Promoting Independence Following a Spinal Cord Injury

A Manual for Mid-Level Rehabilitation Workers



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World Confederation for Physical Therapy World Federation of Occupational Therapists

Abstract

This manual is for mid-level rehabilitation workers to use when they work with children or adults who have had a spinal cord injury, their families, and with other health workers. The manual includes information on what a spinal cord injury is and the emotional and physical effects of this type of injury. It shows how to identify the different levels of injury and covers the basic care of a person following a spinal cord injury.

Suggestions are given on how to promote independence in all aspects of a person's daily life. This includes managing bladder and bowel, preventing pressure sores, exercising, sitting, selecting and using a wheelchair, transferring, using paralysed hands, washing, dressing, standing and walking. Several issues of sexuality are highlighted. Simple adaptations to make it easier to use a wheelchair around the home and compound are described. Finally and perhaps most importantly, ideas are given about how a people with spinal cord injuries can remain active and involved in their communities.

CONTENTS

	Forev Abou	vord t This Guide	v vi
1.	Introduction		
	1.1	What is a Spinal Cord Injury ?	1
	1.2	Where is the Spinal Cord ?	1
	1.3	What does the Spinal Cord do?	1
	1.4	What Happens when the Spinal Cord is Injured ?	2
	1.5	Feelings and Emotions	2
	1.6	Levels of Spinal Cord Injury	4
	1.7	Grades of Spinal Cord Injury	5
	1.8	Will the Spinal Cord Recover After it is Injured ?	6
	1.9	What can be done After a Person has a Spinal Cord Injury ?	6
2.	Basi	ic Care After a Spinal Cord Injury	7
	2.1	Preventing Pressure Sores	7
	2.2	Learning to Urinate	12
	2.3	Learning to Defecate	16
	2.4	Coughing	20
	2.5	Pounding Headaches and High Blood Pressure	22
	2.6	Feeling Faint and Dizzy when Sitting or Standing	23
	2.7	Why the Paralysed Parts of the Body Jerk and Jump	23
	2.8	What to Eat and Drink	25
	2.9	The Joints Feel Harder to Move	26
	2.10	Swollen Hands and Feet	26
	2.11	Weak Bones and Fractures	27
	2.12	Pain	27
	2.13	Staying Cool in Hot Weather and Warm in Cold Weather	28

3.	Pro	moting Indepenence	29
	3.1	Moving the Paralysed Parts of the Body	29
	3.2	Preventing Elbow Contractures	32
	3.3	Exercises	33
	3.4	Learning to Roll and Sit Up	37
	3.5	Choosing and Using a Wheelchair	42
	3.6	Moving On and Off a Wheelchair	49
	3.7	Using Paralysed Hands	56
	3.8	Washing	65
	3.9	Dressing	69
	3.10	Standing	75
	3.11	Walking with Callipers	77
4.	Sexu	al Issues Following a Spinal Cord Injury	85
	4.1	Sexuality	85
	4.2	Physical Effects of a Spinal Cord Injury on Sexuality	85
	4.3	Things to Consider Before Sexual Intercourse	85
	4.4	Things to Consider During Sexual Intercourse	86
	4.5	Safe Sex	86
	4.6	Specific Issues for Women	86
5.	Chil	dren with Spinal Cord Injuries	89
6.	Inco	mplete Spinal Cord Injuries	91
7.	Living at Home		
8.	Keeping Active Following a Spinal Cord Injury		
9.	Summary of When to Ask for Help 99		
10.	Fur	ther Reading and Acknowledgements	101

Foreword

In all countries, rehabilitation following a spinal cord injury is a challenge to those who are injured. In developing countries, especially in the transitional period after a war, it is also a particular challenge to rehabilitation personnel who may feel they do not have adequate staff, facilities or equipment to assist all individuals who have spinal cord injuries. The World Health Organization (WHO) has learned through community based rehabilitation programmes that in developing countries very often people with spinal cord injuries cannot obtain guidance on how to function at an optimum level with their impairments. Based on the need for dissemination of information about rehabilitation following spinal cord injury to all levels of rehabilitation personnel, WHO approached the World Federation of Occupational Therapists (WFOT) and the World Confederation of Physical Therapists (WCPT) for collaboration in the production of a manual for mid-level rehabilitation workers (MLRWs)*. This manual is a result of that collaboration.

We extend our gratitude to the WFOT and the WCPT for their on-going collaboration with WHO. In particular, we wish to thank the authors of this manual, Mr Michael Curtin and Ms Gay Harrison, selected by WFOT and WCPT respectively; as well as Ms Shona Grant, who prepared the illustrations. The authors' draft was sent out to therapists in each of the six WHO Regions for review. Their thoughtful responses, which were also appreciated, contributed to the final version of this manual. Our gratitude also goes to Dr Ann Goerdt, a former WHO staff member, who coordinated the tasks necessary for the preparation of this manual.

We believe that this manual will be useful to teachers as a guide for training MLRWs for the process of rehabilitating people with spinal cord injuries, and also for MLRWs as a reference in their work.

Final your

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^{*} Countries have different titles for MLRWs, e.g. rehabilitation assistants or technicians, or physical or occupational therapy assistants.

About this Manual

This Manual will help Mid-Level Rehabilitation Workers (MLRWs) to assist centre based and community based rehabilitation personnel to work with people who have had a spinal cord injury. The Manual shows how people who are paralysed can learn to do things for themselves. The Manual gives information on how to assist someone who has a spinal cord injury and suggests when to ask for help from a therapist or doctor. The MLRWs can teach others, such as the families and the Primary Health Care Workers (PHCWs), how to encourage people who are paralysed to be independent. Furthermore the Manual can be used to educate other people in the community about the abilities of people with spinal cord injuries. Educating community, political and business leaders will help to promote changes in attitudes towards people with disabilities. It will also encourage opportunities for people with a spinal cord injury to have access to education, job training and work within the community.

Independence does not mean that the person who is paralysed must learn to do everything by himself. For some people this will not be physically possible. Independence means that the person who is paralysed knows what he wants and when he needs it. If he is unable to do something for himself then he will be able to tell someone else how to do it for him. He will be able to organise when things are to be done.

The ideas and suggestions within this Manual are not suitable for every country. The ideas and suggestions are guidelines. This Manual should be translated into the language used by the rehabilitation workers and the people who have a spinal cord injury. Changes may be needed to make it more suitable for a particular community. For example, equipment shown in the Manual may be different from things which are already used in a community to help a person who is paralysed to cook or to wash.

Put drawings of your equipment in your translated version of the Manual. Throughout the Manual reference will be made to specific Training Packages which come from "Training in the Community for People with Disabilities", World Health Organisation, 1989 (page 99). The Training Packages will provide more information on some of the topics discussed in this Manual. However, the Training Packages do not contain information specific to spinal cord injuries which is why this Manual has been produced. Using this Manual and the selected Training Packages will help rehabilitation workers and families to promote independence following a spinal cord injury.

The term "tetraplegia" is used in preference to "quadriplegia" in this manual. Both these terms have the same meaning. However, "tetraplegia" is the term officially accepted by the International Medical Society of Paraplegia.

Both men and women have spinal cord injuries. To accommodate this the terms he or him and she or her are used throughout the Manual. The drawings show both men and women.

1. Introduction

1.1 What is a Spinal Cord Injury?

A spinal cord injury occurs when the spinal cord is damaged. Most spinal cord injuries are a result of accidents which break the bones of the neck or the back. When the bones of the neck or the back are broken they may damage the spinal cord. This is because the spinal cord lies in a tunnel made by these bones. This usually paralyses the muscles and causes loss of feeling below the level of injury.

> Motor vehicle accidents are a common cause of spinal cord injury. Other causes of spinal cord injuries include falling from a bicycle or other type of transport; diving into shallow water or hitting his head on a submerged rock or tree; and falling from a height.

People may also have a spinal cord injury as a result of violence. They might be stabbed, shot or blasted. All of these may damage the spinal cord. The spinal cord may also be damaged by disease or infections such as tuberculosis. Some children may be born with damage to their spinal cord. See"Promoting the Development of Infants and Young Children with Spina Bifida and Hydrocephalus" (page 101).

1.2 Where is the Spinal Cord?

The spinal cord starts at the bottom of the brain and ends at the small of the lower back. It lies in a tunnel made by a group of bones which sit one on top of each other. These bones are called vertebrae. The column of vertebrae is known as the backbone. Each of the vertebra of the backbone can move. This lets you bend and turn your body. You are prevented from bending and turning too much by the shape of the vertebrae, and by the strong muscles and ligaments which run along the backbone.

1.3 What does the Spinal Cord do?

The spinal cord has 31 pairs of nerves which connect it to different parts of the body. The nerves on the right side of the spinal cord connect the spinal cord with the right half of the body. The nerves on the left side of the spinal cord connect the spinal cord with the left half of the body. The nerves tell the spinal cord what the body is feeling. The spinal cord then sends this information up to the brain. The brain sends information back down the spinal cord. The spinal cord sends the information from the brain down the spinal nerves to the muscles. This is how the brain tells the muscles how to move the joints.







