes before getting into the wheelchair.
    - Wear TED stockings and an elastic abdominal binder (corset). These help to keep the blood pressure higher.
    - Sometimes medications will be needed.

- Swelling (Oedema) in the Legs and Feet
  - This is also quite common and occurs because fluid collects in the legs and feet especially when you are in a wheelchair all day.
  - Normally this fluid would be pumped back to the upper body when we walk but if the legs are paralysed, this can not happen and fluid collects.
  - You can minimise this problem by:
    - Wearing ‘TED’ or special oedema stockings.
    - Trying to put your feet up in the middle of the day to encourage the fluid to move out of the legs.
  - The swelling usually does not cause major problems but it can look unattractive and it may be necessary to buy larger sized shoes.
  - Occasionally the swelling can make it more difficult for sores or scratches on the legs to heal.
  - Often this problem will improve with time as the body adjusts to the changed circulation.
E. TEMPERATURE CONTROL

Human beings need to keep their body temperature close to 37°C or 98°F.

There are a number of ways in which this can be done:

- Although we do not pant like a dog in hot weather, some heat can be lost through the breath.
- The blood vessels that supply the skin surface also tend to expand, bringing more hot blood to the surface, and the heat from the blood is then lost by a process known as “radiation”.
- The sweat pores on the surface of the skin also open up, discharging moisture, which in turn is evaporated from the skin.

These processes enable heat to be lost effectively from the body when we are too hot.

In cold weather:

- The surface blood vessels shut down, reducing blood flow to the skin and therefore conserving heat.
- At the same time, “goose bumps” appear and the hairs stand on end - in hairy people this can help to preserve heat.

These two processes can of course be assisted by adjusting clothing and by artificially raising or lowering the surrounding temperature, using heaters, fans or air-conditioning.

After SCI, the person who is paralysed is generally not able to control their body temperature in those areas of the body that are effected by the injury. Hence they tend to be much more effected by the extremes of heat and cold.

The greater the surface area of the body that has been effected, the more likely the problem is to arise.

Hence a person with tetraplegia suffers considerably more than a paraplegic from problems with temperature control.

If temperature control is a problem for you there are several things that you must remember:

- Always **wear appropriate clothing** for the environmental temperature - you may need to wear more or less clothing than before the accident.

- Remember to **use heaters, fans and air-conditioning** if necessary.

- If you become too hot (**Hyperthermia**) or too cold (**Hypothermia**), this can cause serious medical problems and you should seek medical assistance if you think this is happening.
What Is It??

**Autonomic Dysreflexia** occurs when a sensation below the level of the spinal cord lesion, that would normally be painful causes excessive reflex activity in the autonomic nervous system.

- if the cause of the dysreflexia is not found and treated, the blood pressure can rise to dangerously high levels possibly resulting in:
  - brain haemorrhage
  - fits
  - heart palpitations

Who Gets It??

- it occurs with spinal cord injuries above T6-7

What Are The Symptoms And Signs??

- sudden rise in blood pressure
- severe pounding headache
- bradycardia (very slow pulse)
- flushing/ blotching of skin on the head and neck
- sweating
- goose bumps
- nasal stuffiness
- blurred vision
- chills without fever
- shortness of breath and anxiety

What Are the Common Causes??

- **BLADDER**
  - distended bladder, blocked catheter, UTI
- **BOWEL**
  - Constipation
- **SKIN**
  - pressure sores, burns, ingrown toenails, tight clothing
- **OTHER**
  - fractures, kidney stones, labour, menstrual cramps, distended stomach
What Is the Treatment??

**AUTONOMIC DYSREFLEXIA IS A MEDICAL EMERGENCY**

1. **SIT UP** or lower your legs,
   - This helps to lower the blood pressure
   LOOK FOR THE CAUSE of the problem
   LOOSEN TIGHT CLOTHING
   TAKE BLOOD PRESSURE if possible

2. **BLADDER**
   - check for blocked or kinked catheter or overfull leg bag
   - irrigate or change the catheter

3. **BOWEL**
   - manual evacuation may be needed if constipated
   - use an anaesthetic jelly to numb the area first

4. **FURTHER TREATMENT**

   **IF BLOOD PRESSURE DOES NOT SETTLE QUICKLY**
   or **THE CAUSE CANNOT BE FOUND**

   - take a Glycerol Trinitrate (GTN) medication
     ➢ anginine tablet
     ➢ GTN patch
     ➢ GTN spray

**REMEMBER**

Anything you do in attempting to solve the problem has the potential to worsen the situation as it may irritate the system more, at least temporarily:

- e.g. unblocking the catheter, inserting a catheter or emptying the bowel

All these things must be done with great care.

If the blood pressure and symptoms do not settle quickly, **SEEK MEDICAL ASSISTANCE**

You must know what to do because other people, including doctors, may not know.

Always carry an information sheet or autonomic dysreflexia card with you so that you can remind yourself and show other people what to do. These cards can be obtained through the Queensland Spinal Cord Injuries Service.
**G. RESPIRATION**

Breathing is the involuntary intake of air through either your nose or your mouth. The two purposes of breathing are:
- To get oxygen to your tissues for survival, and
- To remove carbon dioxide (a waste product of cells).

Your respiratory system comprises your nose, mouth, upper and lower respiratory tracts.

- Air from the atmosphere enters the body via your nose or mouth.
- It then passes through the **upper respiratory tract**, which consists of:
  - **Pharynx**: common pathway for food and air,
  - **Larynx**: where the vocal cords are contained,
  - **Trachea**: the passageway extending to where it divides.
- The surface cells of this part of the airway have minute hairlike projections
- These projections move in such a manner that inhaled dust or germs become trapped in the mucous and travel towards the throat to be coughed out.

- After the airway divides the air passes into the **lower respiratory tract**, which comprises the right and left **bronchial trees** - so called because the airways get smaller and smaller (→ like an upside down tree).
- The airways terminate in the **alveoli** - thin walled air sacs. Networks of tiny blood vessels surround these chambers (→ where the oxygen in the air is exchanged for carbon dioxide from the body).

The supply of air/oxygen reaching the alveoli depends on the movement of the respiratory muscles.
Breathing in (inspiration) uses many different muscles. The nerves, which supply the muscles to breathe in, come from your spinal cord. Therefore, the level of your injury will determine how your breathing is effected.

The **diaphragm** is the primary muscle for taking in a breath. When this dome-shaped muscle contracts, it flattens, descending into the abdominal cavity, causing the lungs to inflate. You can notice the diaphragm at work when you see the abdomen moving in and out with your breathing.

The **intercostal muscles** connect the ribs. When they contract, the chest wall is lifted up and outwards. You can tell these muscles are working when your chest wall is enlarged when you take a breath in.

The **accessory muscles** are located in the neck and shoulders. When they contract, the first two ribs are elevated and the sternum (or breastplate) is raised.

The **abdominal muscles** push the diaphragm up, causing the alveoli to be squeezed into a smaller space. These are the muscles that you use when you cough or sneeze.

Breathing out generally takes no effort or energy. Breathing in does require energy. The faster you breathe, the more energy it takes.
How does having a Spinal Cord Injury effect your Breathing?

The way your breathing is effected following spinal cord injury will depend on the level of your injury, whether the injury is complete or incomplete and how much improvement or recovery you may get. Breathing also tends to improves with time (no matter what the level of your injury) as your body adjusts to the new situation.

Tetraplegia

- If you have a very high injury in your neck (C1-3) all the muscles that you need to breathe, including the diaphragm may be paralysed. This is rare but it may mean that you need a ventilator (respirator) to help you to breathe.
- If your injury is lower in the neck (C4 - C8), your diaphragm will be working and therefore you should be able to breathe on your own. However, your abdominal and intercostal muscles will all be paralysed and you will not be able to breathe as well as you did before your injury. You will need help to cough to clear your sputum and are more likely to have problems with chest infections from time to time.
- The higher the injury in your neck, the more difficulty you may find with your breathing.

Paraplegia

- If you have a high paraplegia (above T6), some of the intercostal muscles and all of the abdominal muscles will be paralysed and therefore breathing may still not be as good as before and you may need assistance to be able to cough well.
- The lower the level of your paraplegia (T6-T12) the more intercostal and abdominal muscles you will have working and the better your breathing will be.
- If your injury is below T12 all of the respiratory muscles will be working and your breathing should be close to as good as it was before your spinal cord injury.

Keeping Your Lungs Healthy

1. Limit or stop smoking. Smoking is the single most dangerous factor hampering your respiratory health. Smoking:
   - Increases your secretion of sputum.
• Decreases the activity within the cells of your lungs.
• The constant irritation also causes destruction of the alveoli, which in turn causes:
  I. Loss of gas exchange.
  II. Accumulation of secretions.
  III. Reduction in the lungs’ ability to rid itself of pollutants.
  IV. Increase in the likelihood of getting a respiratory tract infection.

• There is evidence that the smoking of marijuana can cause narrowing of the large and small airways. Other respiratory problems are likely as marijuana lowers resistance to disease by inhibiting your immune system.

2. Do breathing exercises on a regular basis:
   This is particularly important if you have a cervical or high-thoracic level of injury.

   These exercises are a method of building up the strength of your working respiratory muscles, and will decrease the risk of respiratory problems.
   • If you have an incentive spirometer, use it at least twice a day.
   • If you don’t have one, take as deep a breath in as you can, hold it for a count of three, then push all the air out. Do this 5 to 10 times at least twice a day.

3. Having someone help you to regularly “Assist cough”:
   The cough reflex has an involuntary stimulus. Following a spinal cord injury above T12, the impulse travelling down the cord to stimulate the abdominal muscles, is interrupted. Associated factors, such as decreased movement of your chest wall and decreased volume of air able to flow in and out of the lungs, also effect the ability to forcefully expel sputum (or cough).

   The inability to effectively cough allows secretions, with trapped microbes, to remain in the lungs. This increases the risk of respiratory tract infections. Infections of the upper respiratory tract are common, of the lower respiratory tract less common but more serious in nature.

   The concept of assist coughing is to help provide enough force behind an exhalation to expel the obstructing matter.
4. Try and stay away from known pollutants.
   - Pollutants are things such as smoke, dust and dangerous chemicals, as well as cold and flu germs (from people around you).

5. If you get a cold or sore throat,
   - Do more breathing exercises.
   - If you have a cold perform “assisted coughing” two or three times a day. This should help prevent the build up of secretions and the risk of pneumonia.
   - Take it seriously! → If a cold or sore throat does not go away in a week or so, contact your local doctor.

**Methods of Assisted Coughing**

If you are unable to assist your cough yourself → you need to ensure that your carer, family and close friends know how to assist you (this will be of life-long benefit to you).

When you are sitting in your chair (diagram below),
In most first-aid literature, this procedure is called “The Heimlich Manoeuvre”.

- Your assistant stands behind you and wraps their arms around your waist.
- A fist is made with one hand and is held by the other hand.
- The fist is then placed against the abdomen, at a point slightly above your umbilicus and below your rib cage.
- Take as deep a breath as possible.
• When you breathe out, your assistant presses their fist into your abdomen in a forceful upward thrust under your rib cage which must be well co-ordinated with your breathing out.

When you are lying on your back (diagram below):
• The basic procedure remains the same.
• Your assistant’s hands can be placed:
  a) Both hands on the abdomen, under your sternum or
  b) Both hands on your lower ribs or
  c) One hand under your sternum to thrust, whilst the other arm is on your lower rib cage to brace and compress your chest wall.

Practice will establish for your assistant which method they find the most effective to use.

This procedure can be used to expel objects obstructing your airway (when you are choking) as well as to cough out phlegm or sputum.

You can help yourself to cough (called ‘self-assisted coughing’) by:
• Bracing your arms,
• Leaning forward, and
• Putting pressure on the abdomen.

Other Things that may effect your Respiratory Health

Weight:
Additional weight (in excess of 20% of optimal weight) invites a number of undesirable respiratory complications, such as:
  a) Shortness of breath.
  b) A greater tendency to get respiratory infections.
  c) Impairment of blood circulation (which effects the transportation of oxygen throughout the body).
Fluid intake:
Dehydration effects the thickness of your blood and, therefore, impairs the exchange of oxygen and waste products within your body. It also effects the tenacity of sputum (it is harder to cough out). Fluid intake must be sufficient for you to avoid these problems.

Assessing Your Respiratory Function

Before leaving hospital, you and your family should be aware of what is your “normal” breathing pattern. You need this information so that you can tell if there are changes to this pattern.

How?
The best way for someone to observe your respiratory pattern is for you to lie on your back (before you get up in the morning might be a good time) and to remove shirt or bedclothes to below your waist. Try to breathe naturally, as a conscious awareness of breathing produces a different pattern.

What to look at?
A normal pattern of breathing for a person unaffected by a spinal injury consists of:
• Rhythmical breathing in and out.
• Equal responses on right and left side
• No major pausing between breathes.
• A rate between 16-20 breaths per minute is considered normal for an adult, although deep breaths or sighs (6-10 an hour) can be expected.

With your spinal cord injury, the muscles in your chest wall are effected as your chest wall does not move in and out as it used to, looking at the rise and fall of your abdomen will give an indication of your respiratory function.

What to watch for?
• Signs of increased respiratory effort such as shortness of breath, nasal flaring, facial tension and the muscles in your neck straining. These are all signs that you are finding it harder to get enough oxygen into your lungs.
• A moist unproductive cough and repeated ineffective attempts to cough are the first signs of retained sputum.
• An increased rate of shallow breathing (greater than 26 per minute) or laboured, difficult breathing are also signs of retained sputum.

• A rise in body temperature (to more than 38°C) is an indication of infection, perhaps of the respiratory tract.

• An increased pulse rate (of over 100 per minute) may be a compensatory mechanism when you are not getting enough oxygen.

• Subtle changes in your level of consciousness such as restlessness, irritability and confusion should be investigated as to the cause, as they can indicate a problem with your respiratory function.

• Pain when you breathe in may have a cause other than muscle fatigue consult your GP.

• Shoulder tip pain may be referred pain from your neck injury, but it can be from an irritated diaphragm.

• If blood is present in your sputum you will need to consult your doctor.

• Early morning headache, fever, or unusual drowsiness.

• Lower reading of airflow through your incentive spirometer.

⇒ If you experience any or several of these symptoms consult your local GP.

RESPIRATORY PROBLEMS

Sleep-induced Apnoea
This syndrome enables you to breathe adequately whilst awake but ‘forget’ to breathe whilst you are sleeping. Some people have always had a mild form of this syndrome, but haven’t known until there is someone watching them sleep (as happens in the Acute section of the ward). Typically, lethargy and headaches in the morning may occur.

• If ongoing and serious problems occur, special tests called sleep studies may be recommended and you may need treatment to assist with the problem.
Restricted Diaphragmatic Movement

If you have suffered a spinal injury, unrestricted diaphragmatic movement is essential to make breathing easier. It is therefore necessary to:

- Sit straight in your chair and not develop a slouch or 'C' curve. Incorrect posture has the potential to seriously effect the ability of the diaphragm to work unrestricted.
- Severe constipation will increase your abdominal pressure, which will stop the free movement of your diaphragm, making it harder to breathe. Constipation must therefore be avoided or resolved as quickly as possible.

Nasal congestion

Nasal congestion is annoying and is usually aggravated by lying on your back or stomach.
- Turning side to side in bed may be helpful.

By far the most common respiratory problem is infection.

Treating Respiratory (Chest) Infections

- Increase the number of times you do your breathing exercises. Do them every 2-4 hours.
- Assisted coughing can be done to increase the effectiveness of your cough. Do not attempt to do this if it has never been demonstrated to you.
- Change your positions more frequently by moving from sitting to lying and by turning from side to side. This will change the areas of your lungs that get air and will help you keep all areas of your lungs working.
- If you are producing excessive sputum, "postural drainage" may be required. Do postural drainage after your breathing exercises, whenever time and place allow, but only if you and your assistant have been taught how to do it properly.

Postural drainage:

This means that if your body is placed in certain positions → the loosened sputum can drain (with gravity) into the upper lungs, which are easier to clear with an assisted cough.

The best positions are demonstrated on the following page:
Position 1:
• Lying on stomach with hips elevated 18-20 inches on pillows.
• Purpose - to drain posterior basal segments.

Position 2:
• Lying on back with hips elevated 18-20 inches on pillows.
• Purpose - to drain anterior basal segments.

Position 3:
• Sitting upright or semi-reclining.
• Purpose - to drain the upper lung fields and allow a more forceful cough.

• Chest vibration and percussion can also be done while you are in these positions. Get someone who has been taught how to do it properly, to rhythmically compress or clap his/her hands on your chest. This also aids in removal of secretions.

Vibration and Percussion
Your assistant (usually in conjunction with assisted coughing) uses these two techniques. The aim of these techniques is to dislodge secretions and
make them more mobile, so that they can be coughed out more easily. Both these techniques are best performed after your physiotherapist explains and demonstrates them to your carer and family.

Vibration
• Your assistant places their whole hands in contact with your chest wall.
• Vigorous, rhythmical, intermittent pressure is applied when you breathe out.

Percussion
• Place a towel over your chest, side and back for comfort.
• Your assistant has their hands in a relaxed, cupped position. This is to ensure that the repeated impact is not painful. The fingers are kept straight and the tip of their thumb is at the side of the middle joint of the index finger (with no resulting space).
• Your chest wall is then clapped in a rhythmical fashion.
• The percussion is stopped whilst you are coughing. An assisted cough may then be performed to assist you to bring up resultant phlegm or sputum.

• Refer to the position diagrams and clap over the following areas:
  Position 1: From below the shoulder blades to approximately three inches above the bottom of the ribs - not over the backbone or kidneys.
  Position 2: From below the nipple line to the bottom of the ribs (including the sides of the chest - not over the stomach.
  Position 3: Directly under the collar bone.

• Consider taking a warm (not hot) bath or shower. This warms and humidifies the air with steam. Steam can help liquefy secretions so that they become easier to cough up. Do this once or twice a day then cough.
• If you have a fever or excessive sputum → you need to collect a specimen in a small, clean jar and contact your local doctor.
If your symptoms don’t go away in 5-10 days and your treatment does not seem to help → consult your doctor.
If your symptoms are getting worse or you have a fever → call your doctor.

Some respiratory infections may need antibiotics to kill bacteria or medications to help you breathe better and easier. A doctor must make these decisions. Serious breathing problems may need to be treated in the hospital.

**Prevention of Respiratory Problems**

Prevention is the cornerstone of respiratory care in your home. Cares, such as deep-breathing exercises, assist coughing and regular respiratory assessments should be practiced continuously and continually. Avoiding predisposing environments and the early recognition of a chest infection can save a lot of hard work for your carer (as well as distress for you).

Some basic hints you might be able to tell the carer are:

- Avoiding people with a cold or flu is one of the best ways for the client to prevent contracting a significant problem.
- Dress appropriately for the weather, to avoid extreme body temperature changes.
- Eat a well balanced diet to keep up general resistance and minimise risk of infection.
- Know the early signs of a chest infection developing:
  - Productive cough
  - Temperature
  - Increased spasm.
- Regular assisted coughing, done more frequently if the cough becomes productive, will help prevent the development of more serious complications. An assisted cough daily is recommended. This should be increased to hourly if cough becomes very productive and **early medical advice** should be sought.
- **Smoking is not recommended**, as this will only increase the risk of a chest infection developing (and decrease wound healing - if applicable).

**Medications that may be used to Treat Respiratory Problems**

Medications should not be taken without your doctor’s orders.
<table>
<thead>
<tr>
<th>DRUG</th>
<th>STRENGTH</th>
<th>ACTION</th>
<th>ADVERSE REACTIONS</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Bronchodilators:</strong></td>
<td>These drugs reverse the effect of bronchospasms which constrict the airways (as in asthma).</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ventolin (salbutamol)</td>
<td>Orally; Effective 15min - 4hr Inhalation; &quot;Puffer&quot; or solution Effective 5min - 4hr</td>
<td>• Bronchodilatation (by stimulating β2-adrenoceptors) • Uterine relaxation</td>
<td>• Can cause urine retention. • Muscle tremors (especially hands) • Fast pulse, low blood pressure, flushed skin, palpitations • Nausea, headache</td>
</tr>
<tr>
<td>Atrovent (ipratropium)</td>
<td>Inhalation: &quot;Puffer&quot; or solution Effective 3-5min Peak 10-2hrs Duration 4-6hrs</td>
<td>• Bronchodilatation (by blocking vagal reflexes)</td>
<td>• Rarely urine retention • Dry mouth • Mild visual disturbances</td>
</tr>
<tr>
<td><strong>Mucolytics:</strong></td>
<td>These drugs reduce the viscosity (or 'tackiness') of mucus. This makes the secretions easier to 'cough' out.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Biscolvan (bromhexine)</td>
<td>Tablets or elixir</td>
<td>• Reduces viscosity of mucus • There is likely to be an initial increase in the flow of secretions</td>
<td>• Nausea • Diarrhoea • Indigestion • Abdominal fullness</td>
</tr>
<tr>
<td>Mucomyst (acetylcysteine)</td>
<td>Inhalation: 3-5ml</td>
<td>• Reduces the viscosity of mucus</td>
<td>• Bronchospasm (used after Ventolin) • Nausea • Inflammation of the mucosa of mouth • Discharge of thin nasal mucus</td>
</tr>
<tr>
<td><strong>Decongestant:</strong></td>
<td>These drugs help reduce the amount of secretions produced by the mucosa.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sudafed, Logicin (pseudoephedrine)</td>
<td>Nose drops; Oral; 60mg tablets</td>
<td>Reduce the amount of secretions produced by the mucosa.</td>
<td>• Overuse will cause a reactive overproduction of secretions</td>
</tr>
</tbody>
</table>
Healthy Eating

Introduction

There are lots of reasons to eat. Apart from the fact that it tastes good, food has important cultural and social significance. Food is a complex mixture of nutrients without which we would not survive.

Nutrients in Food

Maintenance of good health relies on a balanced intake of nutrients. Nutrients are substances the body needs in order to function.

The major nutrients in food are:

- **Carbohydrate** provides energy for activities such as breathing, movement, thinking, and maintaining body temperature.

- **Protein** is the basic building block, the bricks and cement of the body. Muscle, skin, hair and blood are all made of protein. Protein is needed for growth and repair of all body parts.

- **Fat**, a concentrated source of energy provision and storage.

- **Vitamins and Minerals**, essential for health but are only needed in small amounts by the body. Too much or too little can cause an imbalance, resulting in sickness.

- **Fibre**, the undigested part of plant food. Fibre provides food for the bacteria that keep the bowel healthy and helps prevent constipation.

- **Water**, the most essential nutrient of all. Water is needed for every bodily function, and is constantly lost as sweat or urine. Water needs to be replaced regularly. Aim for at least 6 to 8 glasses of water or fluid each day.

The Ingredients of a Healthy Diet

Nutritionists group food according to common nutrients they contain. The basic food groups are:
- **Bread & Cereals.** These are a major source of carbohydrate. Wholemeal or wholegrain breads and cereals are a good source of fibre, B group vitamins, and magnesium.

- **Vegetables.** These are rich in vitamins and minerals, antioxidants, vitamin C and fibre. Yellow vegetables are a particularly good source of B-Carotene. Green vegetables are a good source of the vitamin, folic acid.

- **Fruit** provides fibre, energy and water, and is the main source of vitamin C.

- **Meat and Protein Foods** provide protein. Red meat is a particularly good source of iron and zinc. Animal food provides Vitamin B12. Legumes are a good source of protein and fibre.

- **Dairy Foods** are an excellent source of calcium and also provide protein, and energy.

- **Fats and Sugars** are a good source of extra calories or energy if underweight.

### What is a Healthy Diet?

Variety and moderation are the keys to good nutrition. The main points of a healthy diet are to make sure you have:

- **Smiley** Lots of fruit and vegetables to provide vitamin C, antioxidants, fibre and other essential vitamins & minerals.
- **Smiley** Lots of bread and cereal foods, to provide energy, fibre, and vitamins.
- **Smiley** Some dairy foods to provide calcium, protein, and energy.
- **Smiley** Some meat and protein foods to provide adequate protein, iron, and zinc.
- **Smiley** Very few fatty and sugary foods.

A diet high in fruit, vegetables, bread and cereal foods, with adequate protein and dairy foods, will tend to be high fibre, lower fat and rich in essential vitamins and minerals.

Generally, this would translate to reduced risk of pressure areas, constipation, and obesity, as well as a lower risk of heart disease and cancer.
Some Important Issues in SCI

1. Weight Control
2. Constipation
3. Prevention of Urinary Tract infection
4. Alcohol
5. Pressure Area Care

Weight Control

Initially post injury, loss of appetite and weight loss can usually be reversed with High Protein High Energy supplements, for example enriched milks, yogurts, cheese and biscuits. Often, small meals with mid-meal snacks can assist appetite and intake. Some ideas on eating extra protein and energy are given below.

How to gain weight
Use enriched milk drinks. Add 3 tablespoons of milk powder to 1 cup of milk. Flavour with Milo, Ovaltine, ice-cream etc.

Try fruit smoothies. Blend a banana into enriched milk.

Try yoghurt, ice-creams, or milk puddings between meals.

Snack on nuts, dried fruit, biscuits and cheese, or 'health' food bars.

Make soups on enriched milk instead of water.

Add cheese or cheese sauce to soups and vegetables.

Add cream to breakfast cereal, drinks, and mashed potato.

As your appetite improves, and you regain the lost weight, you may cut down on the snacks.

In the post acute stage, prevention of weight gain is a higher priority. Excess weight gain may result in reduced mobility, difficulty with transfers, and increased risk of pressure sores. The most effective way of preventing weight gain is to eat lots of fruit, vegetables, bread and cereal foods, and very little fatty foods. Remember that take-aways and fast foods in moderation can be still be part of a healthy diet. Some tips on ways to eat less fat are presented below.
**How to Eat Less Fat**

- Cut the fat off meat
- Take the skin off chicken
- Choose low fat milk, for example, Physical Skim or Trim milk
- Choose low-fat yoghurt and low-fat cheese
- Cook with less oil, butter, or margarine
- Only use a thin scrape of butter or margarine on bread
- Use tomato based sauces, rather than cream sauces for pasta dishes
- Don’t add extra butter or margarine to vegetables
- Use oil-free salad dressings
- Only have snacks like chips, chocolate and cake occasionally
- Eat take-aways only occasionally

---

**How to prevent Constipation**

☑ Aim for at least 2 pieces of fruit daily
☑ Aim for at least 5 different vegetables daily, about 2 to 3 cups daily
☑ Have wholemeal or wholegrain bread each day
☑ Don’t skip meals, especially breakfast
☑ Choose a high fibre breakfast cereal
☑ Drink at least 6 - 8 glasses of fluid each day
Constipation

Constipation can be a major source of distress and can cause dysreflexia. Both fibre and fluid are important in preventing constipation. Fibre is the indigestible part of plant foods. Fibre absorbs water from the bowel, and adds bulk to the bowel motions making them softer and easier to pass. The best way to eat more fibre is to eat more fruit, vegetables, legumes such as baked beans or lentils, and wholemeal or wholegrain bread and high fibre breakfast cereal.

Preventing Urinary Tract Infections

Generally, at least 2 litres of fluid each day is needed to keep the urine dilute and reduce the risk of infection and kidney stones. Cranberry juice may be effective in preventing bacteria binding to bladder walls.

What about alcohol?

Alcohol is high in calories and provides no nutrients. Too much alcohol, along with a poor diet, can lead to weight gain and increase the risk of pressure sores. Remember, drink alcohol in moderation only.

Pressure Area Care

People with pressure sores need a nourishing diet with increased amounts of zinc and vitamin C in their diet. If you have pressure sores, talk to the dietitian to see if you are getting the right amounts of protein, energy, zinc and vitamin C.
I. SEX AND SEXUAL FUNCTION

Anatomy of the Male Sex Organs

<table>
<thead>
<tr>
<th>Anatomy</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Scrotum</td>
<td>• Pouch of skin that contains the testes and its tubes</td>
</tr>
<tr>
<td></td>
<td>• Assists in keeping the testes at the right temperature for sperm production (~ 2 degrees below body temperature)</td>
</tr>
<tr>
<td>Testes</td>
<td>• Egg shape glands that produce the sperm</td>
</tr>
<tr>
<td></td>
<td>• Also produce the male sex hormone—testosterone.</td>
</tr>
</tbody>
</table>

Epididymus
• The long tube behind the testes in the scrotum in which the sperm are stored

Seminal vesicles
• Small glands located behind the bladder that add fluid to the sperm

Prostate gland
• Small gland at the bottom of the bladder which adds more fluid to the sperm
• The urethra passes through it

Ejaculatory duct
• Small tube that carries the semen (sperm plus added fluids) into the urethra
• This occurs close to the time of ejaculation

Urethra
• The thin elastic tube that runs through the penis
• During ejaculation, the bladder is closed off so that urine does not escape and
• the urethra carries the semen to the outside of the body
Penis
- contains the urethra
- it consists of 3 cylindrical tubes made of erectile tissue
- these tubes fill with blood during sexual stimulation (producing an erection)
- the erection assist in depositing the sperm effectively
- the end of the penis is slightly larger and is called the **glans**

Anatomy of the Female Sexual Organs

**Clitoris**
- the external projection of this organ is located just above the urethral opening at the top of the inner labia
- highly sensitive and its only real purpose is for pleasure
- made of the same type of erectile tissue as found in the penis

**Vulva**
- folds of skin at the entrance to the vagina
  - *Outer labia*
    - larger folds on the outside
    - these have skin and hair
    - contain glands that produce the lubrication fluid needed for intercourse
  - *Inner labia*
    - smaller folds of skin inside the larger folds
    - these are soft, pink and moistened by secretions

**Vagina**
- hollow muscular tube / opening into the body
- has a moist lining which is made up of folds of skin
- it lengthens and widens with sexual intercourse
- it accepts the penis during sex
- also the passageway during childbirth

**Uterus**
- pear shaped muscular organ located in the pelvis
- its purpose is to carry and nurture a child
- each month of the female cycle it builds up its lining, if no fertilised egg is received it expels the lining in a process called menstruation (a period)
- the **cervix** is the opening of the uterus into the vagina
Fallopian Tubes
- these tubes are attached to the top of the uterus
- each month they carry an egg from the ovaries to the uterus, ready to be fertilised

Ovaries
- two small organs located in the pelvis they produce and store the eggs until they are ready to be released each month
- they also produce the female sex hormones - oestrogen and progesterone

Sexual Function (Before the Injury)

Sexual function is a complex interaction between:
- spinal cord reflexes
- influences from the brain
- hormones
- psychological factors

Nerve Supply
The important parts of the spinal cord for sexual function in both male and female are:
- T11,12 - L1,2
- S2 - 4

In the male:
Sensation (to perineum) S2-4
Erection T11,12 and S2-4
Ejaculation T11,12 and S2-4

In the Female:
Sensation (to perineum) S2-4
Clitoral erection and
Vaginal lubrication T11,12 and S2-4

Male Sexual Response Cycle

- What happens when a man becomes aroused?

Sexual arousal is a result of a combination of signals that stimulate our senses including:
- Smells
- Sounds
- Seeing something sexually exciting
- Touch - especially in erogenous zones
The physical signs of arousal that the body shows include:

- penis becomes erect
- scrotum tenses and testes rise
- emission and ejaculation may occur
- nipples become erect
- muscles tense
- breathing becomes rapid
- pulse and blood pressure rises
- skin becomes flushed

**Orgasm** is the culmination of all these feelings:

- when orgasm occurs there is a pumping action that discharges semen from the penis in spurts

Following orgasm:

- muscle tension decreases
- pulse, blood pressure and breathing gradually return to normal
- relaxation occurs

**Female Sexual Response Cycle**

- What happens when a woman gets aroused?
  - vagina moistens
  - clitoris swells
  - labia swell and open
  - uterus contracts
  - nipples become erect
  - muscles tense
  - breasts enlarge
  - breathing becomes more rapid
  - pulse and blood pressure rise
  - skin becomes flushed

- **Orgasm** in the female involves:
  - withdrawal of the clitoris from its normal position
  - strong contraction of the muscles of the vaginal walls and rectal area
  - tensing of other muscles

Following orgasm there is:

- muscle relaxation
- gradual fall in pulse, blood pressure and breathing
Erogenous Zones

Remember, the erogenous zones are not only the genitals but also the neck, ears, lips and almost any other part of the body. Some or all of these areas may contribute to arousal and stimulation.

Reflexogenic Vs. Psychogenic Stimulation

In the male: Erections can be either:

1. Psychogenic
   - caused by a message sent from the brain
   - e.g. seeing an attractive person, watching an erotic movie or fantasising
2. Reflexogenic
   - caused by direct stimulation
   - the brain is not important at all
3. Combination of Both

In the Female: the same applies to vaginal lubrication and clitoral erection.

Sexual Function (After the Injury)

Sexual function following spinal cord injury depends primarily on:
- Level of injury
- Completeness of injury
- Time since the injury may also be important

The main aspects of sexual function that may have been affected are:

In the Male:
- SENSATION in genital and other areas below the level of injury
- ORGASM may be changed
- Ability to achieve and sustain an ERECTION
- Ability to EJACULATE

In the Female:
- SENSATION in genital and other areas below the level of injury
- ORGASM may be changed
- Ability to achieve VAGINAL LUBRICATION
The degree of paralysis of muscles around hips, pelvis and legs may be important for both sexes with respect to positioning for sexual activity and intercourse.

What Can Be Done to Help Overcome Sexual Problems following SCI?

- **General Points**
  While sexual activity following SCI may be different from before this does not mean that it cannot be:
  - exciting and stimulating
  - satisfying
- **You can have:**
  - a sexually active life
  - maintain intimate relationships
- **Remember:**
  - Sex is a natural part of life and we are all sexual beings - this has not changed simply because of your SCI
  - Sex and sexuality are important parts of your overall rehabilitation - the staff in the Spinal Unit are happy to discuss issues with you whenever you feel ready
  - There is more to sex than just sexual intercourse e.g. foreplay, touching, caressing, exploring, oral sex, masturbation/mutual masturbation
  - The inability to move much does not mean the inability to please or be pleased
  - Loss of genital function and/or sensation does not mean loss of your sexuality
  - Communication with your partner is very important

Treatment of Problems with Erections

- **Different Positions**
  - Some people find that using particular positions during intercourse help maintain erections better
  - This requires patience, experimentation and communication with partner
- **Vacuum Devices**
  - Small vacuum pump is applied to penis to draw blood in
  - Elastic ring is applied to base to stop the erection subsiding - tends to cause slightly “bent” erection
  - Must not be left in place for more than 30 minutes
  - Advantage: - non-invasive
  - Disadvantage: - erection does not look normal
• **Penile Injections (Caverjet)**
  - Injection of medication directly into side of penis
  - The medication (Alprostadil/Prostaglandin E2) assists the blood to enter penis and produces erection
  - Advantage:  - Erection is more normal looking
               - Inexpensive
  - Disadvantage:
    - Care must be taken with dose given or erection can last too long and this is dangerous
    - overcoming the whole idea of "injections"

• **Intra-urethral Pellets (MUSE)**
  - Small pellet the size of grain of rice put into urethra
  - Same drug as the injections (Alprostadil)
  - Adv:  - no injections
  - Disad:  - sometimes does not work as well as injections
            - expensive

• **Oral Medications (Viagra)**
  - Tablet form
  - Different medication (silendafil)
  - Only works if there is arousal stimulation
  - Adv:  - no injections
  - Disad:  - needs to be taken 1 hour before sex
            - expensive
            - cannot be used if you use anginine (used to treat autonomic dysreflexia)

• **Penile Implants**
  - complex surgical procedure to implant a device into penis to assist with erection
  - rarely used but sometimes appropriate
  - complications

**Treatment for Problems with Ejaculation**

• this may be difficult to treat
• it may improve with time
• retro-ejaculation sometimes occurs where the sperm go back into the bladder instead of coming out the right way
• vibrators may sometimes help with ejaculation

**Treatment for Problems with Lubrication**

• use a water-based lubricant e.g. KY jelly
• direct stimulation may assist reflex lubrication
Treatment of Sensory/Orgasmic Problems

- sensation may improve with time
- explore erogenous zones/areas above the level of injury - these may become extra-sensitive
- orgasm may not be the same as before but can be just as good
- Don't expect miracles the first time!!

Other Things to Think About

- **Intercourse Positions**
  - muscle weakness, spasm or balance problems may make sexual activity more difficult than before
  - experiment with other positions
  - a member of the team or your local health professional can give you advice about other positions to try or how to manage spasms or lack of balance
  - communication with partner is very important

- **Bladder And Bowel Problems**
  - A member of the team can also give you advice about:
    - avoiding bladder or bowel accidents
    - problems related to your type of bladder management and how to overcome them
    - communication

- **Spasticity**
  - spasms may aid or interfere with sexual activity
  - talk to a member of the team

- **Autonomic Dysreflexia (AD)**
  - if you are prone to AD this can sometimes occur during sexual activity
  - especially with ejaculation/orgasm if you experience these
  - if severe, the activity should be temporarily ceased
  - check other causes of AD i.e. bladder/bowel
**Safe Sex**

**Remember:**
- Unless you are 100% certain that the person that you are having sex with does not have a STD (sexually transmitted disease) you should be having “Safe Sex”
- It is not possible to tell whether someone has an STD or not just by looking!!
- SAFE SEX is either:
  - Non-penetrative sex
  - Sex with condom and water-based lubricant
- HIV/AIDS, Hepatitis B and C are usually transmitted by unprotected penetrative sex
- Other STDs e.g. herpes, gonorrhoea, can be spread in other ways
- HIV/AIDS is not only a disease of gay men
- Using a condom is the safest form of intercourse
- Take responsibility for your own health and the health of your partner

**Contraception**

**Remember:**
- If you can ejaculate or have any discharge from your penis during sexual activity you may be able to get your partner pregnant
- Some form of contraception will be needed by yourself or your partner
- SCI women usually begin menstruation (periods) a few months after the injury
- Once periods begin again you can get pregnant
- Fertility in SCI women is usually normal unless there is some other fertility problem
- Contraception will be needed unless you are attempting to get pregnant
- Your doctor or other member of the team can give you advice
**J. FERTILITY AND PREGNANCY**

**Women**

Menstruation returns to a normal pattern after the acute physical and psychological trauma has passed.

- This may take anywhere from 6 weeks to 2 years after your spinal cord injury but usually within 1 year.