A DECKET AND A DECKET



1.4 What Happens when the Spinal Cord is Injured ?

When the spinal cord is injured messages about what the body is feeling, below the damaged area, cannot get to the brain. Also information from the brain cannot get past the damaged part of the spinal cord to tell the muscles how to move. Feeling and movement of the body below the damaged part are affected. The person will also be unable to or find it difficult to control his bladder and bowel.

If the person has no feeling or voluntary movement below the damaged part, the spinal cord injury is said to be complete. If the person has some feeling or voluntary movement below the damaged part, the spinal cord injury is said to be incomplete (pages 91).

How a spinal cord injury affects a person will depend on the level of injury and whether the injury is complete or incomplete. It will also depend on many other factors such as the person's age, gender, cultural background, personality, physical build, religious beliefs, social and educational background, marital status and financial position.

1.5 Feeling and Emotions

The muscle paralysis, loss of sensation and loss of bladder and bowel control are the obvious result of a spinal cord injury. What is not so obvious is the emotions a person has, and how he copes with these emotions, following a spinal cord injury.

There are no set ways in which he will react following a spinal cord injury. Because everyone is different everyone will react differently. Some of the emotions he may feel are:

- . Disbelief at what has happened. He may deny what has happened, not believe what he has been told or have unrealistic expectation of what he will be able to do.
- . Depression. As he realises what has happened he may start to feel that it is all hopeless. He may not want to talk to people. He may refuse to co-operate or try to do anything for himself.
- Anger. He may feel angry at what happened. He may feel that his injury was unjust and unfair. He may be angry about not being able to work or play sport or to look after his family. He may resent people who are not paralysed. He may take his anger out on his family or the hospital staff. He may keep his anger to himself.
- Anxiety. He may worry about how the injury will effect his life and his relationships with his family and friends. He may not understand what has happened or what will happen. He may feel vulnerable because he thinks he is unable to do things for himself.
- Grief. He may start to think about all the things he could do before his injury and some of the things he may not be able to do again. He may grieve for some of the things he thinks he will be unable to do again.

Learning to cope with his feeling and emotions

In the first few months following a spinal cord injury it is common for people to experience some of these feelings. Each person will react differently. Some will go through all the feelings, some will not. Some will appear to have several of the feelings at the same time. These are normal reactions to the traumatic injury. In most cases the strength of these feelings will decrease with time.

As each person understands what has happened and begins to have more control over what he does he will learn to live with a spinal cord injury.

To learn to cope emotionally following a spinal cord injury she should:

- . Learn as much about her spinal cord injury as possible.
- . Accept that it is common to feel the way she feels.
- Talk with someone else about her feelings. This may be someone in her family, a friend, rehabilitation worker or someone who has had a spinal cord injury. Be honest about her feelings and concerns.
- Keep active. Do as much as she can for herself. Stay physically and mentally active. Do things that she enjoys doing. Try to do new things.
- . Make a decision that she will get on with life despite the spinal cord injury.

Learning to cope with the reaction of other people

One of the most difficult things for the person to deal with following a spinal cord injury will be the reaction of other people towards her. Many people will stare at her in her wheelchair. Many will have difficulty talking with her. They may feel embarrassed. Many have good intentions of offering to help but tend to be patronising. Children will ask a lot of questions. She must learn to deal with these reactions. She should think of how she would have reacted to someone in a wheelchair before her spinal cord injury so that she can try to understand why other people react the way they do.

She should not feel embarrassed about being in a wheelchair. She must learn to be sociable with other people and show them that she is the same person she was before her spinal cord injury. People may have to meet her several times before they feel comfortable with her.

Relationships with family and friends may become strained. People close to her will probably go through similar feelings to her own. They will be especially anxious and worried about her. They will have concerns about her coming home. She and her family and friends must talk honestly about their concerns and worries. They need to support each other so that they can all learn to live with her spinal cord injury.

How to help a person cope with his emotions

Helping her to deal with these feelings and to cope emotionally is just as important as the exercises and activities to help her do things for herself. Rehabilitation workers can help a person with a spinal cord injury to deal with her emotions by being honest with her, telling her as much as she will understand about the effects of her injury and explain clearly why she is doing the various exercises and activities. The rehabilitation worker may also offer emotional support and be someone for her to talk with about her feelings.

She will also need the support of her family and friends. She will need to know that she is accepted back into her community. She will need to feel that she can lead a worthwhile life. She will need to understand what has happened and how it has affected her body physically. She will need to learn what things are possible for her to do and what she will find difficult.

There is no magical way to help her deal with her emotions. It will take time, she will need to be motivated and she will need to be supported.

1.6 Levels of Spinal Cord Injury



Whatever the level of spinal cord injury the person will have some difficulty controlling his bladder and bowel.

1.7 Grades of Spinal Cord Injury

The grade of sitting balance achieved is a good indication of what each person will be able to after rehabilitation. People with a spinal cord injury will reach one of six grades of sitting balance. The grade reached will depend upon many factors such as the level of injury, other injuries, age, gender, physical build, motivation, and environment. It will also depend upon the person making the decision to get on with life despite the spinal cord injury. Good support and an encouraging attitude of the person's family, friends and health workers are essential. The activities in this book will be separated into the six grades of sitting balance to provide guidance on what people with a spinal cord injury can achieve.

Grades One to Four are different grades of tetraplegia.



Grade Five is the same as high paraplegia.



Grade Five

. He can sit without support. . He can lift both his arms up at the same time in all directions.

. He will need a helper in the beginning when he tries to do things in this position.

Grade Six is the same as low paraplegia.



Grade Six

She can sit without support.
She can throw and catch a ball above her head.

do things in this position.

. She does not need a helper.

1.8 Will the Spinal Cord Recover After it is Injured ?

Once the spinal cord has been injured it cannot be repaired and it will not regrow. There may be some improvement as the spinal cord recovers from spinal shock. Spinal shock occurs immediately after every spinal cord injury. The spinal cord stops working and the person will be unable to move. Spinal shock may last for a few hours but could last up to six weeks. During the period of spinal shock it is difficult to know how badly the spinal cord is damaged.

There may be some improvement when any swelling, bruising or bleeding of the spinal cord goes away. Any recovery will usually happen within 6 months following a spinal cord injury. People with an incomplete spinal cord injury may show signs of improvement for up to two years following a spinal cord injury. The more time that passes without any improvement, the less likely it is that any major improvement in feeling or movement will occur.

If the spinal cord is damaged as a result of infection or tumour it is possible that it will completely recover.

1.9 What can be Done After a Person has a Spinal Cord Injury ?

Immediately after the injury, the person must be taken to hospital. She will probably stay in hospital for several months. While she is in bed she must start to do some exercises to keep the muscles which are not paralysed strong. She must also begin to learn how to manage her bladder and bowel. She must learn about relieving pressure so that she will not develop pressure sores. She must get in the habit of eating healthy food and drinking about three litres of water a day. If she can do some things for herself like eating and washing then she should be encouraged to do them.

While she is in bed waiting for her backbone to mend she must not twist or turn her body until the doctor says it is safe to do so. Once the backbone is stable she will be allowed to sit up in a wheelchair. It may take from a few weeks to a few months before she is ready to sit in a wheelchair.

When she is sitting in a wheelchair, she must then start to learn ways in which she can become independent. She must learn how to move around in a wheelchair. She must continue exercising to keep her muscles strong. She will develop routines for relieving pressure to prevent sores. She must become competent at managing her bowel and bladder. She must learn how to wash, dress and feed herself.

She should also begin to learn how to do things around the house and compound and find ways to do paid work and to become involved in her community. Children must return to school.

By looking at things she can do and by staying active she will learn to cope with her spinal cord injury.

It is important that her family and friends accept her, encourage her to do things by and for herself, respect what she wants to do and include her in what is happening.

2. Basic Care After a Spinal Cord Injury

2.1 Preventing Pressure Sores

See WHO Training Package 10

What is a pressure sore ?

A pressure sore is an area of damaged skin and flesh. A pressure sore is usually caused by sitting or lying in the same position for too long without moving. Normally when we sit or lie in the same position for a long time, we begin to feel uncomfortable. We move or shuffle about to change our position. People who have a spinal cord injury may not be able to feel when they are uncomfortable. They will not feel that they have been in one position for too long so may not change their position.

A pressure sore can develop in only a few hours. It usually starts with the skin changing colour. The skin may appear slightly darker than usual. If the sore is not treated quickly, it may develop into an open blister within a few days. Over a longer period of time it will become a deep hole in the flesh. If a pressure sore develops it may take months to heal. It may even require surgery. If it becomes infected and is poorly treated it can kill.

Pressure sores develop on the parts of the body which take the person's weight and where the bones can be easily felt under the skin. The areas most at risk depend on whether the person is sitting or lying on the back, front or side:



Sores may also be caused by the person:

- . Wearing tight clothes.
- . Grazing or rubbing the skin when moving on and off the wheelchair.
- . Burning the skin with hot water or by being too close to a fire.
- . Putting hot plates on her lap while cooking or eating.
- . Being biten by insects.
- . Putting on a condom too tightly.
- . Lying or sitting on wrinkled linen or uneven surfaces.

Although these sores are not directly caused by pressure they will still take a long time to heal. If any sore develops it is important to keep all pressure off it so that it can heal as quick as possible. Any pressure on an existing sore will cause it to get worse.

How to recognise a pressure sore

When the pressure on an area of skin is removed or relieved the skin in that area will become darker. The darkness should normally fade within two to three minutes.

If the darkness lasts for more than five minutes it may be a sign that the pressure had been too much or had been for too long. The dark area of skin may feel warm to touch. During this stage, a pressure sore can be stopped from developing by completely removing all the pressure from the dark area of skin. This will give the skin time to recover. No pressure should be put on that area of skin until the skin looks normal.

If the pressure is not removed until the dark area of skin disappears then a blister may form over this area. The skin will break down and cause a hole or ulcer to develop. Finally the flesh and perhaps the bone underneath the skin will become infected. If a pressure sore becomes infected and is not treated properly then the person will die. If a pressure sore has become a hole or ulcer he will need to see a doctor and may need to stay in hospital.

How to prevent a pressure sore

The best way to avoid a pressure sore is to move frequently. The person should not lie or sit in the same position for too long. Relieving pressure is the most effective way of preventing sores.

If the person cannot do this himself, someone else must help him.

Relieving pressure when in bed

When the person is lying down he must change his position between lying on either side, to lying on his back, to lying on his front every two to four hours. The mattress must be firm but not hard. A thick sponge foam mattress is ideal. The mattress must offer support to his body. The mattress must not be too soft so that his body touches the base of the bed underneath the mattress.

In the early months after a spinal cord injury pillows, pads or folded towels and blankets must be placed underneath him to protect the bony areas of his body. These must be placed so that the bony parts are between the pillows, pads or towels. This will reduce the risk of pressure sores.







- Always make sure that the catheter tube is not stretched or pulled when changing positions.
- Make sure that the catheter bag hangs securely from the side of the bed.
- . He must not lie on his front until his backbone is mended.

When he starts to sit up and becomes more active, there will be no need for the pillows, pads or folded towels and blankets. If a dark area of skin or a pressure sore develops then the pillows, pads or folded towels and blankets may be used to removed pressure of the affected area.

When lying in bed, a bed cradle to hold the sheets off his feet will make it easier for him to turn. Always use clean sheets which have no big wrinkles in them. A big wrinkle may cause a pressure sore. If the sheets become wet or dirty change them immediately. Lying on wet or dirty sheets will cause a pressure sore.

Relieving pressure when sitting in a chair

All people with a spinal cord injury must sit on a firm cushion. This will help to prevent pressure sores. Sitting directly on the canvas or hard wooden or metal seat of the wheelchair will cause a pressure sore. Different cushions suit different people. Try a variety of cushions. He should try each cushion for at least one day but preferably longer. If the cushion causes red marks then try another one.



Pressure relief techniques in the wheelchair

As well as sitting on a good cushion the person must relieve pressure when sitting on a wheelchair by doing one of the following. The wheelchair brakes must always be put on before relieving pressure.



. Tilt the wheelchair backwards. This is a good way to relieve pressure for those who need help.



. Bend forwards with her arms hanging down in front. This is the most effective way to relieve pressure while sitting in a wheelchair.



. Lean to one side and then to the other side.



. Lift her buttocks off the cushion by pushing up on the armrests or the back tyres.

Whichever method of relieving pressure is chosen it must be done for at least one minute. In the first few months of sitting in a wheelchair pressure must be relieved every 20 to 30 minutes. As the person becomes more active and if there is no sign of a pressure sore, she can relieve pressure less frequently.

Never sit for more than one hour without relieving pressure.

How to check if a pressure sore is developing

The skin must be checked twice a day. The skin must be checked once before getting out of bed. The skin must be checked once in the evening before going to sleep. A mirror should be used to check the parts of the body which are difficult to see. If she cannot check her skin herself she must ask someone else to check it for her.



If an area shows a sign of a pressure sore developing then she must not put any pressure on the affected area. She must keep the pressure off the affected area until the dark area has disappeared.

What to do if a pressure sore has developed

If a pressure sore has developed, the person must not sit or lie on the affected area. If after a couple of days the affected area is not better, or if the skin has broken down, she **must see a doctor**. The hole will need to be cleaned every day. A deep hole will have to be closed over by surgery. She should stay in bed until the hole heals. While in bed she must relieve pressure from the other parts of her body to prevent another sore from developing.

The affected area should have no pressure on it until it has completely healed. Once a pressure sore becomes a hole it may take several weeks or months to

heal. If the bone becomes infected it may take longer.

If a the person has a pressure sore on his buttocks and he wants to move around then he can try to move by lying on a prone trolley. The trolley must have a firm mattress on it for him to lie on. He will also need to have pillows, pads or folded towels and blankets placed underneath him (page 8). While on the prone trolley he must relieve pressure from the other parts of his body to prevent another sore from developing.

Other precautions to prevent pressure sores



- . She must sit in the wheelchair correctly (page 42).
- . She must wash the body carefully everyday (pages 65-68).
- . She must dry the body by gently patting the paralysed parts with a towel (page 68).
- . She must change wet or dirty clothes immediately.
- . She must eat healthy food and avoid becoming too fat or too thin (page 25).
- . She must wear loose fitting clothes (page 69).
- . She must wear shoes or slippers when in the wheelchair to protect the feet from being knocked.
- . She must be careful no to burn herself around fires and stoves and when carrying hot drink or food.
- . She should not use talcum powder because it soaks up the skin's natural oils and dries the skin.
- She should not knock, bump or drop paralysed arms and legs, especially when transferring on and off the wheelchair (pages 50-55).
- . She should not lie or sit on wrinkled linen or bedclothes.

2.2 Learning to Urinate

What is the bladder ?

The bladder is the part of the body which holds urine. The bladder lies within the pelvis. When the bladder is full of urine a message is sent to the spinal cord and then to the brain to say you need to urinate. Sometimes when it is not convenient, like when you are on a bus, the brain will stop the bladder from emptying. When it is more convenient the brain tells the bladder to empty the urine.

What happens to the bladder after a spinal cord injury ?

A person with a spinal cord injury will not feel when she needs to urinate. She must learn a different way to urinate. If she does not learn a way to manage urinating, she will continually wet herself. This will be embarrassing and may cause a pressure sore. If she does not learn how to empty her bladder completely she will get a urinary tract infection. If she develops an infection she may become very sick and have a high fever. She needs to see a doctor as soon as possible for treatment.

After a spinal cord injury the person will have one of two types of bladders.

A bladder that spasms:

If she has spasms in her legs she will usually have a bladder that spasms. With a bladder that spasms the nerves between the bladder and the spinal cord are not damaged. But the connection to the brain is damaged. Therefore the brain is not able to control when the bladder needs to empty.

The walls of the bladder stretch as the bladder fills with urine. When the walls stretch too much it causes a spasm of the bladder. The spasm squeezes the bladder and empties the urine.

A floppy bladder:

If she has floppy legs she will usually have a floppy bladder. With a floppy bladder the nerves between the bladder and the spinal cord have been damaged. There is no reflex bladder movement.

This type of bladder continues to fill with urine and stretch. If it is not emptied the bladder stretches until it cannot hold any more. The urine will then drip out. The bladder will not empty completely. The bladder will stay stretched. If the urine stays in the bladder for a long time it will cause an infection of the bladder.

How to empty the bladder

During the period of spinal shock, while she is in hospital, a "Foley catheter" is kept in her bladder all the time. This catheter empties the urine from her bladder. After a few weeks the "Foley catheter" will be removed and one of the following methods tried. If she is wet after trying one of the methods for several days then try another method. Some methods work better with a bladder that spasms. Some methods work better with a floppy bladder.

To stop her bladder from becoming infected and to stay healthy she must drink about three litres of water each day. For any of the following methods to work she must stick to a regular routine of emptying her bladder. She should empty her bladder every three to four hours. When sleeping she may want to go six to eight hours without emptying her bladder. She will need to stop drinking a few hours before going to sleep.

Tapping and gentle pressing (for both men and women)

A bladder which spasms can be emptied by:

- Tapping gently on the lower part of the abdomen where the bladder is and then applying gentle pressure on the bladder with the heel of the hand or a flat hand (not a fist) to help empty the bladder.
- . Repeat this several times until no more urine comes out.
- Tap and gently press the bladder either in bed or in a wheelchair or on the toilet.
- This may be used by men who wear a urinal sheath or men and women who empty their bladder on the toilet or commode.

- A floppy bladder can be emptied by:
- Pressing on it with the heel of the hand or a flat hand while leaning forwards and tightening the abdomen muscles to help empty the bladder.
- Tapping is not necessary as there is no reflex.
- This may be used by men and women who empty their bladder on the toilet or commode.

Hard pressure when tapping or pressing the bladder may push the urine upwards towards the kidneys. This may cause a urinary tract infection.

A **man** who taps and presses his bladder may wear a condom sheath on his penis which is attached to a catheter tube and a plastic bag. When the bladder is tapped and pressed the urine runs into the condom sheath, down the tube and into the bag. The condom sheath, the tube and the bag can be worn under his clothes. The condom sheath must be removed once a day and the penis washed and dried. The bag must be emptied regularly so it does not become too full.