The uterus (womb) works normally through conception and pregnancy and fertility for women with SCI is usually unaffected in the longer term.

**Men**

Fertility in men with SCI may be markedly reduced. This depends to some extent on:

- the level of the injury
- whether the injury is complete or incomplete

**Reduction in fertility occurs for 2 main reasons:**

- **Ejaculation is difficult**
  - only ~ 10% of men with complete UMN lesions above T11
  - even less common in LMN lesions or below T11
- **Semen / sperm quality is reduced**
  - especially the motility (speed and quality of movement) of the sperm
  - there are many possible reasons for reduction in semen quality including:
    - recurrent UTIs, prostate or testicular infections
    - increased scrotal temperature
    - infrequent ejaculation leading to stasis
    - method of bladder management

**Methods of Semen Retrieval**

There are 2 main methods of obtaining semen if ejaculation by natural methods is difficult or impossible.
• **Vibroejaculation**
  - a vibrator is applied to the penis and may stimulate ejaculation
  - this usually only works in lesions above T9-10
  - it can be done at home
  - may cause autonomic dysreflexia in people prone to this (lesions above T6)
• **Electroejaculation**
  - vibrators do not work in all cases
  - electroejaculation involves use of an electrical probe placed into the rectum
  - a small electrical current stimulates the nerves of the seminal vesicles (where the semen is stored)
  - causes emission rather than true ejaculation
  - this can only be used if you have no sensation in the rectum
  - it cannot be performed at home, only in the SIU
  - may also cause autonomic dysreflexia.

The semen that is obtained by these methods can then be used for artificial insemination of your partner.

---

**Methods of Improving Semen Quality**

• **Reducing Infections**
  - be aware of correct methods of bladder management and catheter care etc
  - infections need to be treated quickly and properly
• **Reducing High Testicular Temperature**
  - wear loose trousers and underpants
  - the type of cushion you use may be important
  - sit with legs apart if possible
• **Improving Low Semen Turnover**
  - regular ejaculation by whichever method
• **Type of Bladder Management**
  - self-catheterisation probably best
  - IDC or SPC better than reflex voiding (urodome)
  - Avoid high bladder pressures whichever method is being used.

---

**Getting Your Partner Pregnant**

If you are able to ejaculate you should have as much chance as anyone else of getting your partner pregnant during intercourse unless the quality of the sperm is too poor.
Artificial Insemination / IVF

The use of artificial insemination and advanced in-vitro fertilisation (IVF) techniques:

- has assisted with the problem of poor sperm quality for SCI men.
- once the semen has been collected your partner can undergo these procedures to increase the chances of getting pregnant using your sperm.

- **Artificial Insemination**
  - Means that some other procedure is used to put the semen into your partner's vagina or uterus
  - This can be done at home or in the SIU using a plastic syringe
  - Often a fertility specialist is needed
    - The sperm can be washed and prepared to increase their motility

- **IVF**
  - Procedures are much more complicated, time-consuming and expensive
  - A fertility specialist is needed
  - The egg and sperm are combined and fertilised artificially
  - Only one or a few sperm are needed in some of these techniques

- **Donor Insemination**
  - Occasionally sperm of adequate quality cannot be obtained using any of these techniques
  - In this situation some couples consider and choose donor insemination.

The combination of vibro- or electroejaculation plus IVF has greatly improved the fertility possibilities for couples wanting children where the man has SCI.

Please see your doctor for further information about these procedures.

Pregnancy in SCI Women

Many spinal cord injured women, both those with quadriplegia and those with paraplegia, have had successful pregnancies and healthy children. If you are planning to get pregnant you should discuss this with your family doctor, obstetrician and SCI doctor.

Some medications that you are taking may need to be stopped prior to conceiving. As a general rule of thumb, drugs are normally avoided during pregnancy and especially during the first 12 weeks.
• The uterus (womb) works normally during conception, pregnancy and childbirth.
• There may be a higher incidence of complications both during pregnancy and labour.
• May be more difficult the higher the SCI.
• Many SCI women have relatively few problems and have non-complicated pregnancies and deliveries.

**Issues for SCI Women during Pregnancy**

• **Respiratory**
  - Some women with quadriplegia have some respiratory problems due to the womb pressing up underneath the diaphragm in the later stages of the pregnancy.

• **Bladder Management**
  - The normal bladder routine is likely to be upset during pregnancy
  - If you are self-catheterising or bladder trained, these may become difficult in the last 3 months of pregnancy. This is an individual thing and best discussed with the obstetrician if and when problems arise. An *indwelling catheter* may be required.
  - Urinary tract infection is one of the most common causes of premature labour.
    - You must be diligent in the cleaning of catheters and leg bags etc.
    - It is advisable to have an IVP 3 months after the birth of the child to check on the health of the kidneys.

• **Bowel Management**
  - Constipation is a common problem in pregnancy.
    - Increase the amount of fibre in your diet
    - Laxatives may need to be started or increased in number.

• **Posture**
  - Posture and balance in the wheelchair may become a problem as the pregnancy progresses
    - due to the weight of the baby pulling the body forward.
    - for women with lower level injuries the natural tendency is to arch the back to counterbalance the weight.
    - this may lead to back pain.
  - Your local physiotherapist can give you advice on:
• Appropriate exercises for the lower trunk during pregnancy and after the baby is born
• Back care and the increased risk of damage to the back during pregnancy.

• Transfers
  - Wheelchair transfers may become increasingly difficult because of increasing weight and decreasing balance.
  - In some cases women may have to resort to other means of transferring, either by being lifted or using a hoist.

• Pressure Relief
  - Pressure sores are one of the most common problems associated with pregnancy and one, which is readily avoided.
    - Must do regular skin checks to detect any problems early
  - Pressure relief requirements are usually unchanged during the first half of the pregnancy.
  - During the second half of the pregnancy, due to increasing weight and decreasing balance, pressure may become a problem.
    - If using a foam cushion you may need to change to a better pressure relieving cushion, e.g. Roho or Jay.
    - If already using a Roho cushion, the pressure should be checked and adjusted as necessary.
  - For those women able to roll independently but with difficulty, it may be necessary to use a pressure relieving mattress e.g. ripple mattress temporarily.
  - Please contact your local physiotherapist or other health care professional for further information about any of these issues.

• Sleeping Position
  - In the early stages of pregnancy, prone lying is still possible.
  - As pregnancy progresses, lying flat on the back or stomach will become too difficult:
    - Especially for those with quadriplegia because breathing becomes difficult due to pressure on the diaphragm by the enlarged uterus.
    - Pressure on the large vessels in the abdomen will decrease circulatory return.
    - Nausea and dizziness are warning signs that you should not sleep or exercise while lying on your back.
The use of a partial sitting position when in bed is often more comfortable:

- It can help relieve heartburn (a common discomfort amongst all pregnant women, able-bodied or not).
- This, however, may increase pressure and shearing on the skin on the buttocks.
- Lying on your side in a partial sitting lying should be the position of choice and comfort.

• Swelling of the Feet

- This is a common occurrence in pregnancy.
  
  - As the uterus enlarges, it hampers the return of fluid from the feet.
  - For those who already have swollen feet as a result of spinal injury, pregnancy may make it worse.
  - It may be necessary to increase the shoe size to prevent problems from tight shoes.
  - Wearing of support tights or compression stockings may also help

- Wherever possible, the feet should be elevated to help the swelling go down.

• Labour

- It is sometimes difficult to tell when labour starts.
  
  - Some obstetricians prefer admittance to hospital in the last weeks of pregnancy to await the onset of labour.
  - This is a very individual thing and best discussed with the doctor.

- The choice between a vaginal delivery and an elective caesarean section is influenced by many factors including the mother’s general health and position of the baby in the womb.
  
  - this should be discussed in detail with the doctor.

- Many women these days have epidural anaesthetics in labour as a method of pain relief.
  
  - as a result, in essence are temporarily paralysed and have no feeling, yet the process of birth continues.

- The potential for autonomic dysreflexia during labour for women with injuries above T5 exists, but in practice this a rare problem.
• Specialised Treatment

- Advice with modifications and equipment to assist SCI women with issues regarding child rearing including:
  - modifications to baby cribs or cots
  - designing appropriate change tables etc.,
  - instruction on techniques for simplified approaches to baby care tasks
  - conservation of mother’s energy

- can be obtained from the Spinal Injuries Unit Occupational Therapy Department or the Independent Living Centre of Queensland.
K. SPASMS

What Are Spasms?
Spasms are involuntary, reflex movements of various parts of your body that sometimes occur after spinal cord injury. They can occur in any part of your body that is affected by the SCI e.g. legs, trunk, arms.

Spasms:
- Start after the period of Spinal Shock has finished
- This can be any time from a few hours to weeks
- Reach a maximum at 18-24 months after injury

What Is A Reflex?
A reflex is a movement or action that occurs without a command from the brain.
Remember what happens when the doctor taps your knee with a hammer?
- The leg jerks without you making it happen
- This is a reflex action.
Reflexes often protect us from harm e.g. rapidly moving the hand away from something that is very hot happens before we are aware of being burnt. The body has acted automatically before the brain has had time to register the pain or send a command to move the hand.

Spinal cord injuries are divided into two types, depending on whether or not there are reflexes present below the level of injury.
If reflexes are present, the injury is called Upper Motor Neuron (UMN):
- Usually injuries above T12/L1
- Spasms usually occur
If there are no reflexes present, the injury is called Lower Motor Neuron (LMN):
- Usually injuries below T12/L1
- Spasms do not occur, the limbs are floppy

Why Do Spasms Occur?
Spasms occur after SCI because the reflexes can not be controlled properly by the brain.
The messages that the brain would normally send down the spinal cord to stop the reflexes from working cannot get past the area in the spinal cord that has been injured.
The reflexes become uncoordinated, spasms occur and the limb moves in a jerky, erratic way.
What Causes Spasm?

• Touching, movement or pressure or pain may be enough to start a spasm and it may then be difficult to stop.
• Spasms can occur at any time but are often worse first thing in the morning.

What If Spasm Suddenly Becomes Worse?

BE ALERT! If spasms suddenly become worse than usual or the pattern of the spasm changes it may be a warning sign that there is something else going wrong in your body.

Spasm may be a symptom of another problem:
• urinary tract infection
• constipation
• pressure sores
• or any other illness that would normally cause you pain or discomfort.
Always get a medical opinion if you have more spasm than usual but cannot work out why.

Spasm May Be Useful!

If spasms are not too severe they can be useful to help you to:
• maintain muscle bulk
• improve circulation
• reduce swelling in the limb
• perform particular movements with the limb
Most people learn to live with the spasms and learn how to control them.

What Problems Can Spasm Cause?

If spasm becomes severe it can cause you problems:
• difficulty with performing certain activities e.g. transfers or doing self-catheters
• difficulty sitting or lying comfortably
• pressure sores due to excessive friction
• contractures (loss of mobility) of joints

If you are having any of these problems then your spasm probably needs to be treated.
Treatment of Spasms

• Physical Treatments

Spasm may be controlled or eased, at least in some cases, by:

• Active and passive limb movements
  ➢ Should be done regularly 3 times a week
  ➢ Helps maintain range of movement of joints and prevent contractures
  ➢ This is particularly important in the early stages after injury.

• Prone lying (lying on your stomach)
  ➢ For 20 minutes per day
  ➢ Helps to stretch out hips and knees fully
  ➢ Standing in backslabs, callipers or on a tilt table will also assist

• Stretching of certain “Trigger Points” in the muscle
  ➢ Done before certain activities that you want to perform

Your physiotherapist can assist you with all these treatments and teach you or your carer how to perform them.

• Drug Treatments

The following drugs may be useful to help you manage the spasms. NO MEDICATION SHOULD BE COMMENCED WITHOUT CONSULTATION WITH YOUR DOCTOR.

Oral medications (Tablets):

• Diazepam (Valium)
  ➢ start at a low dose 2 mgs at night and increase slowly
  ➢ drowsiness is the main side effect

• Baclofen (Lioresal)
  ➢ Start at low dose
  ➢ maximum of 100mg per day
  ➢ best effect if taken 3-4 times per day
  ➢ may cause confusion or depression especially in older people
  ➢ sometimes causes nausea and tiredness
  ➢ may be better if combined with a small dose of valium
  ➢ should not be stopped suddenly

• Dantrolene Sodium (Dantrium)
  ➢ tends to be less effective than baclofen but may be useful in some individuals
  ➢ side effects may be a problem especially effects on the liver
• **Nerve or Muscle Blocks**

In some cases, medications can be injected directly into a muscle or the nerve supplying the muscle to help with reduction in spasms. These are usually not performed:

- within 6-12 months after the SCI
- if recovery of function is still occurring

You will need a thorough examination by your doctor and physiotherapist before this can be performed.

Some important points to know about these blocks are:

- they work very well for some people but they are not suitable for everyone
- they are not permanent and may need to be repeated
- they sometimes cause loss of feeling or loss of movement in the skin and muscles that are supplied by the nerve
- they can sometimes be painful if you have any feeling

You should talk to your doctor or physiotherapist if you would like to know more about these blocks.

• **Intrathecal medications**

Some individuals with very severe spasm that cannot be controlled using other methods may be assessed for insertion of an *intrathecal pump device*.

This system delivers medication, usually baclofen, directly into the fluid surrounding the spinal cord (i.e. into the intrathecal space).

The system consists of:

- a reservoir, which is surgically implanted into the stomach wall
- a fine plastic tube which runs into the spinal fluid.

It has the advantage that the dose of baclofen used is much less than with tablets and therefore there are fewer side effects because of the lower doses needed.

**BUT:**

- it involves a fairly major surgical procedure
- there are some risks involved
- the pump needs to be refilled once every 4-6 weeks

This treatment is not suitable for everyone and you would need thorough assessment at the Spinal Injuries Unit to determine if you would be suitable or would benefit from the pump.
• Surgical Treatments

There are multiple surgical procedures that may be considered in the treatment of spasms. Many, however, are irreversible and such options are usually a “last resort”.

Some of the reasons that surgery may be considered are:

• if contractures have developed. This is permanent shortening and tightening of a tendon that cannot be stretched out.
• If no other treatments have worked and the spasm is very severe
• If there are severe side-effects of medications

Some of the procedures that might be considered include:

Tendon Division
• Muscle tendons in the legs can be cut
• This may help to break up the pattern of the spasm

Myelotomy
This operation involves cutting part of the spinal cord itself
• This would only be considered if everything else has failed
• It usually works quite well but sometimes the spasm returns

Points to Remember about Spasm

• Not everyone gets spasm.
• Changing or worsening spasm may be a symptom of another problem.
• Spasm can be sometimes be useful.
**L. POSTURE**

A good posture is essential in preventing the development of pressure sores. It can also help in maximising stability and functional ability in the wheelchair, maintaining good alignment of the spine, and minimising pain.

The basis of good posture is the alignment of the **PELVIS**. The pelvis forms the primary weight bearing area during sitting. Altered muscle tone and skeletal abnormalities can make the pelvis tip forward or back, tip to the side, or rotate on the sitting surface. These positions can increase the pressure on the bonier parts of the pelvis and raise the risk of skin breakdown. Additional support for the trunk or legs can help to correct some of these postures and keep the pelvis in a level position. An individually prescribed cushion, and the correct backrest, are essential parts of postural control.

**Correct Posture**

In the sitting position there are some common posture problems.

1) **Scoliosis**

- Scoliosis is a sideways curvature of the spine.
- It is associated with pelvic obliquity (a tip of the pelvis to one side) leading to increased pressure on the lower side.
2) Kyphosis

- Kyphosis is a “C” shaped, or slumped curvature of the spine.
- It can lead to increased pressure on the tail bone where there is little padding and less blood supply.
- This posture can lead to pain in the neck and shoulders, and make it more difficult to use your arms and hands.
- It can even affect your breathing.

The development of poor postures can be prevented by -

1) Posture assessment and re-assessment as necessary by a physiotherapist.
2) Keeping the back upholstery of your wheelchair in good condition (not allowing it to sag).
3) Frequent checking of posture. Every time you are assisted, or transfer yourself into your wheelchair, check to see if your hips are as far back as possible. Ensure your knees and pelvis are straight. Use a mirror if necessary, and take the time to adjust your posture.
4) Using a lumbar support where required.
5) Maintaining good strength in your shoulder blade and thoracic muscles.
6) Preventing muscles from shortening, particularly in the hip and the hamstrings. Stretch regularly, using the program shown to you by your physiotherapist.
M. CONTRACTURES

Definition

Contractures occur when soft tissue such as muscles become shortened and prevent the joint moving through a normal range of movement. In the person with spinal cord injury where muscles are paralysed and unable to move the joint in a particular direction, the risk of contractures is high. This is especially so when joints are kept in one position for prolonged periods of time.

Prevention is the Best Management

What To Do

A. Daily Passive Ranging

Movement of each joint daily is important to maintain range. If you are a person with paraplegia you will probably master this independently. If you are a person with quadriplegia you may or may not require assistance.

Your therapist will instruct you and your carers in the correct method required, and provide handouts as necessary.

Useful guidelines to follow:
- Never force a joint to move during a spasm.
- Always handle joints and limbs gently so as to avoid joint, ligament or muscle damage - Do Not Use Pressure.
- Move joints slowly to prevent the onset of spasm.

B. Positioning

Correct positioning is essential in your bed and wheelchair. Lie on your tummy for about 20 minutes daily (or every second day) to stretch your hips and trunk.

- Wear shoes as this will support your feet in a good position.
- Ensure your feet are well positioned on your wheelchair footplates - don’t let your toes point down towards the floor.
- Wear necessary splints (refer to Splinting Chapter for details)
**Common Causes Leading to the Development of Contractures**

- Incorrect positioning in bed or incorrect posture in the wheelchair
- Incorrect ranging of joints or failure to range
- Muscle spasm
- Local trauma causing swelling

It is difficult to separate these four closely linked factors in relation to the formation of a contracture.

**Treatment Options if Contractures have Developed**

1. Consult your local therapist (community, hospital, Spinal Outreach Team).
2. Passive movements and active exercises as recommended.
**N. SPLINTING**

A person’s upper extremity strength and function may be impaired if the spinal cord relating to the spinal nerves of T1 or above is damaged.

Upper extremity splinting can be used to:

- increase function
- prevent deformity
- substitute for reduced muscle power and/or joint alignment.

Splints can be static or dynamic (allow movement). Individual splints will be prescribed and fabricated by your Occupational Therapist (SIU or SPOT, or community OT).

Hand splinting is often combined with other treatment techniques such as stretching and strengthening for maximum effectiveness. Splints may be prescribed for wear during the day at night or worn to assist hand function for a particular activity during the day e.g. self-catheterisation. You and your family will be taught the correct way to wear, use and care for the splints. If you have any queries or problems with a splint please contact your Occupational Therapist.

**Precautions**

Any device applied to your body has potential to cause problems. Some possible problems and recommendations are listed in the next table.