A **woman** is not able to wear a condom catheter. If she needs to protect herself from wetting her clothes in-between tapping and pressing her bladder every three to four hours she must wear disposable padding in her pants. If she has frequent body spasms she may pass a lot of urine into the padding. If she does urinate a lot even after tapping and pressing her bladder she should try another method (see page 15). Pads must be changed regularly. She must not keep a wet pad in her pants as this will cause an infection. The pad must be carefully placed to prevent a pressure sore from developing.

Some men will not need to wear a condom catheter. Some women will not need to wear padding. These men and women can control when they urinate by tapping and pressing on the bladder. They do not accidentally urinate at other times. They must be able to get to a toilet every three to four hours.

How to make a condom catheter



If the penis becomes swollen or looks sore remove the condom immediately. Do not put another one on until the penis looks healthy again.

Inserting a "standard catheter" every 3 to 4 hours (for both men and women)

If he is not able to urinate well enough by tapping and gently pressing, a "standard catheter" can be inserted into his bladder every three to four hours. This is called intermittent catheterisation. The catheter may be inserted while in bed or while sitting on a wheelchair or toilet. A doctor or nurse must show him how to insert the catheter correctly to make sure his bladder will empty completely. This method is only suitable if he can do it without help, if there is a regular supply of "standard catheters", if it can be done every three to four hours, and if the room where the catheter is inserted is clean. To reduce the risk of infection he must wash his hands and genitals before inserting the catheter. The same catheter may be re-used for two to three weeks if it is **properly rinsed after each procedure**. Store the catheter in a clean and dry place.

Using an indwelling catheter (for both men and women)

A catheter which stays in the bladder all the time is called an indwelling catheter. The type of catheter which is used for this is called a "Foley catheter". It is either inserted into the bladder through the genitals or through a small hole in the lower abdomen. Because the "Foley catheter" is left in the bladder all the time it continually empties the urine from the bladder. The "Foley catheter" is connected to a tube which is connected to a plastic bag. The plastic bag is strapped to the leg. The bag needs to be emptied regularly so that it does not become too full. The bag must always be placed lower than the catheter so that the urine drains out of the bladder. Using an indwelling catheter is the easiest method of controlling the bladder. However it should only be tried if the other ways are not possible or successful. It does have its problems. An indwelling catheter can cause infection, bladder stones or a sore on the underside of the penis. If the catheter is inserted through a hole cut into the lower abdomen the hole must be cleaned every day. Sometimes this hole can increase the strength and the frequency of spasms. An indwelling catheter must be changed once every four weeks. A new catheter should be inserted. A doctor or a nurse must show the person how to do this. A supply of catheters must be available.

Tp prevent an infection a person must

- . Drink three litres of water a day.
- Empty his bladder every three to four hours and stick to a routine.
- Wash his genitals at least once a day, and definitely after defecating.
- . Wash his hands before touching genitals or catheter.
- . Keep the catheter and other equipment clean.
- Wash out the collection bag once a day with soap and water.
- Never pull or stretch the catheter. Be aware of this when moving on and off the wheelchair.
- Never lift the collection bag above the bladder because the urine will flow back into the bladder.
- Check regularly that the bladder is emptying and that the catheter is not kinked.

Signs of an infection

- . He feels unwell with fever and pain.
- His urine is cloudy or pink in colour and smells.
- He has difficulty urinating or urinates unusually small amounts.
- . His spasms become stronger and more frequent.
- . He develops dysreflexia (page 22).

Treating a bladder infection

- He must see a doctor immediately who will prescribe drugs to treat the infection.
- . He must drink more water to clean out bladder.
- . He must empty his bladder more frequently until the infection has cleared.

2.3 Learning to Defecate

What is the bowel?

The bowel is the part of the body which stores faeces. The bowel lies behind the bladder. When the bowel is full a message is sent to the spinal cord and then to the brain to say you need to defecate. Sometimes when it is not convenient, like when you are on a bus, the brain will stop the bowel from emptying. When it is more convenient the brain tells the bowel to empty the faeces.

What happens to the bowel after a spinal cord injury ?

A person who has a spinal cord injury may not feel when she needs to defecate. She must learn a different way to defecate. If she does not learn a way to manage defecating, she will continually dirty her pants. This will be embarrassing. Sitting or lying in faeces will also cause pressure sores and may cause bladder infections.

After a spinal cord injury the person will have one of two types of bowel:

A bowel that spasms

If she has spasms in her legs she will usually have a bowel that spasms. With a bowel that spasms the nerves between the bowel and the spinal cord are not damaged. But the connection to the brain is damaged. Therefore the brain does not know when the bowel needs to empty.

The walls of the bowel stretch as the bowel fills with faeces. When the walls of the bowel stretch too much it causes a spasm of the bowel. The spasm squeezes the bowel and empties the faeces.

A floppy bowel

If she has floppy legs she will usually have a floppy bowel. With a floppy bowel the nerves between the bowel and the spinal cord have been damaged. There is no reflex bowel movement.

This type of bowel continues to stretch as it fills with faeces. If it is not emptied the bowel stretches until it cannot hold any more. The faeces will then drip out. The bowel will not empty completely. The bowel will stay stretched. If the faeces stays in the bowel for a long time it will become constipated.

How to empty the bowel

To empty the bowel the person must stick to a routine that works. Some people will defecate every day. However because it takes a little time, most people will be able to defecate every second day. Whether the person defecates every day or every second day she must do it at the same time each day.

It will take a few days or sometimes a few weeks before she will learn to control when to defecate. To help her to defecate she must eat healthy food and drink three litres of water a day (page 25).

When to defecate ?

It is best to defecate before washing because the buttocks and hands will need to be washed afterwards. Some people find it easier to wash in the morning and some find it easier to wash later in the day or during the evening. Some people will need to take a mild laxative about 12 hours before defecating. The laxative helps the faeces move into the bowel. The laxative will also make the faeces soft and easier to push out or remove. A doctor will recommend a mild laxative.

Eating a high fibre diet and drinking three litres of water a day will reduce the need for a mild laxative (page 25). A high fibre diet and lots of water will also help the faeces to move into the bowel and make it soft.

Some people may find it easier to defecate after eating some food or having a hot drink.

Where to defecate ?



- . If he cannot or does not want to sit, then lay him on his left side on the bed.
- Place a plastic sheet and a towel underneath him to protect the bed from getting dirty.
 - If possible he should defecate in a sitting position because it is easier.
 - He can sit on a toilet or a commode.





A commode can be made from a wooden chair.



How to defecate if the bowel spasms

If the bowel spasms a suppository may need to be inserted to defecate. The type of suppository should be decided by a doctor. The suppository should be inserted while in bed. It may take up to 30 minutes for the suppository to work.

He will not be able to feel the suppository being inserted. It needs to be inserted carefully and



correctly. A doctor or nurse will show him or his helper how to insert a suppository. Whoever inserts the suppository must wear a plastic glove or use a plastic bag to cover their finger. Put some water or lubricating jelly or vegetable or mineral oil onto the end of the suppository. This will make it easier to push the suppository pass the anus and into the bowel.

If possible, just before the suppository works he should sit on a toilet or commode. While sitting on a toilet or commode he must relieve the pressure off his buttocks every five to ten minutes. If he is unable to sit on a toilet or commode then he must lie on a bed on his left side.

Just before he defecates it may help to massage the anus with the finger wearing a glove. The glove should have some water, lubricating jelly, or vegetable or mineral oil on it. This will make it easier to massage the anus. He inserts his finger about two centimetres into his anus. This will relax the anus so the faeces can come out. This may have to be repeated two or three times until there is no faeces left.

In many countries suppositories may not be available and for many people suppositiories are not necessary. Eating a high fibre diet and drinking three litres of water a day will make it easier to empty his bowel. At the same time every two or three days he can massage his anus, as explained above, to remove the faeces.

Always clean and wash the bottom area well after defecating.

How to defecate if the bowel is floppy

The faeces will have to be removed with the fingers because a floppy bowel will not spasm to empty the bowel. Sometimes a suppository might help to empty the faeces. Wear a plastic glove or use a plastic bag over the finger. Lubricate the glove with jelly or vegetable or mineral oil. Gently ease the finger into the bowel, turn it around and withdraw it bringing the faeces out with it. Wait a few seconds and then repeat. Continue to do this until all the faeces has been removed. The person should try to tighten his abdomen muscles to help the faeces come out.

He must not sit for long periods on a toilet or commode as this will cause a pressure sore. The whole procedure should take about 20 minutes. Always clean and wash the bottom area well after defecating. Do not strain too much as this will cause haemorrhoids.

Always be gentle when taking out the faeces otherwise the skin around his anus will tear. A tear in the skin can lead to a pressure sore (pages 7-11) and dysreflexia (page 22). If there is any bleeding from the anus he must see a doctor as soon as possible.

Always clean and wash the bottom area well after defecating.

Two ways to massage the anus and remove the faeces from the bowel are:



. Leaning forwards, reaching his anus from the front between his legs.

Complications

Constipation:

The faeces will be hard. Some brown watery faeces may leak out and stain the person's clothes. It will be difficult to remove the faeces. He may develop dysreflexia (page 22) and have more spasms. Constipation is caused by not eating enough fibre and not drinking enough water (page 25). Some drugs will also cause constipation. To remove the faeces take an extra dose of laxative. Defecate every day until a normal pattern is re-established.

Diarrhoea:

With diarrhoea there are frequent loose watery faeces. The bowel may empty suddenly and explosively. The watery faeces may leak continuously. Diarrhoea is usually caused by some illness, a abdomen upset, eating spicy foods, drinking unclean water, some medication, or too much laxative. If the person has diarrhoea it is best not to eat too much. The diarrhoea should get better within one or two days. Otherwise see a doctor. Drink lots of water to prevent dehydration.



- . Leaning to one side, reaching his anus from the side.
- . This is a better position for women because there is less chance of faeces getting into the genitals and causing an infection.

Haemorrhoids (piles):

Haemorrhoids are painful veins around the anus caused by straining too much when emptying the bowel . Haemorrhoids can be prevented by not straining too much when defecating, by not sitting on the toilet too long, avoiding constipation and removing faeces gently. If the person has haemorrhoids see a doctor, eat good food, drink three litres of water a day and be gentle when removing faeces so the haemorrhoids do not worsen.

Skin tear:

A skin tear around the anus can be caused by straining too much, by inserting suppositories incorrectly, or by removing faeces with a finger too roughly. A skin tear around the anus may increase the strength and number of spasms (pages 23-24) and cause dysreflexia (page 22). If the person has a skin tear he should increase the amount of fibre in food he eats so that the faeces are softer. He should also be more gentle when removing faeces with his finger. Because there is a possibility of pressure sores he must let the skin tear heal by keeping all pressure off the area. If the skin tear does not get better see a doctor.

2.4 Coughing

All people with tetraplegia and some people with high paraplegia will have difficulty coughing. This is because the muscles that help to cough are paralysed. Coughing is important. Coughing keeps the lungs clear of phlegm. Phlegm is a fluid which is made in the lungs. People who have difficulty coughing cannot remove phlegm and may get a chest infection. If any phlegm that is coughed up is yellow or green it is a sign of a chest infection. The person must see a doctor for treatment.

Keeping the lungs clear while on bedrest

While on bedrest the person needs to be turned regularly from side to side to relieve pressure (page 8). Turning him will also help to keep his lungs clear of phlegm. If he starts to develop phlegm in the lungs, raise the foot end of the bed two bricks high so that his feet are a little higher than his head. This will help to drain the phlegm from his lungs so that it can be coughed up and spat out. The foot end of the bed should be raised up two times each day for about 20 minutes each time. It is best to do this when the person is lying on his side. If he is still on skull traction be careful that the traction weights do not touch the floor when the end of the bed is raised. To help keep the lungs clear he must be encouraged to breathe as deeply as possible as regularly as possible.

Do not raise the foot end of the bed if he has had a head injury during the accident.

While on bedrest he will need one or two people to help him to cough. The helper must push just below where his ribs meet.

One helper assisting the person to cough in bed.

- . Place your hands just below where his ribs meet
- . ask him to take a deep breath while you count to three
- on the third count push up and backwards towards his shoulder blades
- . you push up at the same time as he coughs.



Two helpers assisting the person to cough in bed. He needs two helpers if he has large chest or very thick phlegm.



- . You place your forearm where his ribs meet and your other hand on his upper chest
- . the other helper puts both hands on his chest
- . ask him to take a deep breath while you count to three
- on the third count both helpers push the chest at the same time
- . you and the other helper push at the same time as he coughs.

Keeping the lungs clear while in the wheelchair

There are different ways for a person to cough while sitting in a wheelchair. The way chosen will depend on the level of the spinal cord injury. When coughing in a wheelchair, the wheelchair brakes must be on.

GRADE ONE AND TWO

The helper stands in front of the wheelchair.

- . Stand in front of her
- put the heels of your hand just below where her ribs meet
- . ask her to take a deep breath while you count to three
- on the third count push up and backwards towards her shoulder blades
- . you push at the same time as she coughs.





The helper stands behind the wheelchair.

- . Stand behind the wheelchair
- reach around him and clasp your hands just below where his ribs meet
- . ask him to take a deep breath while you count to three
- on the third count pull up and backwards towards his shoulder blades
 - . you pull up and backwards at the same time as he coughs.

GRADE TWO, THREE, FOUR AND FIVE

Some people at Grade Two and all those at Grade Three, Four and Five will be able to cough without help while sitting in a wheelchair. They may still need help coughing while in bed.

To cough without help while sitting in a wheelchair:

- . he takes a deep breath
- . leans forwards
- . as he leans forwards he tries to cough.
- . He must put one arm over the backrest to stop himself falling forwards and to help pull himself up.



Repeat coughing until the lungs are clear. It takes practice to do a good cough.

2.5 Pounding Headaches and High Blood Pressure

People with tetraplegia or high paraplegia may develop high blood pressure with a pounding headache. They may also sweat, shiver, have a blotchy face and a slow pulse. They may also be worried and anxious. This is called dysreflexia.

It is an emergency. The cause of dysreflexia must be removed as soon as possible.

What causes dysreflexia?

Dysreflexia is caused by a pain in the paralysed parts of the body which is not felt. The pain will usually last for a long time before dysreflexia occurs. Dysreflexia will cause a pounding headache and high blood pressure. This is the body's way of dealing with the persistent pain which is not felt.

The most common causes of the pain are a full bladder, a urinary tract infection or constipation. The pain can also be caused by kidney or bladder stones, pressure sores, an ingrown toenail, a woman's monthly period, pregnancy or childbirth.

How to treat dysreflexia?

- . The blood pressure must be lowered immediately by:
 - sitting the person up if he is lying down
 - loosing his clothing.

. Check if the bladder is full by feeling the lower part of the abdomen:

- if the bladder is full then check for twists or blockages of the catheter and remove them
- if the blocked catheter cannot be fixed remove the catheter and insert another
- if he does not have an indwelling catheter and the bladder is full, insert a catheter to drain off the urine
- drain the catheter bag if it is full
- if he has a urinary tract infection he must see a doctor who will prescribe some drugs (pages 15).
- . Check whether his bowel are constipated:

- if constipated remove faeces (page 19).

- . Check if he has pressure sores that may be developing:
 - if a pressure sore is developing keep his weight off the sore area (pages 7-11).

. If dysreflexia is caused by a woman's periods, by pregnancy or childbirth she must see a doctor.

. She must be checked by a doctor during her pregnancy (pages 86-87).

. She must have her baby in hospital (page 86-87).

2.6 Feeling Faint and Dizzy When Sitting or Standing

Feeling faint or dizzy is common amongst people who have a tetraplegic injury and some people who have a high paraplegic injury. This happens because the circulation in the paralysed parts of the body is poor. The faint and dizzy feelings are common when sitting or standing after a long period of lying in bed. These feelings may happen for a few days every time she sits or stands. For some people the feelings may last for up to one year.

How to decrease the risk of becoming faint or dizzy ?

To decrease the risk of becoming faint or dizzy after lying in bed for a long period of time, she should be sat in a semi-reclined position in bed for a week or two before sitting in a wheelchair. She stays in this semi-reclined positioned for two hours, two or three times a day. To decrease the risk of her becoming dizzy or faint when starting to stand it is best to become use to sitting first. Only begin to stand her when she does not feel dizzy or faint when sitting (pages 75-76).

If the person feels faint or dizzy:



When standing:

- Bend forwards over the table of the standing frame (pages 75-76).
- If the dizzy or faint feelings do not stop then sit in the wheelchair.
- He may need to be tilted backwards or need to bend forwards when sitting.

2.7 Why the Paralysed Parts of the Body Jerk and Jump

Why do the paralysed parts of the body jerk and jump?

As spinal shock wears off, the paralysed parts of the body may start to jerk or jump if they are moved or touched. The jerking or jumping movements of the paralysed parts of the body do not mean that voluntary movements are returning. The jerking or jumping movements are reflex movements. These movements are called spasms.

Spasms happen when the nerves below the damaged part of the spinal cord are not damaged. These nerves still carry messages about what the body is feeling to the spinal cord. However, because the spinal cord is damaged, the messages cannot get to the brain to tell the person what is felt. Instead the spinal cord sends the information back down the nerves to the muscles. This makes the muscles move. This movement is called a reflex because the movement is not controlled by the person. The movement is not voluntary. When the reflex movements continue for a short time and become a series of jerking or jumping movements they are called spasms.

Spasms are common following a spinal cord injury. Spasms are more common for people who have tetraplegia or high paraplegia. Spasms may become stronger during the first two years following a spinal cord injury. After two years the spasms should not become any worse and may even occur less often or be less strong. However, spasms will never totally disappear.

What can be done about the spasms ?

If the spasms become too strong or happen too frequently they will cause contractures. If contractures develop they will make the spasms worse which in turn will make the contractures worse. The strength and frequency of spasms can be reduced by:

- . Moving the paralysed parts of the body everyday (pages 29-31).
- . Standing in callipers or a standing frame (pages 75-76).
- . Sleeping on his front for part of the night to stretch the muscles of his hips and knees (page 8).
- . Keeping active (pages 95-98).
- . Sitting correctly in the wheelchair (pages 42).
- . Emptying his bowel and bladder regularly (pages 12-19).
- . Preventing pressure sores (pages 7-11).
- . Early splinting of the elbow if needed (page 32).
- . Wearing loose fitting clothing (page 69).