<table>
<thead>
<tr>
<th>PROBLEM</th>
<th>POSSIBLE CAUSES</th>
<th>WHAT TO DO</th>
</tr>
</thead>
</table>
| Skin irritation, red areas, blisters | • Pressure due to splint fitting incorrectly  
                                           • Splint applied incorrectly  
                                           • Poor sensation | • Remove splint  
                                           • Contact your Occupational Therapist  
                                           • Review how to apply the splint  
                                           • Review wearing regime |
| Increase in swelling     | • Straps fastened too tightly  
                                           • Improper positioning of arm/hand | • Loosen straps  
                                           • Review how to apply the splint  
                                           • Keep arms supported |
| Pain                     | • Splint/straps applied incorrectly                | • Review wearing regime  
                                           • Consult your Occupational Therapist  
                                           • Keep arms supported |
**Maintenance of the Splints**

1. Clean your thermoplastic splint with soap and room temperature water (NOT HOT WATER). Just sponge the splints; do not submerge them in water.
2. Elastic and/or velcro strapping may be scrubbed with mild soap, water and a small brush.
3. If your splint still has an odour after cleaning, try wiping it with a little toothpaste. If relining of the padding is necessary consult your Occupational Therapist.
4. All thermoplastic materials can be damaged by heat. Do not allow splints to lie in sunlight, hot cars or on or near heaters.
5. Instruct people on how to store your splints in a safe place. Be sure not to allow heavy objects to rest on top of them.

**Types of Splints**

Some of the more common types of splints that the occupational therapists in the Spinal Injuries Unit make and their purpose are listed in the table below. Occupational Therapists also make many other types of splints depending upon a person’s needs.

<table>
<thead>
<tr>
<th>TYPE OF SPLINT</th>
<th>PURPOSE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Boxing Glove</td>
<td>To reduce swelling in the hand in the initial period after admission.</td>
</tr>
<tr>
<td>Resting Pan</td>
<td>To support the hand and wrist in the normal resting position, i.e. the functional position.</td>
</tr>
<tr>
<td>Short Opponens</td>
<td>To support the hand in the functional position and to facilitate positioning of the thumb and fingers for tenodesis grasp.</td>
</tr>
<tr>
<td>Engen Splint</td>
<td>To utilise the tenodesis grasp to achieve a stronger pinch. Generally used for specific functional activities, such as self-catheterisation.</td>
</tr>
<tr>
<td>Wrist Support Splint</td>
<td>To support the wrist while performing functional activities (e.g. propelling wheelchair, feeding, brushing teeth, etc.)</td>
</tr>
<tr>
<td>Writing Splint</td>
<td>To assist in positioning of a pen.</td>
</tr>
<tr>
<td>Typing Splint</td>
<td>To assist with keyboard access.</td>
</tr>
</tbody>
</table>
O. TENDON TRANSFERS

Tendon transfers are an option available to persons with tetraplegia between the levels of C5 and C7 as a means to improve upper limb function and independence.

- They are usually considered 1-2 years following the initial injury when neurological recovery has plateaued.
- Each client must be initially assessed by the surgeons and therapists regarding goals for the procedure and potential for surgery. Then, if surgery is deemed appropriate, they will be re-assessed prior to, and following, any surgical procedure.
- Intensive therapy is required after surgery.

The most common types of transfers performed in the Princess Alexandra Spinal Unit are:

1. Hand Tendon Transfers:

Procedure: One of the wrist extensors is redirected and joined to the tendons that bend the fingers, and the thumb is straightened so that when the wrist is actively extended, the fingers bend in and the thumb closes in tightly to the side of the index finger.

Post-operative Management: A forearm and hand plaster is usually worn for 4 weeks, followed by a lightweight splint (sometimes the splint may be applied earlier depending upon instructions from the surgeon). An intensive restrengthening and retraining program (usually 6 - 12 weeks long) follows this.

Benefits: Active finger bending (flexion) and an improved lateral pinch allows greater independence in self-catheterisation, dressing, domestic and community skills, wheelchair mobility skills and writing. An overall enhancement of independence in all activities of daily living is generally achieved.

2. Deltoid to Triceps Transfer:

Procedure: The posterior part of the deltoid muscle is released and attached to the elbow via a donor graft (usually a tendon from the lower leg).

Post-operative Management: A long arm plaster with the elbow straight is worn for 6 weeks. Following plaster removal, an elbow-hinge brace is applied and gradual elbow bending allowed over the next 6 weeks. An intensive re-strengthening program follows. (This could be from 6 - 12 weeks).
Benefits: This transfer enables the person with tetraplegia to actively extend and control the elbow. This assists in pressure lifts, transfers, wheelchair mobility skills, bed mobility, reaching and driving, and generally enhances independence.

Considerations:

Before the decision is made to go ahead with any surgery it is extremely important that the client is well aware of the implications of the surgery and the required care post surgery.

1. On completion of surgery to the arm/hand, immobilised clients will required assistance with transfers, pressure care, mobility (will probably need power chair), bowel and bladder management, self-care and living arrangements (will need carer assistance). This will be required during immobilisation and for varying periods after the removal of the plasters, casts or splints.

   Careful planning is required to ensure appropriate supported management is available post-operatively if the client is returning home to be with a carer.

2. Following any type of surgery, clients must be motivated to participate in an intensive re-strengthening and retraining program.

   The Occupational Therapist and Physiotherapist can provide more details on tendon transfers. Videos are also available for viewing from the Occupational Therapy Department, Spinal Injuries Unit.
Unfortunately pain is a relatively common problem following spinal cord injury.

Acute pain can occur soon after the injury and can be caused by many factors including:

- Damage to the bones, muscles and ligaments of the spine at the time of the injury.
- Damage to the spinal cord and/or spinal nerves at the time of the injury.
- Damage caused by other injuries e.g. fractures or muscle injuries of arms, legs or other body parts.
- The effects of any surgery required to treat these injuries.

This acute pain may be severe but it can usually be treated well with standard medications and usually improves over a period of weeks as the damaged tissues heal.

Pain that continues on for a period of months or years is usually called chronic pain and unfortunately, this type of pain may be much more difficult to treat.

Remember, that not everyone suffers from problems with pain and that there are many things that can be done to help.

Types of Pain after SCI

There are different types of pain that occur after SCI and it is important to know about the different types because the treatments are different.

- **Musculoskeletal pain**
  - This is pain that is caused by damage to bones, ligaments, muscles or joints.
  - It is usually felt above the level of the injury or in areas where you have normal or near normal feeling.
  - It is usually felt close to the damaged tissue i.e. if the shoulder is injured the pain is felt at or near the shoulder.
  - It may be sharp or “dull and aching”.
  - Chronic musculoskeletal pain is often caused by “wear and tear” of muscles or joints or because of problems with posture or muscle imbalance.
• **Neuropathic (Nerve) Pain**

  - This is pain that is caused by direct damage to the spinal cord or spinal nerves.
  - It is usually felt at the level of the injury (where feeling on your skin starts to become less) or below the level of the injury (where there is no feeling).
  - It may be sharp, burning, stinging or shooting or it may be very difficult to "find the right words" to describe it.
  - Even though this pain may be felt in the legs or hands or stomach it is usually not caused by problems in these areas but because of damage in the spinal cord at the site of the original injury.

**Psychological Factors**

  - In the past, pain has been a poorly understood aspect of medicine. As we have come to understand more about pain and what causes it we have realised that **psychological factors (the way we all think and behave when we have pain)** are very important.
  - We all know that when we are sick or in pain we may feel grumpy, irritable or depressed. This is a natural response to pain and suffering.
  - This is important to remember because sometimes pain, especially when it becomes chronic is difficult to treat with medications alone.
  - We also need to consider and treat our psychological reactions to pain as this helps us to reduce, control and cope with pain better.

**Treatment of Pain**

Treatment and management of pain is a multi-disciplinary task i.e. there are many members of the team in the spinal injuries unit that may be able to help you with the pain. **You are a very important member of this team.**

• **General Points**

  - Unfortunately pain is sometimes not easy to treat and many different types of treatment may need to be tried.
  - Your pain is probably different from other peoples pain and what works for someone else may not work for you.
  - Medications are not always the answer and all medications have potential side effects.
  - You should avoid excessive use of narcotic type drugs e.g. panadiene forte, endone, morphine as these can be addictive and can also cause severe constipation.
  - You must avoid using illegal drugs or excessive alcohol to cope with the pain.
• Physical Treatments
  ➢ Musculoskeletal pain that is caused by problems with joints or muscles often respond to simple “hands on” treatment such as massage, hot or cold packs, muscle stretching or strengthening, ultrasound or electrical stimulation.
    ▪ Adjustment to the way you sit, walk or perform activities may also help.
    ▪ Your physiotherapist, occupational therapist or nurse may be able to help with these things.
    ▪ Simple medications such as regular panadol or anti-arthritic drugs may also help.

• Medications
  ➢ Neuropathic (nerve) pain often does not respond well to simple medications such as panadol or to narcotic medications (these should be avoided)
  ➢ Medications that tend to work better for nerve pain include:
    ▪ Anti-epilepsy drugs such as tegretol, epilim or gabapentin
    ▪ Anti-depressant drugs such as amitriptyline or dothiepin
  ➢ All of these drugs have potentially serious side-effects and must not be commenced unless you have discussed the issue with your doctor.
  ➢ Unfortunately nerve pain is sometimes difficult to treat and requires “a trial and error approach” in combining the medications that give the best effect for your individual pain.

• Psychological Management
  ➢ Psychological strategies such as relaxation, meditation and special techniques and ways of thinking about the pain can be very helpful in controlling pain.
  ➢ Your social worker or psychologist can teach you these techniques and talk to you about other ways of coping with the pain.

• Other Management
  ➢ Occasionally nerve blocks, spinal injections or surgery may assist with pain management.
  ➢ This will be discussed with you by your doctor if these techniques might be helpful for your type of pain.
**Q. AGE AND AGING**

As with the general population, people who have spinal cord injury can suffer the effects of aging and wear and tear on your body as you get older.

If you are older when you first suffer the injury, it may take you longer or be more difficult for you to achieve your goals in rehabilitation. The staff in the Queensland Spinal Cord Injuries Service are aware of this and will help you to achieve the things you want to if possible.

As you get older you may find that it becomes more difficult for you to do all the things that you could do when you were younger. Remember that the illnesses and problems that everyone may get when they get older can also happen to you.

**Common Problems associated with Aging with SCI**

- **“Arthritis” and joint problems** are common as people get older.
  - These problems are often more common in the hips and knees but remember that you may be using your arms as your major means of moving around and therefore you may have more problems with pain and/or arthritis in your shoulders, elbows or wrists.
  - The muscles, tendons and ligaments around these joints can also suffer wear and tear from overuse and may become painful or weaker.

- **Syrinx (Cyst in the Spinal Cord)**
  - Occasionally some time after a SCI, a syrinx or cyst filled with spinal fluid can form at the site of the original damage in the spinal cord. Usually this causes no problems.
  - Sometimes, however the cyst can expand up or down the spinal cord and this can lead to difficulties.
  - If you notice that you are losing muscle movement or feeling where you had movement or feeling before, or if your pain or spasm suddenly becomes more severe and there is no other cause, you should seek medical advice.
  - It may be necessary to have some tests done to make sure that you do not have a syrinx.
• **Nerve Compression**
  - Occasionally with getting older and with “wear and tear” on your arms, nerves in the arm may become compressed against bones or muscles.
  - You may notice increasing weakness or changes in the feeling in your hands or arms.
  - This can be very important because it can effect your ability to transfer or do other things.
  - If you think this is happening your should see your doctor and have it checked out.

### Quality of life Issues and Maintaining Independence

These remain important issues as a person ages with spinal cord injury. When a person first suffered a spinal cord injury, he or she went through a period of adjustment, learning to adapt to the limitations of the disability and re-establishing his or her life and relationships with meaning and purpose.

As aging occurs, it may be harder to do things and a person may tire more easily. A similar period of adjustment may be necessary. Likewise if a person is older at time of injury the rehabilitation process may take a bit longer to accommodate different levels of fitness and health.

### What does aging with spinal cord injury mean?

It is related not necessarily to our age but rather how long we have lived with the injury.

If a person does notice changes it is important to take stock of your situation assess whether any changes are needed or any extra assistance is required.

This can sometimes feel at odds with the fierce independence often developed by people living with spinal cord injury.

Independence remains the primary goal. Making minor changes can often ensure that independence continues.

If you feel there are unwelcome changes in your life it is frequently useful to discuss your situation with a health professional.
Adjustment to a traumatic life event such as a spinal cord injury is a very individual experience. We are all individuals with different backgrounds, life experiences and personal histories. We have different coping styles and handle situations in very different ways.

Experiencing a spinal cord injury challenges a person to tap into their strengths and to often find new ways of doing things, not only in a physical sense but also an emotional one. There is no right or wrong way to adjust, just as there is no right way to grieve for a loss. Sometimes however it helps to talk about these issues with health professionals and loved ones.

Understanding what is happening to you is the first step of coping with your situation and regaining a sense of control over your future. Experiencing a spinal cord injury may well be the worst thing that has happened to you. You cannot change what has happened, leave it behind, or even choose to ignore it. One way or another you have to deal with it and only you can do that.

Soon after your injury

During the early days of your hospitalisation, experiences can be frightening and overwhelming, both for yourself and your loved ones. There are heightened emotions both positive and negative. People describe many different experiences immediately following their injury. If you were injured as a result of an accident or other traumatic event you may experience certain symptoms. You may feel stunned or removed
from the event, or you may feel you are re-experiencing the incident and feel distressed. These and other symptoms are not uncommon. It is important to talk about these things. Your social worker is available to you to discuss these issues.

**The adjustment process**

As the crisis situation settles, you will start to become familiar with the routine of the unit and know more about the rehabilitation process. Adjustment does not stop when you finish your rehabilitation. It is a process which starts now and will continue for quite some time.

**There is a definition which describes adjustment as a “life in which disability is no longer the major focus”.**

Adjustment involves coming to terms with the changes that have occurred and restoring order and balance to many areas of your life such as:
- Bio-organic – bladder, bowel and skin.
- Environmental – where you live, how you get around, access issues and equipment.
- Psychosocial – emotions and feelings, relationships, financial, life goals and roles.

People will experience many different emotions. You may feel frustration, anger, fear, helplessness, sadness, loss of control and anxiety about your future. You may also feel positive emotions and be able to share those feelings with your family. You may feel them all at various times. This is normal and it is important to acknowledge these feelings even though they may be painful. You can't begin to deal with something until you acknowledge it is there.

However you should not be too surprised if you find yourself reacting in ways that seem out of character for you. This is a crisis stage and as you regain a sense of control over your life you will start to feel like you again. You will find your sense of humour, sense of pride and accomplishment and hope for the future.

Sometimes a person can become stuck in feelings of sadness and hopelessness which can mean you are experiencing a depression. If this happens it is important to talk to someone about your feelings.

However, it is normal to experience many different emotions. If we learn to talk about our worries and seek solutions the fog does begin to clear.
Your GP, social worker or a psychologist can help you deal with these issues.

Studies have been done that indicate people with spinal cord injury who take charge of their health and become responsible for their future and wellbeing experience less depression. One of the first steps towards taking charge is to educate yourself about your spinal injury - ask questions, read information, attend all available education sessions and talk to other people who have been there before you.

Having an acquired disability produces a lot of questions such as am I the same person? Why did this happen to me? How will others react to me? Will I still be useful? Can I still work? Can I still form relationships? How do I feel about myself? As a person comes to terms with the disability he or she will gradually find his or her own answers to these questions and begin to live a meaningful and satisfying life.

Examining your feelings towards disability

It is often said that one of the hardest things about coping with an acquired disability is that you are suddenly thrust into it with all your able bodied beliefs attitudes and misconceptions.
Have you ever known anyone with a disability?
First impressions or initial attitudes are not always accurate and may change over time. Our own misconceptions often shape our fears and how we think things will be.

It is important to examine your own attitudes and talk to those close to you about theirs. You might be surprised and may find attitudes change over time with information and understanding. You will still be you to those who know you. You may also find you may have a strong influence over misguided beliefs others may have about disability.

The process of your adjustment is greatly influenced by your philosophical attitude towards life. Some people have a very flexible attitude and take one day at a time. Others prefer to plan tomorrow. Whichever is your style it is important not only to take charge when and where you can but also to have realistic expectations of yourself and remember to remind yourself of the progress you have made in a difficult situation. Remember no one chooses to have a spinal injury, but those who have lived with spinal cord injury for many years report that there is a positive side.

Adjustment does occur and you can once again be actively engaged in life, relationships and all that is important to you.
B. RELATIONSHIPS

When a spinal injury occurs, those people close to you will be as effected emotionally by your injury as you are and will feel many of the same emotions including feelings of grief, helplessness and fear.

They too will be going through an emotional journey as they see you move through your rehabilitation and adjustment process.

Their reactions may be quite different from your own. There may be times when you don’t understand their reactions and visa versa.

At this time it is important to stop and think about your relationships, how they work and how you communicate with each other. Think about other stressful periods in your life and how your relationships were effected then. This will give you a clue to handling your current situation and the pitfalls to avoid.

Effective communication is the most important skill to develop in your relationships at this time. If things were rocky prior to your injury, it won’t be any different afterwards. The situation will still have to be dealt with. Stress can put pressure on even the best of relationships.

Learning to talk to each other even about the “hard” feelings and really listening to the other person can help to strengthen your relationships. You will have many questions and fears that you will need to talk to others about, especially your partner.

Your social worker is available to you during your hospitalisation to provide counselling to you individually or as a couple.

Here are some tips on how to help you through this time:

• **Learn to talk about feelings.** If people have to mind read they usually get it wrong. People won’t know what you think and feel unless you tell them. Discuss your fears and hopes so they may be shared.

• **Be assertive about your needs** - not demanding or aggressive. Work out how and with what you’d like to have help. If your family and friends are doing too much, talk to them about it. Let them know how it makes you feel and why you’d prefer that they do not do too much for you.
• **Show appreciation to your loved ones.** Telling them you love them is a good place to start.

• **Remember you don’t have hide your feelings** and be strong for your family and friends. This only makes it harder to talk about things that really matter.

• **If there is a problem you can’t sort out alone don’t be frightened to ask for help.**

Relationships change in everybody’s life, whether you have a disability or not. As a person with a spinal cord injury, your relationships will bring challenging experiences that offer potential for growth.
C. SEXUALITY

Sexuality is much more than what happens between two people in bed.

When we talk about sexuality, we are talking about how people express themselves, of their maleness and femaleness. Sexuality is displayed in the way a person presents themselves, carries themselves, body image and grooming habits. Sex is the physical interaction between two people which is an expression of sexuality. Sex may or may not be an intimate experience. It may or may not be with someone of the opposite sex.

Having a spinal cord injury, although a major disability, does not mean sex is no longer part of your life.

You can lead a sexually active life, maintain intimate relationships or pursue new ones, if you so wish.

Loss of sensation and physical changes have the biggest impact. The goal of sex is not necessarily orgasm. Instead of orgasm being purely physical and focused on the genitals, it becomes more a state of mind. The body compensates for sensory loss by making other areas more sensitive.

Many people with spinal cord injury describe sex as a more intimate and spiritual experience. Pleasure can be found in rediscovering your own and partner’s bodies in new ways through touch and exploration.

True intimacy and pleasure requires the ability to communicate with your partner.

Talking about what feels good, about how and where to touch and about any fears and anxieties. Talking about bladder and bowel function and how it relates to sex is often an important issue.

Many of us feel uncomfortable talking about sex but having a spinal cord injury and the physical changes this brings means sex becomes an issue we cannot ignore.

Sometimes letting people know you wish to talk about sex can be difficult to initiate. You can raise the issue with a health care professional with whom you feel comfortable. You will be taken seriously. If that person cannot help you, they will find someone who can. Your doctor, nurse and social worker are always available to talk about these issues.
You can make an appointment for the Sexual Rehabilitation Clinic where you can talk about sexual matters that are important to you in private.