What to do if the spasms do not improve

When the previous methods do not reduce the spasms a doctor may try to use drugs. These drugs relax the muscles. If the doctor prescribes these drugs, the doctor's directions must be followed. Sometimes even drugs will be unable to reduce the spasms. Sometimes surgery may be beneficial. Surgery may involve cutting the nerves from the spinal cord. This is a drastic option and should only be considered after all other methods have failed. The side effects of surgery must be discussed with the person before any surgery is done.

Are spasms useful ?

A certain amount of spasm may stop the muscles from becoming thinner which offers some protection against pressure sores. Spasms can be used to help the person move on and off his wheelchair and can be used to help the person empty his bladder and bowel (pages 12-15).

When spasms become too strong or occur too frequently they can cause problems.

Why do the legs feel floppy ?

When some people have a spinal cord injury, they damage both the spinal cord and the nerves coming from the spinal cord. This is common for those people with low paraplegia.

When the nerves are damaged the reflex movement does not happen. Messages about what is felt do not get to the spinal cord. Messages about how to move do not get to the muscles. The muscles do not move either voluntarily or by spasms. Because the muscles do not move they will become thinner and that part of the body becomes floppy.

A person who has floppy legs needs to take extra care in preventing pressure sores because of the thin and wasted muscles of the buttocks (pages 7-11).

2.8 What to Eat and Drink

People with spinal cord injuries must eat a variety of good food and drink about three litres of water everyday to stay healthy and to manage their bladders and bowel properly.

Healthy eating

- . Eat a wide variety of foods every day.
- . Eat food which is high in fibre.
- . Eat plenty of fruit and vegetables.
- . Do not eat much fat and sugar, especially if the person is overweight.





Eat food with plenty of fibre which is found in fruit and vegetables, beans and pulses, brown rice and wholemeal flour. Fibre makes faeces soft and easier to empty and reduces the need for laxatives.

Eating food which is high in fibre will only be effective if the person drinks about three litres of fluid a day.

What to drink

Drink about three litres of water a day to keep the bladder clean and to prevent a urinary tract infection. Drinking this much water will also help to make faeces soft. The water must be clean. If the water available is not clean it should be boiled for 20 minutes and cooled before drinking.

The person may drink tea, coffee and juice instead of water.

Milk is important for providing protein and a wide variety of vitamins and minerals. Drink no more than 600 millilitres a day. More than this amount may cause problems with the kidneys.

Do not drink too much alcohol. Alcohol can cause serious problems for people with a spinal cord injury. Too much alcohol will increase the number of times needed to empty the bladder. People who drink too much alcohol may wet their clothes or bed, may forget to relieve pressure and cause a pressure sore, and may transfer on and off a wheelchair badly or fall out of the wheelchair and become injured. Too much alcohol also causes dehydration and diarrhoea.

2.9 The Joints Feel Harder to Move

Sometimes after a spinal cord injury bone will grow in the muscles and ligaments around the joints. The growth of the bone is called ossification. No one knows why this happens. It only affects a few people. The growth of the bone happens in the joints below the level of the injury. It is most common in the hip and knee joints. The joints become progressively stiffer and harder to move. The person may start to have difficulty moving on and off a wheelchair because the hip or knee will not bend enough. He may also have difficulty dressing as there may be problems bending or straightening the knee when putting his pants and trousers on. Sitting correctly in a wheelchair will be difficult. This may cause a pressure sore.

The first sign of the bone growing may be that the joint feels spongy when moving the leg. It is more likely to occur during the first four months following an injury.

What can be done about the bone growing in the muscles and ligaments around a joint?

It cannot be prevented. Gently moving the joint each day may stop the joint from becoming totally stiff. Surgery may be done to remove the bone. Surgery must not be attempted before the bone has stopped growing. This may take 18 to 24 months. If the bone is removed too soon there is a greater chance that more bone will grow.

2.10 Swollen Hands and Feet

The paralysed parts of the body may become swollen. Swelling occurs because the circulation is poor. Swollen hands and feet are common during the period of spinal shock. Swollen hands are common amongst people with high tetraplegia who are unable to move their arms. Swollen feet are common amongst those people with floppy legs. It is important to try to decrease the swelling. Swelling can cause the hands and feet to become deformed.

How to prevent and treat swelling

- . Whether in a wheelchair or in bed, support swollen hands on pillows so that the hands are higher than the elbows.
- . Wear hand splints if necessary (pages 56-60).
- . Gently move the joints of the swollen parts (pages 29-31).
- Support swollen feet higher than the knees by raising the foot end of the bed two bricks high. If the swelling goes down over night while laying in bed then it is not too serious, but if the swelling does not go down then stay in bed.
- . Keep as active as possible (pages 95-98).

Deep vein thrombosis (DVT)

If the swelling does not go down very much even after being elevated for some time, and the swollen part of the leg or foot is warm to touch, a deep vein thrombosis may have developed. This is a very serious problem. The person must see a doctor immediately and must rest in bed. The doctor will give some medication to remove the deep vein thrombosis. Do not move his leg until the doctor is satisfied that the deep vein thrombosis has disappeared.

2.11 Weak Bones and Fractures

After a spinal cord injury there is a gradual weakening of the bones of the legs because they are not being used. As the bones become weaker they are easier to fracture or break. This could happen by falling out of a wheelchair when transferring on or off it, or by being lifted incorrectly by other people. If the person has had an accident see a doctor as soon as possible who will check whether there is a fracture. A fracture may cause swelling, sweating and dysreflexia.

What happens if the person breaks a leg?

She must see a doctor as soon as possible. The leg might be put into plaster. She may have to lie in bed for some days to some weeks. While in bed she must remember to relieve pressure. She might need help to do this if her leg is in plaster. The plaster cast must be put on by someone who is experienced. To make sure the plaster cast does not cause a pressure sore the cast must be well padded. It must not be put on too tightly or too loosely. The cast may be cut in half and both halves strapped on. This is called bi-valving the cast. It means that the cast can be removed daily to check for any pressure sores which may be developing. The cast can then be strapped back on.

2.12 Pain

It is common for all people with a spinal cord injury to have some pain at the site of the injury for a few days or weeks. This pain is caused by torn ligaments, fractured bones and sore back muscles. A small number of people will have long term pain. This pain will affect what they are able to do. The pain may begin at the time of the injury or may start many months or years after the injury. Sometimes it is very hard to find the cause of the pain. Sometimes it may be due to the backbone not being straight or a nerve being squashed. Always see a therapist or a doctor for advice on how to manage the pain.

To prevent long term pain:

- . Contractures must be prevented (pages 29-36).
- . Spasms must be controlled (pages 23-24).
- . She must sit and lie in correct positions (page 8 and 42).
- . Pressure sores must be prevented (pages 7-11).
- . She must stick to her bladder and bowel routine (pages 12-19).

To treat long term pain:

- . Reassure person and offer support.
- . She must keep busy and active as the distraction will reduce the time spent worrying about the pain (pages 95-98).
- . She must stick to her bladder and bowel routine (pages 12-19).
- . Some drugs prescribed by a doctor might help to reduce the pain.
- . Surgery to straighten the backbone or remove the cause of the pain might be possible.

2.13 Staying Cool in Hot Weather and Warm in Cold Weather

The normal body sweats to stay cool in hot weather and shivers to stay warm in cold weather. People who have a spinal cord injury are unable to sweat or shiver in the parts of their bodies which are paralysed. People with tetraplegia or high paraplegia will be affected more. This is because most of their body is paralysed. So most of their body does not sweat or shiver.

Hot weather

The paralysed parts of the body may become hot in hot and humid weather. By becoming hot the paralysed part of the body will become dehydrated. This may lead to bladder problems and a high fever or heat stroke. Heat stroke is a very serious condition which can lead to death. If the paralysed parts of the body become too hot it will take a long time to be able to cool them down again.

To prevent the paralysed parts of the body from becoming too hot the person must stay in the shade as often as possible, wear a hat and wear cool clothing, avoid getting sunburnt and drink plenty of water. Spraying water over his body or using a fan will help to keep his body cool.

Cold Weather

The paralysed parts of the body may become cold in cold weather. By becoming cold he may develop chest problems, have difficulty breathing or at the very least a cold. A serious chest infection can lead to death.

When the weather is cold he must wear warm clothing. Wear several layers of clothes to keep warm. If possible do not spend too long outside. Stay inside where it is warmer. Do not sit too close to an open fire because this may cause a burn on a paralysed part of his body.

3. Promoting Independence

3.1 Moving the Paralysed Parts of the Body

See WHO Training Package 9

How to move the paralysed parts of the body?

It is very important that the paralysed parts of the body are moved every day. This will prevent contractures from developing. The movement will also help the circulation and prevent swelling. If the person is not able to move the paralysed parts of the body himself someone else must move them for him.