After you are discharged from the unit, you may find other people don’t approach you in the same way.

You may find new people may seem a little anxious or unsure of how to act with you. You may not be seen as a sexual person or a potential partner. You may feel this way yourself at first. Remember most people have limited experience of people with disabilities.

If you already have a partner, you may feel he or she does not approach you in the same way as before.

Likewise you may feel timid or shy about initiating sexual activity. It is common to feel anxious about how you will perform sexually with your “new” body and how you will be seen. You may not know what to expect.

Education on the ways in which your injury may effect your sexual function is a place to start working on these fears. If you want some education about this you can contact the Queensland Spinal Cord Injuries Service. Positive self esteem along with good social and communication skills are important elements.

The onset of paralysis will likely affect your genital function. This does not erase your ability and desire to sexually please and be pleased. You will get to know your body much better than you did before you were injured. You will also learn how to do some sexual acts in new ways.

In the long run, the effect of spinal cord injury on your sexuality has so much to do with how you feel about yourself and how you approach the world.

You must accept yourself as a sexual being and use the skills that you have at your disposal. Work on your self-esteem and self acceptance. By doing this you and a partner can experience satisfaction.

Remember relationships can be difficult for anyone as can be finding a partner whether you have a disability or not.

Remember communication is tool that can help resolve most issues.
A spinal cord injury causes a number of changes in family life and home situations. As you are planning the changes that are necessary in your life to accommodate your needs, remember to include your child in this process.

If you are in hospital, it is important that your child understands why you are away from home and should be able to visit you regularly. If they are not able to visit because of distance, they may be able to speak to you on the telephone. This reassurance is important.

Children of different ages understand things at different levels. Explain the effect of your spinal cord injury in a way they can understand. If you need advice about talking to your child, your social worker may be able to help.

Parents who are newly injured sometimes express concern about their ability to continue to be parents to their children. You may find yourself wondering about how your child will react to you now you are in a wheelchair.

If you have been experiencing feelings of depression or discouragement as part of your adjustment process, you may find yourself questioning your ability to go on caring for your child.

Most children are very accepting and adaptable. They will take their cues on how to respond from those around them. This is why it is very important for you to keep talking openly to your child.

Visits home will help you maintain your relationship with your child. Both you and your children will need time to adjust to the physical changes and understand that this does not change the strength of your relationship.

Research shows that children who have a parent with a spinal cord injury show no difference in their social and emotional development than those who do not.
Helpful suggestions

- Include your child in your rehabilitation program, through hospital visits and weekend passes.

- Help your children to meet other families in a similar situation. Give your children time to talk and play with other children.

- If your children are old enough, allow them to attend your family conferences and education sessions.

- Keep talking with your children about your situation even after returning home.

- Be patient - adjustment for children takes time too.

- The more successfully you make your adjustment the better it will be for your child. Children use their parents as role models. A positive approach goes a long way.

Deciding to become a parent

Women with spinal cord injury, on the whole have no change in their ability to fall pregnant.

On the other hand, for men, reproductive functions are more complex. As a first step, you may wish to explore your physical capability to have children. The place to start is with your spinal injury specialist. You may wish to consult your social worker if you are thinking about becoming a parent. There are parenting courses available in the community.

If you discover you are physically unable to have children there are fertility alternatives and adoption options.

An occupational therapist can assist you in the areas of physical function and caring physically for a child. If you need assistance please contact the Spinal Injuries Unit or the SPOT.
E. STRESS MANAGEMENT

We all talk about stress, but what is stress?

Stress is a normal and necessary response to life changes. We all experience it as a normal part of life. Stress helps us deal with difficulties that life throws in our direction. It only becomes a problem when it causes physical, emotional and psychological reactions that do not go away.

This is called the Stress Response.

This often occurs when we feel helpless in a situation, when too many things have happened to us or when our ways of dealing with stress no longer work. When this is occurring, it time to stop and re-evaluate your situation. It is important to consult with a professional about stress management. Your social worker will be happy to talk to you further about this. Although no one can eliminate stress from your life, there are some ways of reducing the impact stress can have on your health and emotional well being.

People with spinal cord injuries experience many kinds of situations that cause stress - the initial demands of rehabilitation, managing relationships, dealing with the day to day frustration's and adjusting to changes.

In this section we have included many helpful strategies to assist you manage the new situations in your life. However, these strategies cannot work unless you actually use them and they require practice like anything else we do.

Stress management strategies work best in conjunction with counselling sessions.

Relaxation

Relaxation is a commonly used technique to help us manage stress. There are many different kinds of relaxation and it’s important to experiment and find which works for you best. People are sometimes frightened of letting go and losing control when learning relaxation techniques, but in fact practicing relaxation actually enhances self control despite their fears.
Relaxation allows us time out of our situations in order to re-build our physical, psychological and emotional resources. This can be done by watching TV, listening to music, spending time with friends, quiet time, spending quality time on ourselves or by practising specific techniques.

- **Visual Imagery** - can be used to think peaceful, calming thoughts while your mind is racing wildly with other thoughts. Images and thoughts can be used to block out intruding and upsetting ideas. Learning to control your thoughts involves knowing what you need to think about and using them when you want to relax. Use all your senses in your mind - sight, hearing, taste, touch and smell. There are many visual images you can use - real or imagined - pick one that you like the best.

**Example:** Close your eyes and take a deep breath, Breathe out slowly and deeply, concentrating on your breathing for a moment, allowing your breathing to become smooth and rhythmic. Feel the tension leaving you with each breath. Picture yourself lying beneath a palm tree on a tropical island You are comfortable and relaxed. Feel the warmth, smell the sea, listen to the waves gently lapping on the beach. Hear the birds. The sky is blue and you gently watch a fluffy white cloud drift along the horizon. You feel peaceful and calm.

Stay in this image as long as you like. Find your favourite image and practice.

- **Quick Relaxation**

  Use when you need to instantly calm yourself.

  **STEP ONE** - think immediately about your face muscles - what do they feel like? All tense and tight? Slowly relax all the muscles in your face and unclench your teeth.

  **STEP TWO** - go to your breathing and begin to slow it down. Breathe in deeply, counting to three and breath out deeply counting to three. Repeat until your breathing is smooth and you are feeling calm.

**Distraction**

Before a stressful situation, focus attention away from what may be happening inside your body and your thoughts concerning the situation you are worried about, e.g. watching TV, talk to someone, do a relaxation exercise, help someone else or do your exercises.
Stress Coping Thoughts

Thoughts contribute a great deal to our feelings and our ability to cope - negative thoughts can help us feel trapped. Learning to challenge and change negative thoughts goes a long way. Listed below are some positive thoughts that improve our ability to manage situations.

- **Preparation Thoughts**
  - I've done this before
  - This is a good time to make definite plan
  - Stay focused on what I have to do
  - Embarrassment can't hurt me nor can making a mistake, worse things have happened to me and I have coped

- **Confronting Thoughts**
  - No fear thoughts
  - It doesn't matter what others think
  - I will look after myself
  - I have a solution for this problem

- **Coping With Fear**
  - How much fear am I feeling? I'll watch it go down as I relax
  - Concentrate on breathing
  - It will be pleasant when I have successfully met this challenge

- **Congratulate Yourself**
  - I dealt with that and it feels good.
  - I'm getting better at that.
  - I can really relax now.
  - Problems don't have to flatten me any more.
  - I did very well today. I just might do it again tomorrow.

Time Management

This is another important way to deal with stress. When you leave hospital you will no longer have a staff member to help schedule your activities.

**It is essential to develop skills in planning your daily routine.**

Parts of the following were taken from The Relaxation and Stress Reduction Workbook, by Martha Davis, Elizabeth Eshelman, and Mathew McKay.
Time can be thought of as an endless series of decisions, small and large, that gradually change the shape of your life. Inappropriate decisions produce frustration, lowered self-esteem, and stress.

They result in the six symptoms of poor time management:

- Rushing
- Always being caught in the middle of unpleasant alternatives.
- Fatigue or listlessness with many slack hours of non-productive activity.
- Constantly missed deadlines.
- Insufficient time for rest or personal relationships.
- The sense of being overwhelmed by demands and details, and having to do what you do not want to do most of the time.

What to do about it?

- **Prioritise your goals**, list them into what is necessary, important, less important and not important, breaking them down into manageable steps.
- **Work out what is yours to actually worry about**. Not everything is within your control or is your responsibility.
- **Make time to plan**. Ten minutes to work out your priorities saves time and stress. Plan in small chunks of time.
- **Make a decision**. There are no right or wrong decisions, only those that seem the best at that the time with the information you have at your disposal.
- **It’s OK to make mistakes. Learn not to beat yourself up.**
CHAPTER FOUR: RETURNING TO THE COMMUNITY.

Please note that addresses and contact numbers for all organisations, services and resources mentioned in the following sections can be found in Chapter 5 of this handbook.

A. THE TRANSITIONAL REHABILITATION PROGRAM (TRP)

While most people look forward to the time when they can return home, it can be a very stressful and anxious period for you and your family. As you near the end of your rehabilitation, you will be offered the opportunity to participate in the Transitional Rehabilitation Program (TRP).

What is TRP?

This program developed out of a growing awareness by staff and past patients of the Spinal Injuries Unit that rehabilitation services offered only in the hospital environment may not adequately prepare people for the demands of life in the community.

Therefore, the program involves you completing the last part of your rehabilitation in your own home (if situated within 45 minutes driving distance from Princess Alexandra Hospital) or in a house provided by TRP.

Throughout your time in TRP, you will be supported by a multi-disciplinary team similar to your team in SIU, that is, physiotherapist, occupational therapist, registered nurse and social worker.

If you require personal care, this will be organised prior to you commencing the program and provided free of charge by trained carers while you are in TRP.

The aim of the program is to help you make the best possible transition from hospital to community living by fully supporting you through this period. It offers the advantage of allowing you to return to
living in the community at an earlier stage than would normally be possible.

The length of the TRP program may vary from 2 to 8 weeks, depending on the level of your injury and rehabilitation goals. The program also allows you the opportunity to work on your skills in a community environment and provides support to help you solve problems as they arise.

**How is my participation in TRP organised?**

Your program can commence once you and your Spinal Injuries Team decide that inpatient rehabilitation goals have been achieved. The TRP manager will then interview you, providing information on the program.

Members of the TRP team will also meet with you following your referral to the program.

Each team member will explain their role and discuss with you your needs and **what goals you would like to achieve.** These can include consolidation of physical skills, activities of daily living, community access, personal care issues, equipment, home modification issues, leisure and recreation, work and pre-work skills and counselling needs.

At the completion of your program the TRP team will assist you to get to know other community support programs such as the Spinal Outreach Team (SPOT) and Paraplegic and Quadriplegic Association of Queensland Community Advisory.
B. ACCOMMODATION

A basic need for everyone is a place to live. Due to the spinal injury, adjustments to your previous living situation may be necessary. Considerations such as the amount of care needed and accessibility requirements have to be discussed with your family and the team.

The following questions and answers will give you some guidelines.

Is it possible to live at home?

Many people with spinal cord injury return to live with their family. Many live independently. This is a decision only the individual and/or the family can make. The Social Worker will help you to explore the options available.

What help is available?

There are a number of community agencies that will be able to assist with care (see Community Services and Associations 4:J). This prevents you or your family from feeling that you have to cope on your own.

Is the accommodation wheelchair accessible?

For independent and safe functioning from a wheelchair, or for walking with aids, it is often necessary to make modifications to the home. For assistance in the assessment of the home, it is essential to consult your Spinal Injuries Unit occupational therapist. If you live within 60 to 90 minutes from Brisbane, your Occupational Therapist will carry out a visit to your residence. Outside this area he/she will liaise with occupational therapists from Base Hospitals or Community Health Centres throughout Queensland.

Because each person’s needs are different, it is recommended that your occupational therapist be consulted before you begin to modify your home or before purchasing special equipment.

Your occupational therapist will discuss your access needs with you and your family. A Home Access Guidelines Procedure is available to assist you in considering your needs. Home access videos and other books and literature are also available for viewing.

Is assistance with home alterations available?

Some financial assistance for home modifications is available for those who receive Workers’ Compensation, Compulsory Third Party Insurance (CTP) or certain benefits from the Department of Veterans Affairs.
For other people, the options for assistance with home modifications are more limited and include the following agencies:

1. **Home Assist/Secure**

Home Assist/Secure provides free information, advice and subsidised assistance to people with disabilities who live in private or rental housing. They can assist with home repairs, maintenance, minor modifications (e.g., grab rails) and security. There are approximately 22 local offices. The best way to access their contact details is to contact your local occupational therapist, the Spinal Outreach Team or the Queensland Department of Public Works and Housing.

2. **Home and Community Care (HACC) Funded Home Modification Projects**

HACC have funded some pilot home modification projects in several regions in Queensland. The projects all have different strategies for assisting with home modifications. Only people who have left hospital are eligible. Areas which have projects include:

- Brisbane South
- Brisbane North
- Ipswich
- Maryborough
- Charleville
- Townsville

Please note: As these projects are only pilots they may not be ongoing in all or any of these areas. Contact your local occupational therapist or Spinal Outreach Team for more details.

**What Are My Accommodation Options?**

If your accommodation is not wheelchair accessible or not able to be modified, it may be necessary to seek more suitable accommodation. This may include trying to find accessible rental accommodation. Unfortunately this is rarely available on the private market.

1. **Housing Queensland**

People on a low income e.g. a pension, can apply to the Department of Public Works and Housing for public rental housing. As part of this program the Government has recently introduced a priority housing system. The eligibility criteria includes having a disability. The department will assist with modification of these houses or may purpose build a wheelchair accessible house.

Other services provided by this Department include the Bond Loan and Rental Grant Program, Queensland Housing Loan and Disability Grant Program and Rent Subsidy Scheme.
2. Community Rent Schemes

Community Rent Schemes (CRS) are independent community based organisations that can rent you a unit or a house if you have applied for rental housing but are still on the waiting list for suitable accommodation. They can only rent accommodation in the same area as where you are listed for public housing. Like public rental housing, the Community Rent Scheme only provides housing and not support.

There are approximately twenty-eight Community Rent Scheme Housing Organisations in Queensland. Housing is subject to availability.

Contact the Spinal Outreach Team (SPOT), Department of Public Works and Housing or Queensland Disability Housing Coalition for details.

3. Housing Resource Services

The Housing Resource Services (HRS) is provided in twenty-six (26) localities over Queensland. HRS workers are located in independent community based organisations and part of their role is to give people information about available types of accommodation in their area.

What if I cannot return to live with my family?

Some people will not be able to return to their previous accommodation or to live with their family.

Alternatives available may be limited by the level of independence. A fully independent paraplegic would be able to consider living independently for example, and should pursue the options discussed above.

Other options include:

1. Mackay and District Spinal Injuries Association

This organisation provides support, temporary and transitional accommodation for people with a spinal cord injury.

2. Nursing Homes

Not all nursing homes will accept people under the age of 60 years so it is advisable to seek assistance from a social worker to assist with the application. Most larger hospitals employ social workers who will know what is available.

In order to be admitted to a nursing home you will need an assessment from your nearest Aged Care Assessment Service (ACAS).
3. Respite Care

Respite care is available to those who are cared for at home by family and friends. There are a variety of respite care options, both public or private. Services offered by these organisations include day respite, in-home respite and residential respite.

To obtain more information on services in a specific area contact the Paraplegic and Quadriplegic Association of Queensland, Spinal Outreach Team (SPOT), the Queensland Council of Carers Respite Care Bookings Service, Disability Information Awareness Line (DIAL) or your local Community Health Centre.
C. FINANCES AND COMPENSATION

Concerns regarding financial matters can be stressful and add to other problems. Social workers are available to advise about the range of financial assistance available. It is important to seek advice quickly, as financial problems often have a compounding effect. By failing to address them there may be a reduction in the available options.

The following information outlines the range of financial assistance available.

Income Support Payments

Department of Social Security offices are listed under Centrelink in the telephone directory of the white pages. The Social Security Teleservice numbers are supplied in Chapter 5 of this Handbook.

Note: Applications for certain Centrelink payments can be made via the Teleservice Centre.

- Sickness Allowance

Sickness Allowance is available to those aged at least 16 and who have not reached Age Pension age, who have a loss of income due to a temporary illness or disability, but are expected to return to their job within two years. The entitlement is determined by factors such as age, number of dependents and the amount of assets owned by the applicant.

Application forms are available from Centrelink offices and the hospital social worker. Three forms of identification, tax file number and a medical certificate stating the period of incapacity will need to be supplied with the application. The Newstart Allowance - Incapacitated is available if the applicant is unemployed and is unable to look for work.

- Disability Support Pension

Disability Support Pension is available for people over the age of 16 and who have not reached Age Pension age. The applicant must have a physical, intellectual or psychiatric impairment of 20% or more and have a continuing inability to work. It is considered that a person has a continuing inability to work if their impairment prevents them within the next two years from doing any work of at least 30 hours per week at award wages.
The applicant for the pension will be required to provide a report on their impairment and work capacity from their treating doctor. In addition, there may be the requirement for an examination to be conducted by an Australian Government Health Service Medical Officer (AGHSMO).

Application forms are available from Centrelink or hospital social workers. Three forms of identification, tax file number, and a medical report must be provided when lodging an application for a Disability Support Pension.

- Carers Payment

Applicants for Carers Payment must be:

(a) at least 16 years of age.
(b) personally providing a severely disabled person with personal care and/or supervision.
(c) be unable to work for more than 20 hours per week because of their caring responsibilities.
(d) be in Australia at the time the care is given and be a legal resident of Australia.

A severely disabled person is defined as a person who:

(a) has a physical, intellectual or psychiatric disability.
(b) because of that disability needs frequent care in connection with their bodily functions or constant supervision to prevent injury to themselves or to another person.
(c) is likely to need personal care and attention or constant supervision permanently or for at least six months.

There is no longer a requirement for applicants to be residing in the same residence as the person they are caring for.

- Carers Allowance

This allowance can be paid to carers who care for a person at home. It can be paid on top of any income support payment (e.g. Carers Payment or Age Pension).

The eligibility criteria is based on the needs of the person being cared for.

It is not means tested.

The assessment can be undertaken by professionals other than doctors - e.g. occupational therapists, qualified nurses or Aged Care Assessment Teams.

Applications are available from social workers at the hospital, Centrelink or local community health service.
• Mobility Allowance

Mobility Allowance is paid to people with disabilities who are:

(a) unable to use public transport without substantial assistance because of a physical, psychiatric or intellectual disability.
(b) at least 16 years of age.
(c) spending at least eight hours per week on a continuing basis in paid employment, self-employment, voluntary work, and/or vocational training which will assist in finding paid work.

The Mobility Allowance is not means tested.

Work Cover

All Queensland employers must insure their employees against injury or disability occurring in the course of their employment. Thus, an employee injured in the course of their work or travelling to or from work may be eligible for compensation from Work Cover.

Applications and advice regarding eligibility are available from the hospital social workers.

Once eligibility is established, Work Cover will provide assistance with income, medical and rehabilitation expenses. Depending on the nature and severity of the injury the claimant may also be eligible for an additional lump sum compensation payment.

Work Cover will appoint a Rehabilitation Counsellor to assist with rehabilitation planning once a claim is accepted.

It may also be advisable to seek legal advice about other avenues of compensation.

Compensation

If an injury is caused by negligence it may be possible to pursue compensation through the law. These claims are often complex and may take some years to be settled. It is advisable to seek early legal advice from a solicitor with experience in these types of compensation cases.

Contact the Queensland Law Society for a referral to an experienced solicitor in personal injury claims.

Compulsory Third Party Insurance Claims

All registered vehicles in Queensland are covered by Compulsory Third Party Insurance (CTP). If a person, not at fault, is injured in a motor vehicle accident they should be eligible for compensation from the insurer of the “At Fault” vehicle.
Legislation requires the CTP insurer to meet rehabilitation and medical expenses to maximise recovery once liability has been established.

Legal advice should be sought as early as possible regarding these claims. Once again, the Queensland Law Society can refer you to a solicitor specialising in complex personal injury claims. Your social worker will be able to advise about the process and factors to consider in choosing a solicitor.

**Financial Assistance for Equipment and Home Modifications**

- **Medical Aids Subsidy Scheme**

This is a State Health Department Scheme to assist eligible persons to achieve a basic level of independence in their own homes, by providing medical aids and equipment on a permanent loan basis.

**Eligibility:**

Most people who receive a payment from Centrelink, eg. Sickness Allowance or Disability Support Pension are eligible.

All people who have a Health Care Card from Centrelink or a Seniors’ Card.

**Application:**

When it is decided what equipment will be required, an application will be made to the scheme. A Health Care or Health Benefits Card number will be needed to make the application. The occupational therapist or physiotherapist will advise on individual needs.

- **Work Cover**

Work Cover clients will be eligible for the supply of equipment and assistance with home modifications to maximise independence. The occupational therapist or physiotherapist will advise.

- **Other Assistance**

People not eligible through Work Cover and the Home Medical Aids Assistance Scheme (MASS) or Veteran’s Affairs may have to fund their own equipment and modifications. The hospital social worker may be able to advise about local services that might offer support.

If there are any doubts about equipment, these should be discussed with the physiotherapist and occupational therapist. If funding is difficult consult the social worker about available options for assistance.
D. RETURN TO WORK

'Vocation' or 'return to work' can mean different things for different people. For some it may mean returning to the job they held before their injury, for others it may mean taking up study to change career direction and for others it may mean being the homekeeper or engaging in volunteer work.

As is the case for anyone involved in the process of vocational exploration, planning and decision making, many factors impact upon an individual's vocational choice and development of that career choice following spinal cord injury.

Time is required to adjust to acquiring a spinal cord injury, to learn about and develop physical and functional skills and to contemplate what you would like to do with your time and energy.

Questions you may like to ask yourself when considering whether it's the right time to return or start work include:

• What skills do I have?
  - Physical abilities
  - Functional skills
  - Previous education or training
  - Communication skills
  - Confidence and an “I can do it” attitude

• What interests me?
  - Studying/ Reading
  - Office work
  - Computers
  - Talking with others
  - Gardening .................. The list is endless !!

• Can I think of any jobs that I would like to do?
  - Return to previous job
  - Return to previous company in a different role
  - New career path
  - Volunteer
• How long has it been since my injury?
  ➢ Have I been able to address other issues which would impact upon my ability to work?
  ➢ e.g. Self care skills? Mobility? Transport? Carer issues? Further education? Accommodation issue? Community access skills?
  ➢ Am I ready to consider full time, part time or casual work, study or voluntary work as well as the responsibilities associated with that style of work?

• How am I able to deal with potential barriers to working / studying?
  ➢ e.g. Environmental barriers such as inadequate access to buildings, facilities and/or equipment.
  ➢ Workplace discrimination such as naïve employer perceptions as to my potential productivity or my ability to contribute to workplace goals.

Within the community there are a number of services available which provide vocational (work) counselling, rehabilitation and work training and assistance with commencing or continuing study or open employment.

**Employment Services**

1. **Centrelink**

**Services Provided:** Centrelink will be able to provide you with information and assistance regarding career counselling and practical assistance e.g. Austudy, New Start Allowance and other projects and organisations which aim to facilitate the commencement or return to work and/or study. To be eligible for any subsidised employment services, an initial referral from Centrelink is required.

2. **CRS Australia**

**Services Provided:** CRS Australia can help by providing:
  a. advice on choosing the right job
  b. work experience and support
  c. assistance with job redesign, alternative duties or workplace modification
  d. assistance with developing work related skills and abilities eg. training courses
  e. counselling.
CRS Australia are able to give practical advice on how to find the right job such as how to write job applications, how to prepare for interviews and even arrange training with possible employers.

Costs: CRS Australia provides programs free of charge to people with a disability or injury who receive a government pension, benefit or allowance and other people who cannot afford to pay.

Referrals: Anyone can refer you to a CRS unit. Referrals are accepted directly from yourself, friends or relatives or any other professional you are working with (eg. Occupational Therapist).

3. The Paraplegic and Quadriplegic Association of Queensland (PQAQ)

PQ Employment Options

Services Provided: Assists people with physical disabilities to identify employment options and supports people to obtain the employment of their choice. PQ Employment Options provides a flexible service that is coordinated from its Brisbane office.

Costs: Free to members of the association.

Referrals: Anyone can refer directly to this service - as long as you are a member of the Paraplegic and Quadriplegic Association of Queensland.

4. Private Rehabilitation Services

Specialist private rehabilitation services are available to provide work rehabilitation counselling as well as career counselling. Refer to the white or yellow pages under:

“Work” “Vocation” “Career”
E. DRIVING AND TRANSPORTATION

Achieving independence in driving, or having a suitable means of accessible transportation, is an important part of rehabilitation. This can be for many reasons (e.g. employment, social, leisure interests, family reasons, etc.).

**DRIVING**

If you want to drive, you should discuss this with your doctor and occupational therapist. This is to ensure that there are no medical or functional reasons preventing you from returning to driving safely.

Many factors can effect a person's ability to learn or relearn to drive after a spinal cord injury and these can include:

- Level of function
- Physical strength
- Control of movement
- Upper limb/Lower limb function
- Spasm
- Fatigue
- Medications
- Balance and trunk control
- Concentration
- Perceptual deficits
- Visual problems
- Reaction time
- Ability to manipulate controls and switches

**Driving Assessment/Licensing**

Following a spinal injury a person's ability to learn to drive, or resume driving, needs to be thoroughly assessed.
Following discussion with your doctor and occupational therapist a referral may be made for a Driving Assessment. This involves an off and on road assessment and will assist in determining your readiness to resume driving and the need for modifications.

If you require modifications to the vehicle you will be required to undertake a series of lessons and then a practical driving test with Queensland Transport. For a licensed driver, the written test does not need to be redone. Following successful completion of the practical driving test your licence will be endorsed accordingly through Queensland Transport.
The Occupational Therapy Department has a contact list of driver trained Occupational Therapists in Queensland and also of driving schools that have access to modified vehicles.

**Choosing a Vehicle to Drive**

A number of factors should be considered when you contemplate purchasing a vehicle, and these will vary depending upon your needs and level of ability.

If hand controls are required the following are some general points to consider when selecting a vehicle. It is also suggested that you talk with other drivers who have a disability and also discuss options with your Occupational Therapist.

- Automatic transmission
- Power steering (essential for people with quadriplegia, recommended for people with paraplegia)
- Power assisted brakes (recommended)
- Air conditioning (essential for people with quadriplegia)
- Sufficient door opening space to enable transfers (Prior to purchase, you will need to practice transferring self and wheelchair into and out of the vehicle). Two door cars generally have wider openings than four door cars. Hinges on doors can sometimes be modified to increase opening space.
- Dual mirrors with adjustment/positioning etc. located within the car.
- Consider car phone, mobile phone or CB radio contact to be able to call for help if needed.
- Cruise control, power windows, central locking, etc are ideal

**Types of Vehicle Modifications Available**

Any modifications made to a vehicle are required to meet Queensland Transport standards. Any vehicle that is modified should still be able to be driven by a person without a disability. Adaptations of any sort must be made to suit the individual and the licence needs to be endorsed accordingly.

The most frequently prescribed **hand controls** are the push/pat (push forward for the brake and pat down for the accelerator). Push/pull hand controls are also available (i.e. push forward for the brake, pull back for the accelerator).

Other types of adapted controls and equipment are also available (e.g. lever extensions for wipers, blinkers, steering wheel adaptations, seating restraints, wheelchair loading devices, etc).
Vehicle modifications can be conducted at several centres. Contact your Occupational Therapist for further information and for a list of current installers.

**Sales Tax Exemption**

Government assistance for people with a disability wishing to buy a car is available through sales tax exemption. A person with a disability is eligible for sales tax exemption on a new motor vehicle if he/she is able to produce evidence that the vehicle is necessary for employment or business, or undertaking long-term study to gain employment. Applications must be made through the Taxation Department.

**Mobility Allowance**

The Department of Social Security offers a scheme called Mobility Allowance to assist people with a disability who are working. Contact your Social Worker or local Department of Social Security to determine whether you are eligible. If you have claimed sales tax exemption on a new vehicle, you will not be eligible for the mobility allowance for 2 years.

**Other Means of Accessible Transportation**

A specially equipped van similar is the most ideal mode of transport for people unable to transfer into a car. Information on most suitable types of vans, electrically operated lifts/ramps, wheelchair restraints etc., is available from the Occupational Therapy Department. Information on personal hoists and car hoists for your carer to transfer you in/out of the vehicle is also available from your Occupational Therapist.

**Other Services from Queensland Transport**

- **Taxi Subsidy Scheme/Taxi Subsidy Vouchers**

  Queensland Transport offers a scheme where people with a disability are eligible to use the taxis (including maxi-taxis) for approximately half the normal cab fare. Application forms are available from the Occupational Therapy Department or Queensland Transport.

- **Maxi Taxis**

  These taxis provide access for people in wheelchairs. It is suggested that bookings be made in advance as these taxis are much in demand.

- **Disability Parking Permits**

  Queensland Transport also offers a scheme for parking permits. This allows a permit holder to park in designated disabled parking areas and other circumstances, depending upon the permit. Application forms are available from Occupational Therapy or Queensland Transport.
Ambulance

The Queensland Government has introduced free treatment and transport by the Queensland Ambulance Service for all pensioners (including Disability) and Queensland Seniors holding current Pensioner Concession or Queensland Seniors Cards.
Irrespective of our walk of life, cultural background or where we live, involvement in some type of enjoyable pastime is an important part of everyone’s life. From an early age we have all played games, developed hobbies and participated in enjoyable social activities and/or sport.

This may take place socially, something you do with family or friends; it may be something that you do simply for relaxation; or it may involve a more serious approach that could include competition either locally or at a higher level.

We may have even developed some of these to a stage where, if not our full-time occupation, a large part of our time is spent involved with them eg. as a musician, instructor, organiser, coach, official or player. Whatever the activity, it can and does provide avenues for achievement as well as fun and fulfilment.

If your mobility has been changed or restricted as a result of a spinal cord injury, it doesn’t mean that there isn’t still a very broad range of exciting, interesting and fulfilling activities that can be undertaken. In fact, it is important that everyone is still able to participate in activities that will bring the benefits that we have enjoyed prior to injury. It may mean some modification to the way you do these, the equipment you may need or perhaps where they occur.

An important part in identifying what these may be is to try a range of activities on a regular basis, so you can choose which of the many activities is for you. All activities can be broadly divided into leisure, sport &/or fitness and the sections below provide more information under these headings, about the activities and some of the equipment you might be able to use to make it happen.

**LEISURE ACTIVITIES**

The amount of leisure time that people may have after a spinal cord injury may change markedly. Being able to use this time productively can result in enjoyment and challenge, personal growth, good health, and a happy and exciting lifestyle.

Camping and 4 wheel-driving, parachuting and abseiling or perhaps picnics, or walking the dog are but a few of the myriad of pastimes that are and have been accessed by people who have a spinal cord injury. Knowing how and where to access either the equipment or the activity, will influence how easily these can be undertaken.
Some of the activities available include:

**Kayaking, Canoeing or Outrigging.**

Depending on the craft that you choose either a modified seat or outrigger can assist with stabilising the canoe. Single or double paddle are options that can either be held in the traditional way or by using a splint or strapping, if your hand strength is restricted.

**Sailing**

Catamarans or other stable craft are used to permit people with balance problems enjoy this wonderful pastime. People with the most restricted arm function are often able to participate because of the design of craft.

**Cycling (hand or recumbent cycling)**

Cycling is another activity that enables the rider the freedom to travel at a speed and on surfaces that may not be possible using a chair. Both of these modified cycles are commercially available and can be propelled by people with a range of mobility levels.
Snow or water-skiing.

The use of a sit ski is the major modification for both water and snow skiing. This seat (sometimes moulded sometimes a sling) supports your body in a sitting position and allows you to maximise the mobility you have, rather than emphasising the restrictions you have.

Other possibilities are:

- Fishing- electronic reels permit easier retrieval
- Bush-walking- accessible tracks are now available
- Ten pin bowling-ramps and bumpers can be used
- Scuba diving-freedom of movement is amazing
- Gliding- dual cockpits, where a co-pilot with full range of movement assists
- Snooker-splints can assist if hand function is reduced
- Horse riding-modified saddles or buggies assist in these activities
- Golf - as a pastime golf has many benefits to offer participants, whatever age, sex or mobility level someone has. A battery powered golf buggy is now available and its seat rotates 360 degrees and pivots on each corner.

Music, theatre, movies, concerts, painting and other creative pursuits are also more and more available and enjoyed by many. Theatres and other venues are also being made more accessible as people go out to enjoy the diverse range of performances.
Perhaps you are interested in the thrill of competing in one of a wide range of sports such as swimming, track or road racing events, rugby, basketball, tennis, lawn bowls, table tennis or powerlifting. These and other sports are available at a social level or you can follow your dream to represent your region, state or country.

Access to modified equipment and/or some rule modification can make what may initially seem very difficult, not only a possibility but also a very enjoyable past time.

Other simple modifications

- **Archery or table tennis** - for all. If hand function is restricted, use of a mitt or splint is allowed

- **Shooting** – either rifle or pistol events are available, with or without modified triggers

- **Powerlifting** - use the strength you have developed in a different way; maybe benchpressing your way into the record books

- **Swimming** - whether for relaxation or cooling down, exercise or competition
- **Lawn Bowls** – access to synthetic greens and use of pneumatic tyres has increased opportunities in both the generic and disabled sporting arenas.

Tennis – allowing 2 bounces of the ball gives more time for wheelchair users to get around the court.

The activities pictured and information listed above are just a sample of what is possible.

**FITNESS**

The first step towards improved health and fitness is a regular exercise programme that suits your specific needs and capabilities. Whether it is comprised of a planned exercise programme conducted in a gym setting or some modification of normal activities of daily living eg. walking the dog, pushing around the shopping centre or around the house, regular exercise can assist with mobility, transfers and overall access to activities.

A range of equipment is available depending on the setting and can include arm ergometers, wheelchair rollers and multi-stations but may be as simple as equipment that is readily available at home or in your local environment eg. bike paths, swimming pools, hand weights etc.

**How and Where ?**

Within Queensland, opportunities in leisure, sport and fitness can be facilitated through associations such as **Sporting Wheelies and Disabled Sport and Recreation Association Inc.**

The Association’s motto of “No Labels, No Limits” underpins the way in which opportunities for people with any physical disability or vision impairment are facilitated. A broad range of regular adventure based activities for people of all ages and ability levels, as well as access to regular and one off sporting pursuits at different locations in the community, assists people who have acquired a disability to “get involved”.

165
Qualified staff and volunteers assist in running programmes or providing information on how and where to go for “Come and Try”, regular social activities or competitive opportunities. Information on coaching, equipment, accessible venues as well as a range of videos and magazines is also available.

A fully accessible, equipped gymnasium, on site parking and members social area are the focal points of the Associations premises at Bowen Hills, that is also the state headquarters for both services and support.

A state wide network of qualified staff and volunteers assists people from all over the state to enjoy the benefits of leisure, sport and fitness at a community level and beyond. Assistance with training and coaching, delivery of community education programmes and financial support for a variety of programmes and athletes selected to represent the State and Country, are some of the services offered.

Possibly one of the greatest assets the Association can provide people who are newly injured, is access to people with a variety of disabilities who have attempted and succeeded in, a tremendously broad range of life activities, despite or perhaps in spite of, their physical restriction. Many people are willing to share their time and experiences; it can really be a benefit to meet and speak with other “wheelies”.

All people who are admitted to the Spinal Injuries Unit are given complementary membership to the Association for 12 months. This will provide you with access to information about what’s on and where, how to get involved, as well as providing you with direct support through our Leisure Counselling service. Make sure you contact us either before you leave the unit or just after (otherwise we'll contact you!)

Whether it’s abseiling or snow skiing, wheelchair rugby or camping, theatre or fishing there are a variety of leisure and sporting activities that are available for you to experience.

Other Contacts and Simple Hints

Many local sport and recreation clubs also provide opportunities for people to get involved and would welcome an approach from you or someone on your behalf. Specific regional and local areas may also have information available through local Councils, libraries, disability contact groups or other networks.
Some simple thoughts to keep in mind that will make all activities easier include:

- Think about calling theatres, restaurants etc prior to attending, so that you can be aware of access issues: either general, parking or toilet facilities.

- Don’t be deterred by venues that aren’t accessible, there are more and more that are. In venues that aren’t fully accessible however, people are often willing to give assistance, if asked.

- With venues that aren’t accessible they may be willing to consider modifications for access if they know that you are potentially interested in medium to long term involvement. Work with people not against them to help meet your needs.

- Be prepared to take risks with new activities - they often SEEM harder than they really are.

- If transport is an issue for you there may be assistance you can access via taxi vouchers or accessible taxis, local service clubs, other people going to the same place, rail or bus services.

- Use your head and ring around to find out what exists before deciding that it’s too hard. If you do find someone to assist with transport don’t forget to let them know what assistance you do need and what you don’t - eg. that you are able to transfer unassisted but that you will need them to take the wheels off the chair for you. It’s much better to give people more information than they need than not enough.

- Join local associations that will provide you with a range of regular information eg. Sporting Wheelies & Disabled Association, who has a world wide network of contacts and information; Access Arts; if you are in another state but Queensland, there will be a range of services that can assist in pointing you in the right direction.

- Above all, be positive and it will quickly become apparent that there are many things to choose from - your problem will be how can you fit them all in!
G. GUIDELINES FOR TRAVEL

If you use a wheelchair, or have some difficulty with mobility, travel can present some fairly unique challenges. It should come as no surprise then, that a little bit of good planning goes a long way. Planning can minimise many of the hassles and risks of travel, meaning that you have more time to enjoy yourself.

Where do I start?

• Plan well in advance. If you are intending to travel overseas, a number of travel agents now specialise in assisting people with disabilities. They will be able to advise you regarding accessible hotels/motels, tourist attractions, and tours.

• The World Wide Web (or internet) is also an enormous resource for gathering this information. (If you do not have access to the internet at home, try your local library.)

• The Paraplegic and Quadriplegic Association of Queensland Information Service are another valuable resource. Many members of the association travel on a regular basis, and may be able to provide useful first hand information.

• Don’t forget that you will need a passport for any overseas travel, and some countries require an entry visa. Your travel agent will be able to advise you of any special requirements.