- . Moving the paralysed parts of the body should begin immediately after the injury while he is on bedrest.
- . The paralysed parts of the body should be moved at least once a day.
- . Because he cannot feel, the paralysed parts of his body must be moved carefully and gently.
- . Each movement should be done 5 to 10 times.
- . Each movement should be done slowly and rhymically.
- . If a movement is difficult because of spasm or contracture then move the affected part of the body more times.
- . If there is any tightness during the movement hold the affected part of the body in the stretched position for about 10 seconds so the movement becomes easier.

Before moving the paralysed parts of the body it is very important to make sure he does not have a deep vein thrombosis (DVT) (page 26).

After a spinal cord injury the circulation slows down in the paralysed parts of the body. This causes the blood to form clumps. The clumps are a DVT and may block a blood vessel. It happens most commonly in the legs soon after the injury. A sign of DVT is a localised swelling in his leg which feels warm to touch.

Do not move the paralysed parts of the body if he has a DVT. He needs to be treated with anticoagulant tablets prescribed by a doctor. Do not move the paralysed parts of the body until the doctor says it is safe to do so.

Movements while on bedrest

GRADES ONE, TWO AND THREE

If the person has difficulty or is unable to move his shoulders and arms:



- . Place his elbows forwards of his shoulders
- . cross both his arms over his chest
- . gently push each elbow towards the opposite shoulder to stretch between the shoulder blades.

. Gently push both his shoulders down at the same time.

24 C.E



If the person is unable to or has difficulty moving her elbow:



• Straighten her elbow fully while holding her wrist bent back



. bend her elbow fully.
If the person is unable to or has difficulty moving the wrist and fingers:



This is very important for people at Grade Two or Three. It helps them to hold things like a spoon (page 59-64).

Do not touch or move the skull traction when moving the paralysed parts of the body.

All the people at Grade One, Two or Three also need to have their legs moved everyday.

GRADES FOUR, FIVE AND SIX

People at Grades Four, Five or Six need to do exercises to strengthen their arms while in bed by lifting weights (pages 33-36). They should initially lift weights with both arms at the same time so that they put an even strain on the injured backbone and spinal cord. This reduces the risk of causing further damage to the spinal cord. As they become stronger they will be able to lift weights with one arm at a time.

The person will initially need to have his legs moved for him. It is very important that he does not have his legs bent at the hips more than 45° for the first six weeks. This is to protect the backbone which needs time to mend. After six weeks his legs can be bent at the hips to 90°. This is done with the knees bent. This is needed for sitting in a wheelchair. Bending his legs at the hips with the knees straight must wait until the backbone is completely mended.

People at Grade Five or Six will be able to walk using callipers. To walk well in callipers their legs must be able to move backwards at the hips. This movement needs to be done while on bedrest. To move the legs backwards while on bedrest he must be lying on his side.



- . Bend his top leg and support his knee
- . put your other hand on his hip to stop the backbone from moving
- . bend his top knee and gently pull the leg backwards.

. The ankles and feet must also be moved.

For the person to sit correctly in a wheelchair and stand correctly in a standing frame it is important that there are no contractures in the legs.

Movements when sitting in a wheelchair

Once the person is sitting in a wheelchair there may not be a need to do specific movements of the legs as long as he is active and doing things (pages 95-98). If he lies on his abdomen (page 8) and stands regularly then there will be little need to move the legs (pages 75-76).

People at Grade One or Two will need to have their arms and hands moved everyday.

3.3 Exercises

How to do exercises

To learn to move and do things after a spinal cord injury it is very important to make the muscles that are not paralysed stronger. To make these muscles stronger the person must exercise.

These muscles can be made stronger by lifting heavier weights or by lifting the same weight more often. Exercises must be taught carefully. The person must be able to repeat the exercise exactly. Teach the exercise without using a weight first. The person must be able to do the exercise without any effort before using a weight.

When choosing a starting weight it should be a weight that the person can lift ten times with some effort. The person must repeat the exercise an agreed number of times and do these exercises twice every day. The person should increase the number of times the weight is lifted first and then increase the weight being lifted.

When to start exercising

Exercises should start as soon as she is medically stable after the spinal cord injury, while she is on bedrest. The doctor must say that exercises can start.

How long to continue exercising

When the muscles that are not paralysed are strong the person will be able to move on and off the wheelchair, push the wheelchair and do many things without help. When the person is doing things without help the activity will keep the muscles strong. There will be less need to exercise unless she wishes to continue.

Exercises for the neck

GRADE ONE

Those at Grade One will need to strengthen their neck muscles. These muscles hold the head up when sitting. Once the person is off skull traction neck muscle exercises can start. Always check with the doctor before starting the neck exercises.

- . She lies on her back in bed and pushes her head into the bed without lifting up her chin.
- . She should push her head into the bed, hold this position, count to four and relax.
- . She should repeat this 10 times and do this two times everyday.
- . Increase the difficulty of this exercise by increasing the number of times she does this and by holding the push down for a longer time.

Exercises for the arms

GRADES TWO AND THREE

In the bed:

- 1. Lying on his back:
 - . His arms should by his side
 - . both elbows are bent a little
 - he straightens his elbows by turning his arms outwards so his palms face upwards.
- 2. Lying on back:
 - . tie weights onto his wrists
 - . his arms should be straight down by his sides with his palms facing upwards
 - . he lifts his arms off the bed a few inches keeping his elbows straight
 - . he lowers his arms slowly back onto the bed.

In the wheelchair:

- 1. Sitting in the wheelchair, wearing a chest strap if he is unsteady:
 - . tie weights onto his wrists
 - . he loops one arm around the push handle of the wheelchair to keep his balance
 - . he lifts his other arm away from his side, keeping the elbow straight and palm facing upwards
 - . he lowers his arm back down to his side
 - . he exercises his other arm in the same way.
- 2. Sitting in the wheelchair, wearing a chest strap if he is unsteady:
 - . he puts both forearms through loops
 - . he holds his arms away from his sides at shoulder level
 - he pulls both arms down towards his sides with his palms facing downwards
 - . he lifts his arms up slowly.



The weights can be made by filling bags with sand. The weight can be increased by putting more sand in the bags or using more than one bag. If the person is unable to hold the bags then each bag should be tied to the wrists. On the mat:

- 1. Practise rolling (page 37) and balancing (page 36).
- 2. Sit on a mat with her legs stretched out to the front
 - place her arms by her side with hands on mat beside her buttocks
- . her arms are fully straightened with her elbows locked
- she pushes down with her shoulders to lift her buttocks off the mat.

GRADES FOUR, FIVE AND SIX

On the mat:



- . He sits on mat with legs stretched out to the front . he pushes down on the lifting blocks while
- . he holds the handle of a lifting block in each hand
- . he places lifting blocks beside his buttocks





- he pushes down on the lifting blocks while straightening his elbows and bending his head forwards
- . his buttocks should lift off the mat
- . he must repeat this exercise as many times as possible
- . with his buttocks off the mat he may move them forwards, backwards or sideways.

In the wheelchair:

1. Sitting in the wheelchair:



- . She puts the wheelchair brakes on
- . she holds the armrests or wheels of the wheelchair
- . she pushes down on to lift her buttocks off the cushion
- . she lifts her buttocks off the cushion for the count of four
- . she lowers her buttocks slowly back onto the cushion.
- To make it more difficult she can increase the number of times she does it and then increase the length of time her buttocks are off the cushion.
- 2. Sitting in the wheelchair:
 - . She exercises her arms using a pulley system (page 34).
 - . She can hold the loops and either exercise one arm at a time or both arms together.

Exercises to improve sitting balance

At first, most people who have had a spinal cord injury will find it difficult to sit without falling over. This is because some or all of the muscles which help them to sit are paralysed. They will also be unable to feel how they are sitting. Most people can improve their balance. They can learn to sit by supporting themselves with their arms, and they can learn to balance by moving their head, shoulders and arms.

When practising sitting balance (see page 5):

- . She sits on a bench, feet flat on the floor, thighs well supported at 90 degrees.
- . When she first practises sitting a helper should stand close behind her. The helper should be ready to hold her if she loses balance.
- . She should try to support herself sitting on a bench using her arms.
- She should try to find the best position for balancing by moving her head and shoulders until she is stable.
- . If possible she should sit in front of a large mirror so she can see how she is sitting.
- . When she feels stable the helper can stop holding her but should stay behind her in case she falls.
- . If she learns to sit and balance without help then she must practise moving her arms while keeping her balance.
- . When she can balance and move her arms she should practise with her eyes closed as this will be much more difficult.
- . Practise balancing for 15 minutes two times a day;
- by practising every day she will reach her highest Grade of balance (page 5) within two to three months.

3.4 Learning to Roll and Sit Up

See WHO Training Package 11

Learning to Roll

GRADE ONE

The person will be unable to roll without help.



Once the person is on the side you must position the underneath shoulder slightly forwards. This stops the person from rolling onto their front and reduces the pressure between their shoulder blades.

GRADES TWO AND THREE

When rolling to her right:



- . Cross her left leg over her right
- . she places both arms over to her left side



- . she throws both arms over to her right side
- at the same time she lifts her head up and towards her right so she lays on her right side.

GRADES FOUR, FIVE AND SIX

People at these grades may find it easier to cross their legs first. They can roll over by pulling themselves in the direction they want to go.