• When booking flights, accommodation or tours, communicate your specific needs very clearly, and in layman’s terms.
  ➢ Don’t assume that the person that you are talking to understands what it means to have paraplegia or quadriplegia.
  ➢ The word ‘accessible’ means different things to different people - make sure that the person you are talking to understands what you mean by accessible. Ask if there are steps, or if there is a ledge or step in the shower recess.

• Make sure that you have travel insurance and that your equipment (e.g. wheelchair) is covered also.

• Ensure that you have adequate supplies of your regular medication.
  ➢ A letter from your family doctor, outlining your regular medications will be useful.
  ➢ Some prescription medications may be difficult to obtain in some countries, and some may even be illegal.
  ➢ It is also useful to travel with a complete course of the antibiotics that you most regularly take for bladder infections.
  ➢ See your doctor before you leave, and have the prescription filled before you leave home.
• Ensure that you have adequate supplies of any consumable items such as catheters, uridomes, drainage bags or blueys. Have a few in reserve in case you are stuck somewhere a day or two longer than anticipated.
  ➢ Take a spare cushion cover so you can have one in the wash.

• Take a spare tyre and tube for your wheelchair in case you get a flat. Better still consider having solid tyres put on your chair, so that punctures are impossible. Some people even like to travel with a spare axle.

• Always investigate the climate of the country you are intending to visit. This will assist you in planning for any problems if you have difficulty controlling your body temperature.

• Talk to someone who is an experienced traveller - first hand accounts are invaluable.

**Travel by Car**

• You should endeavour to relieve pressure every 100km, or every hour, whichever comes first. You will need to do this whether you are passenger or driver.
  ➢ Pressure relief can be achieved by pressure lifts or by leaning from side to side to remove pressure from the ischial tuberosities.

• If possible, you should use a pressure-relieving device for added insurance. A pressure-relieving cushion can be used, but many people find that this sits them up too high in the car.
  ➢ If you use a Jay cushion, the fluid pad may be removed from the base and used alone to provide some protection.
  ➢ A piece of Velcro the same width as the base can be used to help maintain the shape of the pad.
  ➢ If you don’t wish to use a cushion in the car, a sheepskin will also offer some protection. Cushions or sheepskins are not a substitute for regular pressure relief.

• You should always wear shoes and socks when in a car. The floors of some older cars can heat up, causing burns to feet.
  ➢ If you are in the car for a long period, you should reposition your feet from time to time also.

• Take care not to have your feet directly under heating vents. Hot air can also cause skin burns.

• Be wary if the car has been sitting in the sun. 
  ➢ Seat upholstery, belt buckles and other surfaces can hold a considerable amount of heat. If these surfaces come into contact with your skin, burns can occur.

• If you are travelling long distances in hot conditions, make sure that you drink plenty of fluids (water is best).
**Rail/Bus/Taxi Travel**

- **Brisbane City Council** now operates wheelchair accessible buses on some routes, with plans to expand the service and size of the accessible fleet over coming years. Contact them directly for details.

- **Queensland Rail** is very conscious of the needs of passengers who have disabilities.
  - Not all stations in the CityTrain Network are accessible, but a brochure is available detailing facilities available for passengers at all suburban and city stations.
  - Trains are accessible by ramp, and Queensland Rail staff are trained in how to assist passengers who use wheelchairs.

- **Accessible taxis** are available in all Australian capital cities and most large regional centres. Contact local taxi companies for details.

**Air Travel**

**Check in and transfers...**

- **When you are checking your baggage**, ask that you be allowed to remain in your wheelchair until boarding time. This will allow you to go to the bathroom before boarding, and means you can stay sitting on your cushion for as long as possible.

- **When checking in**, also ask to be seated on an aisle where the armrest is removable - this will mean a safer, easier transfer when you are getting on and off the plane.

- **You will be first on the plane and last off**. This can mean an extra hour or more on the plane, in addition to the flight time, so it is usually advisable to visit the bathroom before boarding.

- **Your wheelchair should be labelled with a 'gate check' tag as well as the regular luggage destination tag**. This will ensure that it is brought to the door of the plane at your destination, instead of being unloaded with the rest of the baggage. Ask for this at check-in also. Your wheelchair will travel in the hold.

- **At the door of the plane, you will have to transfer into an 'aisle chair'**. This is a narrow chair designed to fit up the aisle of the plane.
  - If you require assistance to transfer, airline staff will be available to assist you.
  - Make airline staff aware if you have difficulty balancing - they may need to strap you in or have someone (maybe your travelling partner) stay close by as you move down the aisle.

- **Always take your wheelchair cushion on board the plane with you**, even if you don’t intend to sit on it. Parts of your wheelchair that are easily detached can be easily lost. If unsure, remove it and take it on board too (quick release wheels excluded).
• Take care if you have to transfer or be lifted over the top of an armrest when getting into your seat. Skin damage can occur if you aren’t careful.

• If you use a powerdrive wheelchair, airline staff may enquire as to the type of batteries the chair uses. For safe travel, all batteries must be a sealed variety. These are standard on most modern wheelchairs— if in doubt, check with the wheelchair supplier before you depart.

**During the flight...**

• If you use a pressure-relieving cushion, it may be advisable for you to sit on it if the flight is longer than a couple of hours.
  
  ➢ *If you use a Jay cushion*, you can sit on the cushion as it is, or remove the fluid pad as described in the *Car Travel* section.

  ➢ *If you use a Roho cushion*, be aware that even in a pressurised cabin, the inflation of your cushion will change with altitude. As the plane ascends the cushion will seem to inflate and as you descend, the reverse will occur. It is advisable to take your pump on board to make the necessary adjustments. Wait until the plane has reached it’s cruising altitude before making any adjustments. You will have to readjust when you land.

  ➢ *On long flights, relieve pressure by lifting or leaning on a regular basis*. Leaning forwards is also a useful way of relieving pressure.

• Remember that your legs may swell during long flights.
  
  ➢ This can cause pressure problems in shoes and under leg bag straps. Check this regularly during the flight, and elevate your legs at regular intervals if at all possible.

  ➢ Some people wear support stockings or use bandages to minimise swelling.

**Managing your bladder on long flights...**

• If you have an in-dwelling catheter or use a urodome or other collecting device, management is relatively simple.
  
  ➢ Simply carry a 2 litre screw top plastic bottle in a small bag to empty the contents of your leg/drainage bag.

  ➢ Place a small amount of disinfectant in the bottom of the bottle, and carry some disposable hand wipes to clean your hands afterwards.

  ➢ If the bottle is full, your travelling companion can simply empty it into the toilet.

  ➢ In-flight staff are not permitted to do this for you, for hygiene reasons.
• If you perform intermittent self-catheterisation, the duration of the flight is important. As you will be first on the plane and last off, it is advisable to visit the bathroom just before boarding time. For short duration flights, this will probably be sufficient.

For flights of longer duration, there are number of options available to you:

- **An in-dwelling catheter can be inserted** for the duration of the flight, and removed once you have arrived at your destination.
  - You can be shown how to perform this procedure yourself.
  - While some people prefer this method, many find that it can upset their normal bladder routine, causing problems for a couple of days once removed.

- **On large planes (e.g. 747’s, 777’s, A320’s), there is usually one toilet that is reasonably accessible**, having a door that swings open, rather than folding in the centre like other toilet doors.
  - A collapsible aisle chair should be available on these flights, allowing you to travel to the toilet if you desire (you should check that there is one on-board before departure if you intend to use it).
  - You will then have to transfer from the aisle chair onto the toilet, and this may be a difficult transfer for some people.
  - If you are travelling alone, in-flight staff can assist you in getting to the toilet.

- **Another option is to perform your ICSC in your seat on the plane.**
  - If you are going to empty your bladder in this manner, it may be of benefit to request a window seat, so that you have greater privacy.
  - If you have a travelling companion, this can usually be performed discreetly behind a newspaper or under a blanket.
  - It will usually be easier to urinate directly into a plastic bottle rather than the usual plastic bag, as these are more difficult to handle in such a confined space.
  - Once again, your travelling companion will be able to empty the bottle as required.
  - Some flights can be as long as 14 to 15 hours, so you may have to perform this procedure 2 or 3 times.

**How to manage your bowels on long flights...**

• If your are travelling to destinations such as Europe or the USA/Canada, combined flight times can be as long as 36 hours.

• As most people perform their bowel routine every 2 days, this should not represent a great change from normal.

• **It is advisable to perform your routine on the morning of your departure.**
  - This may mean performing your routine at home on 2 consecutive days at home, giving you as long as 3 days before you should have to go
If you are concerned at having to wait so long, it may be of benefit to arrange an overnight stopover half way. You can also ask your family doctor to prescribe something such as Lomotil to reduce the likelihood of any accidents.

- **If you require a shower commode to go to the toilet**, it is probably best if you take a padded collapsible one from home.
  - If you sit directly on the toilet, make sure that you take some portable toilet seat padding, such as Jiffy Biffy Pads (manufactured by Otto Bock).

When you have reached your destination...

- **International car hire companies**, such as Hertz and Avis will offer rental vehicles with hand controls at most major destinations. You should not have to pay any extra for this service, but should organise it well in advance.

- An **alternative to this is to travel with your own portable hand controls**, which are easily fitted to any hire car. Your occupational therapist will be able to advise you regarding suppliers of these devices.

### Some other considerations...

- **Take adequate supplies of your regular medications in your carry-on baggage**. You will need these during long flights.

- **Packing is one of the keys to successful travel**. Seal any bottles or tubes containing liquid/fluid in plastic bags. If a leak occurs, it effect other items in your bag.

- **If you are taking a shower commode**, remove any easily detached parts, and place them in your bag.
  - Collapse the chair and tape it securely together.
  - Protect any seat or backrest padding with cardboard so that it is not damaged in transit.
  - Attach a ‘fragile’ label.
EQUIPMENT AND SUPPLIERS

Equipment for the person with a spinal injury can cover a wide range of items from the specialised personal items such as cutlery, to pool hoists, car hoists, etc.

The AIM when ordering any equipment for you is to provide only equipment which is NECESSARY to achieve independence. Unnecessary equipment can lead to over dependence and takes up valuable space in your home or is more to carry on yourself, when going out.

Equipment is ordered following detailed trials of different items.

- Supply of Equipment

Can take from 1-2 days to many months and is dependent on:

- Who prescribes the equipment.
- How quickly the financing body processes the prescription.
- Whether equipment is custom-made or from stock.

While an inpatient at the Spinal Injuries Unit, all necessary equipment will be delivered to your home, other than the wheelchair and cushion, which are generally sent to the Spinal Injuries Unit.

If you do not have a permanent address, equipment can be stored within the Spinal Unit for a SHORT time only, due to limited space.

If your equipment has not been received before discharge, organisation of the hire or loan of equipment will be arranged. (See HIRE section for details)

- Repair of Equipment

The method of organisation for the repair of equipment will vary with the body financing the equipment.

If equipment has been provided by the Medical Aids Subsidy Scheme (MASS), repair is organised through your local community health centre.

- Sources of Equipment

1. State Health Department (Queensland)

The Medical Aids Subsidy Scheme (MASS) provides equipment for Queensland residents who meet the eligibility criteria. Applications are processed through Regional Centres dependent upon where the individual lives.
All equipment issued by the Medical Aids Subsidy Scheme of the State Health Department remains the property of the Health Department.

The local Community Health Centre will organise the repair of any piece of Health Department equipment. It is not necessary to contact the Spinal Injuries Unit specifically for this unless a problem arises.

Each piece of Health Department equipment is supplied with a number. This number must be noted in a separate place, and it must be quoted when organising the repair with the Community Health Centre.

The Health Department supplies equipment on a permanent loan basis and as such specifies that you do not do your own repairs. The equipment remains the property of the Health Department and should be returned if no longer needed.

Equipment should be well looked after as replacement equipment is only supplied after a lengthy period eg. 4-5 years, or when the particular piece of equipment ceases to function, becomes unsafe, or is irreparable.

Remember, if new equipment is required, contact the appropriate body eg. Local Community Health Centre / Physiotherapist / Occupational Therapist / Nurse etc. If all else fails, contact the Spinal Outreach Team (SPOT).

If the equipment is supplied in Queensland and you move to another state or country, it is suggested that the equipment be returned and the appropriate body in the new area be approached to resupply the equipment. Please contact the Community Health Centre of the Health Department if this problem arises. Occasionally, a letter from the doctor may allow equipment to be transferred between states.

2. Work Cover Qld

Work Cover will be responsible for the supply, repairs and resupplying of equipment only while you are still receiving benefits, i.e. until the claim is finalised. After that period of time, it then becomes your responsibility to maintain, repair or replace the equipment as appropriate.

3. Compulsory Third Party Insurance

It would become the responsibility of the particular body financing the equipment to assist with repairs, maintenance and resupply according to its own guidelines.
**Maintenance of Equipment**

Most new equipment, particularly wheelchairs, will be supplied with maintenance instructions and warranties. Please read these carefully and take care of the equipment.

**Hire of Equipment**

Hire of different types of equipment may need to be organised if:

- Present equipment needs repair
- Skills levels change temporarily e.g. during immobilisation phase of tendon transfer surgery
- Final equipment not available at time of discharge from hospital

If your equipment needs repair, it is appropriate to ring the manufacturer once the normal procedures have been followed (i.e. Community Health procedures) and make an appointment to have the equipment repair done. This will minimise the time your own equipment is away.

**From past experience, we have not found hire equipment to be disability specific** i.e. not especially designed for those with spinal injury and their particular problems.

It is therefore important to be very specific as to requirements when making the enquiry.

Please note that the hire equipment, although suitable, may not always be similar to your regular equipment, and is meant as a temporary "stop gap" measure only.

**Hire/Loan Agencies are as follows:**

1. Local Community Health Service Centre - check in the white pages of the phone book under "State Government - Health Department"
2. Paraplegic and Quadriplegic Association of Queensland (PQAQ)
3. Blue Nursing Service
4. Red Cross
5. Pharmacies/Chemists. (Check the Phone Book)
6. Surgical Supply Companies
7. Wheelchair Manufacturers
• **Weekend Hire**

For inpatients of the Spinal Injuries Unit:

1. Equipment may be hired for weekend leave and extended Public Holidays from the Occupational Therapy Department, Spinal Injuries Unit.

2. An equipment hire fee is requested to cover the cost of maintenance and purchase of extra equipment.

3. Any damages or loss of equipment is the responsibility of the borrower.

4. Contact the Occupational Therapy Department to organise the hire of equipment.

• **Transitional Rehabilitation Program**

Patients participating in the Transitional Rehabilitation Program may loan equipment during their inclusion in the program.

• **Specific Advisory Centres**

1. Queensland Spinal Cord Injuries Service

2. Independent Living Centre (ILC) (by appointment only)

3. Paraplegic and Quadriplegic Association of Queensland (PQAQ)

4. Sporting Wheelies

• **Specially Designed Non-Commercial Equipment**

It may be necessary to design and construct equipment for individual specific purposes. Organisations that are able to assist include:

1. Technical Aid to the Disabled (TAD)

   TAD is a volunteer organisation. A donation towards material, etc is recommended.

2. Occupational Therapy Department (Spinal Injuries Unit)

3. Spinal Outreach Team (SPOT)

• **Retail Purchase**

Equipment should be trialled before purchase wherever possible. Remember that not all equipment is appropriate for each individual.
It is important to seek advice from the appropriate health professional before purchase as certain pieces of equipment may decrease your level of independence rather than increase it.

(Please Note: The information listed was correct at the time of printing. For further information contact the Physiotherapy or Occupational Therapy Departments in the Spinal Injuries Unit).

• **Cushions**

Contact Physiotherapy Department, Spinal Injuries Unit or SPOT physiotherapist for advice. Various cushions are available that claim to give good pressure relief. It is important to trial each cushion before purchase.

• **Hoists**

Contact the Occupational Therapy Department, Spinal Injuries Unit or SPOT.

When trialing hoists, you need to consider whether the hoist will fit in your home environment and whether it can be dismantled for transport purposes.

• **Mattresses**

A range of pressure relief mattresses are available.

As well, waterbeds and standard mattresses often provide adequate pressure relief but this needs to be assessed before purchase. Also, look at balance and ability to transfer on and off the bed.

• **Sheepskins**

A large and a small sheepskin are supplied when necessary. They can also be purchased through any surgical supply company.

• **Shower Chair**

All shower chairs and bath boards used by people with sensory loss through a spinal injury should be padded.

For further information contact the Spinal Outreach Team (SPOT).
I. SPINAL OUTREACH TEAM (SPOT)

SPOT offers services to people with spinal cord injury and their family and carers, once they are discharged from the Spinal Injuries Unit.

The team is staffed by social workers, occupational therapists, physiotherapists and nursing staff.

Services have an educational / consultancy focus, and may include issues to do with skin care, equipment, finances or anything else which concerns you following discharge.

In addition SPOT works with local service providers to offer specialist advice.

Visits can be made to your home if you live within a 200 km radius of Brisbane or as part of our regular programme of regional visits. Areas visited include Cairns, Townsville, Mackay, Bundaberg, Toowoomba, Mount Isa, Rockhampton and Dalby as well as the Sunshine and Gold Coast.

Each person will be contacted by a team member prior to discharge and can be placed on a follow-up programme of phone calls, designed to contact people post discharge to identify any issues present.

This service is offered for the first 12 months after discharge from hospital or TRP.

You may refer yourself directly to the service, or request that other service providers get in touch should the need for specialist advice arise.

Please see Chapter 5 in this manual for contact details.
J. COMMUNITY SERVICES

There are a number of services and organisations in the community to assist people to remain as independent as possible. Some are aimed at assisting specifically the disabled and their family, while others are for the general community.

• THE PARAPLEGIC AND QUADRIPLEGIC ASSOCIATION OF QUEENSLAND INCORPORATED

Mission: “Enhancing the quality of life with people with spinal disability”

The Paraplegic and Quadriplegic Association of Queensland was formed in 1960 ‘to provide occupational amenities, assistance and accommodation for people with paraplegia or quadriplegia’. Since that time, the Association has evolved into an organisation providing a range of services across Queensland for people with a spinal disability; predominantly paraplegia, quadriplegia and the late effects of polio.

The Association is a not-for-profit, membership-based organisation and it is registered as an Incorporated Association. The Association provides a number of services, some of which are funded by Federal and State Governments. The other services are funded by surpluses generated from the Association’s Art Union and PQ Lifestyles.

Services of the Association:

- Community Advisory Service

This service assists people with a spinal disability and their family members, carers, health care professionals and community service workers with advice, information and practical assistance regarding:

- Health care, eg. skin care, continence management etc

- Equipment, aids and assistive devices: eg. wheelchairs, shower chairs, pressure relieving mattresses and cushions.

- Community services; eg. attendant care, respite services, counselling services, accommodation, etc.

- Government schemes; eg. Domiciliary Nursing Care Benefit, Mobility Allowance, Health Care Card, Continence Aids Assistance Scheme, Medical Aids Subsidy Scheme etc.
The Community Advisory Service provides information and advice via the telephone, visiting people in their own homes (throughout Queensland) and written information. Where necessary the Community Advisers will link people with appropriate community services in their local area. The Community Advisory Service has three Advisers; two based in Brisbane who cover Rockhampton and the areas south and west of this region and one located in Townsville who provides service to clients in the areas north and west of Rockhampton.

- **Information Service**

This service collects and disseminates information pertinent to people with a spinal disability and is available to members and their families, staff, community workers, students and the general public. The Information Service offers a telephone enquiry service, library service and information dissemination service. It is also the production unit for the Association's newsletter 'Paraview' and maintains the organisation's web site. The Information Service responds to a diverse range of calls about community services and schemes, holiday accommodation, aids and equipment, building requirements for mobility access and other similar enquiries. It also loans materials from the Library collection and can search for particular information via the Internet and online databases. If you are looking for information in some way connected with spinal disability, this is the place to come.

- **Member Networks**

The Networks have evolved in response to a call from members for action on local issues that impact on their daily lives. These issues include access to local facilities, transport, accommodation, support and peer contact, etc. Volunteer Facilitators, who are members of the Association link members via the telephone to identify and respond to issues affecting members of the Association in their local area. There are member Networks throughout Queensland and more are developing. Facilitators and members of the Networks are eager to make contact with people and their families while they are in the Spinal Injuries Unit to offer support and information.

- **North Queensland Office**

The Townsville Office of the Association acts as a central contact for members living in North Queensland. The office is concerned with assisting members to make the transition from the Spinal Injury Unit to home, addressing access and equity issues in local areas, establishing and supporting Member Networks and other associated issues important to members. People can obtain information advice, support and education regarding spinal disabilities from the North Queensland Manager, Community Adviser, Member Network Facilitators and office support staff.
PQ Personal Assistance

The Association provides personal and lifestyle assistance on an ongoing basis for members who have received government funding for such assistance. Individual people living in their own homes receive support from workers who assist them to meet their daily personal and lifestyle needs. This support and assistance enables people to develop and maintain their chosen lifestyle in the home and community of their choice. Further information can be obtained from the PQ Personal Assistance Coordinators who are based in the Brisbane office of the Association.

PQ Temporary Assistance

The Association provides short term or temporary assistance with personal care, equipment loans, accommodation and other practical forms of assistance to members of the Association through PQ Temporary Assistance. The service is available to both members and non-members statewide and is coordinated from the Brisbane Office.

Equipment Loan Service

The Association has established a small equipment loan service which is available to members statewide and is coordinated from the Brisbane Office of PQ Lifestyles. Essential items such as manual wheelchairs, pressure relieving cushions and mattresses, shower chairs and hoists are available to members for a flexible time period.

PQ Employment Options

PQ Employment Options assists people with physical disabilities to identify employment options and supports people to obtain the employment of their choice. PQ Employment Options provides a flexible service that is coordinated from the Brisbane office and is available for Brisbane members only at this stage. However, the PQ Employment Options is able to assist regional employment services to better meet the needs of people with physical disabilities who live locally in those regions.

Spinal Education Awareness Team (SEAT)

SEAT’s prime role is the facilitation of prevention and awareness programs throughout schools and the community relative to spinal disability. A comprehensive and effective program is delivered in primary and high schools, sporting clubs and tourist organisations by a team of professionally trained volunteer presenters, all of whom have a spinal disability. Many past patients of the Spinal Injuries Unit have become SEAT presenters and have found the experience leads to various opportunities including as a stepping stone back into the workforce, participation in the wider community and connection to a diverse range of people.
Community Relations

The functions of this service include communication, media liaison, advocacy, support for the Association's services, programs and business activities and to empower members to assist themselves. Community Relations promotes the Association's plans and actions, addresses emerging issues that affect members and seeks to have their needs represented at all levels of decision making. The service is involved in advocating for equitable access statewide and works with members at the local level to achieve this. It is an information source on access to the built environment.

PQ Lifestyles

PQ Lifestyles provides equipment and medical supplies to a wide consumer base. It is the national agent for the Continence Aids Assistance Scheme (CAAS) and the suppliers for the Pensioner Benefit Scheme (PBS) and the Veteran Affairs Continence Scheme. Details and eligibility criteria for these schemes is available from PQ Lifestyles, the Association and the Spinal Injury Unit staff. PQ Lifestyles specialise in continence aids and are the largest stockist in Queensland. Wound care and pressure relieving product ranges are also extensive. In addition PQ Lifestyles operates Script Direct which enables you to purchase most of your prescription and non-prescription pharmacy products at a far reduced price and have your orders delivered direct to your door.

COMMUNITY HEALTH CENTRES

These centres are staffed with nurses and most of the major centres have ancillary staff including social workers, physiotherapists and occupational therapists. Their staff will assist with equipment supply and repairs, This is done through the Medical Aids Subsidy Scheme for those who are eligible. The centres will offer support, counselling, home help with domestic duties and various other services. They are listed in the white pages telephone book under “Health”.

COUNSELLING SERVICES

Individual relationship and family counselling services are available through a range of organisations including Life Line, Centre Care and Relationships Australia. Information on these organisations and private counselling services is available in the White and Yellow pages of the telephone directory.
• PERSONAL CARE SUPPORT SERVICES/ASSISTANCE

- Home and Community Care (HACC)
  - Home and Community Care (HACC) funds a range of services to assist people to return to living in their own homes. These include Community Options Programs, Community Aged Care Packages (CAPS) and Domiciliary Nursing Services.
  - For contact details please see Chapter 5.

- Domiciliary Nursing Services
  - Domiciliary or home nursing services provide care and support enabling people to remain in their own homes.
  - They provide general nursing services and some provide specialised services such as physiotherapy, in-home respite and day care centres.
  - The BlueCare Service, St Luke’s Nursing Service, St Vincent de Paul Nursing Service and the Brown Sisters are all based in Brisbane and some of these services are located throughout Queensland.
  - Referral will be made to a nursing service if it is thought necessary as part of discharge planning.
  - Private and community nursing services can be located in the Yellow pages.

• ADULT LIFESTYLE SUPPORT FUNDING – DEPARTMENT OF FAMILIES, YOUTH AND COMMUNITY CARE

What is Lifestyle Support?

- Adult lifestyle support funding is to assist a person with a disability to live in their own home. Lifestyle support packages may include personal care, household management, recreation and community access and respite and family support.

- The Department of Families Youth and Community Care advertises for applications for funding at regular intervals through newspapers and other media. However, the funds available are very limited and only a small number of applicants are approved each year.

- Funding for lifestyle support is allocated to a nominated community service provider which will provide or co-ordinate the services you require to live in the community.
Who is Eligible to apply for this Funding?

- To be eligible for funding you will need to have a disability which has substantially reduced your capacity for mobility, communication, social interaction or learning and you need support.
- Your disability must be permanent or likely to be permanent.
- You will also need to be between 18 and 65 years of age.

How to Apply?

- To apply for lifestyle support funding, you will need to complete a registration of need forms which can be obtained from your social worker in the Spinal Injuries Unit, community service provider (eg PQAQ) or your Regional Office of Department of Families, Youth and Community Care.
- The information you provide about yourself on this form is presented to the Region Priority Panel which will then give a priority rating. The Priority Panel does not decide about funding, this is decided at a later date by the Department.

Temporary Assistance, Non Recurrent Funding

- This is one off funding, usually for personal care support to temporarily assist with difficult situations or until something more permanent can be put in place e.g. PQAQ (The Paraplegic and Quadriplegic Association) offers temporary assistance resources for spinal injured persons.
- More information about such services can be obtained by contacting the PQAQ, your social worker at the Spinal Injuries Unit or Spinal Outreach Team (SPOT).

**QUEENSLAND MEALS ON WHEELS ASSOCIATION**

- Branches of Meals On Wheels prepare and deliver meals to the homes of those unable to prepare their own meals because of a disability or temporary incapacity.
- A Medical Certificate is usually required and nominal fees apply.
- Local branches are listed in the telephone directory or Domiciliary Nursing Services will advise.
• QUEENSLAND ADVOCACY INCORPORATED

Independent advocacy group for people with a disability in Queensland. It is not a part of any Government Department or Organisation. They offer advice on the rights of people with a disability, including legal advice and work on changing attitudes and policies for people with a disability.

• TECHNICAL AID TO THE DISABLED- QLD INC (TADQ)

This is a voluntary organisation which designs, adapts and makes special "tailor made" aids for people with disabilities. Volunteers, who are engineers, tradesmen and technicians, give their time freely. T.A.D.Q. clients pay only for the materials used to make their aids.

• DEPARTMENT OF FAMILIES, YOUTH AND COMMUNITY CARE

One service offered is the Disability Information and Awareness Line (DIAL). DIAL is an information service on services available to people with disabilities. The information is provided as a guide or a base from which the caller can decide on the appropriate follow-up action. DIAL is supplied from a computer database which holds Queensland wide information on service agencies, issues and diagnostic groups.

• ACCOMMODATION

Government and private agencies providing assistance with housing or accommodation are discussed in Section 4:B “Accommodation”.

• THE QUEENSLAND COUNCIL OF CARERS

The Queensland Council of Carers is a government funded voluntary organisation which has been set up to support carers in the community. A carer is the person and/or family responsible for the care of an individual who needs varying degrees of assistance with the activities of daily living. 104.

The Queensland Council of Carers provides information and counselling as well as setting up support networks throughout Queensland. It also operates a free centralised booking service for respite care in some nursing homes and hostels in Queensland.

• QUEENSLAND DISABILITY HOUSING COALITION

The Queensland Disability Housing Coalition (Q.D.H.C) was established following a public forum on the housing needs of people with disabilities in June 1987. The aims of the Q.D.H.C. are:

➢ To bring together a diverse group of people with all kinds of
disabilities, and others, seeking to ensure a choice of affordable housing options for people with disabilities.

- To promote the right of people with disabilities to live as part of the community in housing which suits their individual needs.

- To develop policies and strategies to enhance and extend the provision of housing.

- To promote the provision of adequate and co-ordinated support services required by people with disabilities living in the community.

- To raise community awareness, understanding and knowledge of housing needs of people with disabilities, through research, negotiation, and community education.

Membership is open to all interested persons and organisations. All members will be sent each issue of the newsletter.

**EMPLOYMENT SERVICES**

These are discussed in Chapter 4:D “Return to Work”.

**OTHER SOURCES OF INFORMATION WITHIN YOUR COMMUNITY**

- Social Workers at Centrelink.

- Lifeline, St. Vincent de Paul, Salvation Army.

- Social Workers at the closest Base Hospital.

- Local Council - Community Development Office for information on local disability networks and forums.
PBF Australia was founded in 1984 and is modelled on the highly successful Swiss Paraplegic Fund, which has over 800,000 members and where it funds all activities that relate to spinal cord injury including prevention, research, acute care, rehabilitation and community support.

The Vision

PBF Australia plans to protect and prevent as many Australians as possible from suffering a spinal cord injury and the impact that follows such an injury.

The Mission

PBF Australia plans to provide financial protection for all Australians against the enormous cost of spinal cord injury through a low cost membership fee.

PBF Australia will continue to work tirelessly to expand its membership base in order to provide financial aid to the hundreds of people with spinal cord injury Australia-wide, who rely on our support.

PBF Australia will fund community programs that address prevention messages, particularly in schools.

PBF has operated in WA and Queensland for several years and continues to grow with a presence in South Australia, Victoria and New South Wales through the Spinal Units in those states. PBF plans in the future to establish links with every state in Australia.

PBF Australia is a non-profit charitable organisation
CHAPTER FIVE:
WHO TO CONTACT
AND HOW YOU
CONTACT THEM?

A. The QUEENSLAND SPINAL CORD INJURIES
SERVICE (QSCIS)

SPINAL INJURIES UNIT
Princess Alexandra Hospital
Address: Ipswich Rd, Woolloongabba, Q, 4102
Phone: (Ward) (07) 3240 2737
(Outpatients) (07) 3240 2641
(Director) (07) 3240 2657
(O.T.) (07) 3240 2191
(PT) (07) 3240 2089
(Social Work) (07) 3240 2741 or 3240 2207
Fax: (07) 3240 5644

TRANSITIONAL REHABILITATION PROGRAM (TRP)
Address: 3rd floor, Buranda Plaza
Cnr Ipswich Rd & Cornwall St, Buranda
Postal Address: PO Box 6053 Buranda 4102
Phone: (07) 3406 2322
Fax: (07) 3406 2399
E-mail: trp@health.qld.gov.au

SPINAL OUTREACH TEAM (SPOT)
Address: 3rd floor, Buranda Plaza
Cnr Ipswich Rd & Cornwall St, Buranda
Postal Address: PO Box 6053 Buranda 4102
Phone: (07) 3406 2300
Freecall 1800 624 832 (for regional clients)
Fax: (07) 3406 2399
E-mail: spot@health.qld.gov.au
B. CENTRELINK

Disability Support Pension/Sickness Allowance
/Carers Payments/Mobility Allowance: 132 717
Family Payments: 131 305
Employment Services: 132 850
Retirement: 132 300
Youth And Student Services: 13 2490
Career Information Service: 1800 627 175

C. COMMUNITY HEALTH CENTRES

HEALTH SERVICES INFORMATION LINE: (07) 3236 4833
(to contact your local community health centre and obtain other information.)

D. CRS AUSTRALIA

Phone: 1800 624 824 (toll free) or your nearest Centrelink office.

E. DISABILITY SERVICES QUEENSLAND

Brisbane: (07) 3405 6734/6732
South Coast: (07) 3287 0742
North Coast: (07) 5490 1045
Ipswich/SW Queensland: (07) 3280 1919
Central Queensland/Wide Bay: (07) 4123 9119
North Queensland: (07) 4727 0666
Website: http://disability.qld.gov.au

DISABILITY INFORMATION AND AWARENESS LINE (DIAL).

Brisbane: (07) 3224 8444
Outside Brisbane: Free Call 1800 177 120
Website: http://disability.qld.gov.au/idial/search.cfm

F. HOME AND COMMUNITY CARE (HACC)

RESOURCE OFFICE
Phone: (07) 3866 9444 or
Free Call 1800 242 636
G. HOUSING QUEENSLAND
Phone: (07) 3227 6816 or Free Call 1800 177 289

H. INDEPENDENT LIVING CENTRE
BY APPOINTMENT ONLY
Address: Cnr. Goring St and Cavendish Rd
          Coorparoo, Q, 4151
Postal Address: PO Box 479
               Stones Corner, 4151
Phone: (07) 3397 1224
Fax: (07) 3394 1013
Email: ilcql@gil.com.au

I. MACKAY AND DISTRICT SPINAL INJURIES ASSOCIATION
Address: 391 Bridge Road
          West Mackay, 4740
Phone: (07) 4957 2180 or mobile (0412) 305 042
Website: www.mackay.net.au/~mdsia

J. MEDICAL AIDS SUBSIDY SCHEME (MASS)
Brisbane: (07) 3250 8555
Rockhampton: (07) 4920 6975
Mackay: (07) 4968 3822
Townsville: (07) 4774 5900
Cairns: (07) 4050 3500
Website: http://165.86.4.72/MASS/home.htm

K. NURSING/PERSONAL CARE SERVICES
Bluecare: (07) 3840 5111
St Lukes: (07) 3368 7600
St Vincents: (07) 3246 2770
Domicare: (07) 3891 5700

191
L.  PARAPLEGIC AND QUADRIPLEGIC
ASSOCIATION OF QUEENSLAND (PQAQ)

BRISBANE OFFICE

Address: Cnr Shafston Ave and O'Connell Street
          KANGAROO POINT QLD 4169
Postal Address: P0 Box 5651
               WEST END QLD 4101
Telephone: (07) 3391 2044
Free Call: 1800 810 513
Fax: (07) 3391 2088
Email: pqaq@gil.com.au
Website: http://www.pqaq.gil.com.au/

TOWNSVILLE OFFICE

Address: 1 Charters Towers Road
          TOWNSVILLE QLD 4810
Postal Address: P0 Box 6132
               TOWNSVILLE WEST QLD 4810
Telephone: (07) 4721 5800
Fax: (07) 4721 5802
Email: pqaqnq@beyond.net.au

PQ LIFESTYLES

Postal Address: PO Box 2802
               MILTON 4064
Telephone: (07) 3858 6498
Fax: (07) 3844 1347 or
National Free Call: (1300) 366 455

M.  PBF AUSTRALIA (PARAPLEGIC BENEFIT
FUND)

Address: GPO Box 9959
         Brisbane, Q, 4001
Phone: (07) 3221 0933
Fax: (07) 3229 7867
Freecall: 1800 809 780
E-mail: info@pbfbne.asn.au
Website: www.pbfbne.asn.au
N. QUEENSLAND ADVOCACY INCORPORATED

Address: Suite G2, Ground Floor
Brisbane Transit Centre, Roma Street
BRISBANE 4000
Phone: (07) 3236-1122

O. QUEENSLAND COUNCIL OF CARERS

BRISBANE RESOURCE CENTRE
Address: 15 Abbott Street
CAMP HILL 4152
Telephone: (07) 3843 1401 or
Free Call (1800) 242 636
Respite Booking Service: (07) 3843 2059

ROCKHAMPTON RESOURCE CENTRE
Address: Shop 2, 16 Blanchard Street
NORTH ROCKHAMPTON 4700
Telephone: (07) 492 1 2298

TOWNSVILLE RESOURCE CENTRE
Address: 1 Gleeson Street
HERMIT PARK
TOWNSVILLE 4810
Telephone: (07) 4725 2388
Website: http://www.qcc.org.au

P. QUEENSLAND HOUSING COALITION (QHC)

Address: Unit 1B, 38 Old Cleveland Road
STONES CORNER 4120
Telephone: (07) 3397 5044

Q. QUEENSLAND TRANSPORT

Taxi Subsidy Scheme/
Disability Parking Scheme: (07) 3834 2011
R. SPORTING WHEELIES AND DISABLED SPORT AND RECREATION ASSOCIATION INC.

STATE HEADQUARTERS

Address: 60 Edmondstone Road, Bowen Hills 4006
Phone: (07) 3253 3333
Fax: (07) 3253 3322
E-Mail: mail@sportingwheelies.org.au

Cairns: (07) 4051 0451
Mackay: (07) 4953 1991
Townsville: (07) 4721 4881
Rockhampton: (07) 49363800
Gold Coast: (07) 5531 3312
Bundaberg: (07) 4152 2923
Maroochydore: (07) 5443 6744
Toowoomba: (07) 4632 7949

S. TECHNICAL AID TO THE DISABLED (TAD)

Address: PO Box 2334
Fortitude Valley B.C 4006
Phone: (07) 3216 1733

T. OTHER USEFUL CONTACTS

AUSTRALIAN QUADRIPLEGIC ASSOCIATION (AQA):

Phone: (02) 9661 8855
Free: 1800 819 0775
Email: aqa@qa.org.au

BACKSTOP Respite Care for Disabled People Inc: (07) 3825 6695

LEGAL AID QUEENSLAND: 1300 651 188

MAXI TAXIS: (07) 3391 1000.
(Brisbane booking number)
PARAPLEGIC AND QUADRIPLEGIC ASSOCIATION OF NSW
(Paraquad NSW):

Phone: (02) 9746 4166
Email: paraquad@paraquad-nsw.asn.au
Website: http://www.paraquad-nsw.asn.au/

QUEENSLAND LAW SOCIETY: (07) 3842 5888

QUEENSLAND ANTI-DISCRIMINATION COMMISSION: 1300 130 670

TAXATION DEPARTMENT: 132 866
(Re: Sales Tax Exception on motor vehicles)

RED CROSS: (07) 3394 7582
We would like to thank PBF Australia for their support with the printing of this Handbook.