Learning to sit up

To learn to sit up without help the person will need to practise a lot.

GRADE ONE

Those people at this grade will need help to sit from lying down.

GRADES TWO AND THREE

Sitting from lying down using loops:



- . He places his right forearm into the side loop
- . he pulls on this loop so that he turns to his right side to lean on his right elbow
- . he must bend his head towards his right side
- he places his left forearm into the loop which comes from the bottom of the bed
- he pulls himself forwards by raising his left forearmhe balances on his right elbow



he takes his left arm out of the loop and throws this arm behind himhis left elbow must be straight with his left hand on the bed



- . he leans over onto his left arm
- . he straightens his right arm
- he slowly pushes himself into a sitting position
- . he must bend his head and shoulders forwards.

GRADE THREE AND FOUR

Sitting from lying down using a rope ladder:

- . She may find it easier to sit in bed using a ladder made of rope which is attached to the end of the bed
- she pulls himself up by pulling on the rungs of the ladder with her wrist bent backwards or with her forearms
- she may need to lean on one elbow as she pulls herself up



Lying to sitting by rolling onto the left side:



• He rolls onto his left side by turning his head towards his left side and throwing his right arm across his body



- he brings his right arm across so that both his elbows are on the floor
- . he 'walks' on his elbows towards his legs
- he 'walks' towards his legs until his trunk is at right angles to his legs



. he hooks his right forearms over his right thigh



• he pulls himself into sitting with his right arm and pushes with his left arm.

Sitting from lying this way will take a lot of practice.

Lying to sitting by using her wrists to get onto her elbows:



. She pushes both her wrists under her thighs with her palms facing downwards



 she pulls on her wrists to bend her elbows while pushing her head and shoulders forwards



. she pushes her weight from side to side and brings her elbows in and backwards



. she throws her right arm behind her and straightens it putting her palm downwards



• she balances on her left elbow and brings her right arm across her trunk



• she balances on her right hand and brings her left arm across her trunk



- she throws her left arm behind her and straightens it, putting her palm downwards
- . she slowly pushes her body more upright while bending her head and shoulders forwards until she is sitting.

Sitting from lying using this way will take a lot of practice.

GRADES FOUR, FIVE AND SIX

Sitting from lying:



- . He puts his elbows out to the side and pushes down
- . he bends his head and shoulders forwards



- . he brings his elbows in so that he lifts himself onto his elbows
- . he holds his head and shoulders forwards



• he places his right arm behind him and straightens it



. he leans on his left elbow and balances



- . he leans on his straightened right arm and balances
- . he places his left arm behind him and straightens it
- he pushes his body more upright with his head and shoulders forward until he is in sitting.

Sitting from lying using this way will take a lot of practice.

3.5 Choosing and Using a Wheelchair

Most people who have had a spinal cord injury will need to use a wheelchair to move around.

Choosing a wheelchair

- . The wheelchair that is most suitable has big back wheels and small front wheels.
- . The wheelchair must have brakes that lock the large wheels when they are on.
- . The wheelchair must support the paralysed parts of the body but allow the freedom to move the parts of the body which are not paralysed.
- . The person must always sit on a supportive cushion to prevent pressure sores (page 9).

Maintenance

- . Keep the tyres pumped up or use solid tyres.
- . Replace back canvas and bottom canvas when they begin to stretch and sag.
- . Oil all the moving parts of the wheelchair regularly.
- . Wipe down the wheelchair frame and seat regularly to keep it clean.

Size

The wheelchair must be the correct size for the person. This makes it easier to push, gives better support and reduces the risk of pressure sores. A wheelchair which fits the person will enable him to do more for himself.



Types of wheelchairs

There are many different styles of wheelchairs. In many situations there will be a limited choice of wheelchairs for people with spinal cord injuries. Whatever wheelchair a person is given it is important that he fits into it comfortably. A wheelchair is his main means of moving around. A wheelchair replaces his legs. The wheelchair must be able to be pushed by him easily. If he cannot push the wheelchair by himself then the helper must be able to push the wheelchair easily. The wheelchair must not cause pressure sores.

Many of the following wheelchairs have been designed by Motivation (page 102) to meet the needs of people in different countries.



- A wheelchair with a frame that is not collapsible is stronger.
- . The frame can be made from water pipes.
- . The rear wheels can be made from rickshaw or bicycle wheels.
- The solid seat can be changed into a commode (page 17).
- . Flip-up footplates make it easier for the person to transfer on and off.



- This wheelchair has a steel frame, adjustable backrest, fixed footrests and rear wheels that can be fixed either more forwards or more backwards to change the chair's centre of balance.
- . When the rear wheels are set forward the chair will tip backwards more easily which is useful for a very active wheelchair user.
- . If the person has poor balance then the rear wheels should be set backwards.

- Wheelchairs that have a folding frame may be easier to put in a car or on a bus and carts when being transported.
- The person needs to check the nuts and bolts on this wheelchair regularly as they may come loose when moving over rough ground.





- A wheelchair for a child should be smaller so that it fits his size.
- The push handles should be high so that an adult can push it without bending over.

- This wheelchair can be made with a wooden or steel frame.
- . Three wheels are less stable than four wheels but this makes it easier to push the wheelchair over rough ground.
- . The solid seat is an ideal surface for cushions.



- A wheelchair with the large wheels in front is easier to push over rough ground.
- . It is more difficult to transfer onto and off.
- . It is heavier than the other types of wheelchairs and does not fold up.
- . It can go up and down low kerbs without the need to be tipped backwards.





- Some people may prefer a bicycle-type wheelchair.
- . These wheelchairs are useful for travelling long distances and for moving over rough ground.
- These wheelchairs are only suitable if the person can transfer on and off it without assistance and can hold the handles firmly.

Learning to move a wheelchair

GRADE ONE

Those people at Grade One need the back canvas of the wheelchair to be at least as high as the bottom of their shoulder blades. Sometimes the back canvas needs to be higher.

To help them sit in a wheelchair without loosing their balance, these people may choose to:



Those at Grade One will not be able to push the wheelchair by themselves. They will depend on other people to push the wheelchair. You will need to know how to push the chair.

Tipping the wheelchair backwards:

- You need to tip the wheelchair back onto the large rear wheels, so that the front casters are off the ground, to be able to move the wheelchair over uneven ground or to go up and down a kerb.
- To tip the wheelchair you need to stand on one of the tip bars while holding on to the push handles of the wheelchair.
- Always tell the person when you are going to tip the wheelchair backwards.

Going up a kerb:



- . You need to face the kerb
- tip the wheelchair back onto the large rear wheels so that the front caster are off the ground
- . push the wheelchair forwards and then lower the front casters onto the top of the kerb
- . push the wheelchair forwards so that the rear wheels move onto the top of the kerb.

Going up steps:

. Tip the wheelchair back onto the large wheels and pull the chair up the steps backwards one at a time.

. Two helpers may be needed to do this.

Going down steps or a kerb:

- . Tip the wheelchair back onto the large wheels and lower the chair down forwards one step at a time.
- . Heavier people need two helpers to lower the wheelchair forwards down a number of steps safely.
- . If going down one step, heavier people may need their wheelchair to be turned around and rolled down the step backwards.

Going up and down a hill:

. When pushing a wheelchair up or down a very steep hill zigzag the wheelchair from side to side.

. This is easier than pushing the wheelchair straight up or down.

GRADE TWO

- . A person at this level may be able to push over a flat surface with inner tubes wrapped around the rims of the wheelchair.
- . This will help her to push the wheels by preventing her hands from slipping off the wheels.
- She should wear gloves to protect her hands from injury when pushing (page 60).
- . She will need help on rough ground and when going up and down steps and slopes.



• To move forwards she pushes on both rims at the same time.with the heels of her hands.



. To turn to the right she pushes forwards on the left rim and backwards on the inside of the right tyre.

GRADE THREE

- . A person at this grade will be able to push over flat ground more easily than a person at Grade Two.
- . She still needs to wear pushing gloves to protect his hands and to make pushing easier.
- . She will be able to push the wheelchair up and down small slopes but will have difficulty over rough ground.

GRADE FOUR

- . The person will be able to push up a gentle slope and tip the wheelchair onto the rear wheels.
- . She may learn to balance on the back wheels.
- . At first she must practise this with someone behind who will stop the wheelchair tipping over.

To balance on the back wheels of the wheelchair:



. first she pulls backwards on the rear wheels of the



. then she quickly pushes the wheels forwards moving her head and shoulders forwards.

GRADES FIVE AND SIX

- . A person at either of these grades will be able to push the wheelchair up and down steeper hills.
- . When pushing up a hill he must lean forwards to stop the wheelchair tipping backwards.
- . When moving down a hill he must balance on the rear wheels as this is easier.
- . Pushing the wheelchair while balancing on the rear wheels makes moving over rough ground easier.



. She tips her wheelchair backwards to go up a

. He balances on his backwheels to go down a kerb or steps.



Going up a flight of stairs:

- . The steps must be deep enough to balance on.
- She will need help when she first tries to do this.
- . You hold the push handles and pull the chair backwards
- . she pulls on the stair rail with one hand
- she pulls back on the wheel with her other hand.

3.6 Moving On and Off a Wheelchair

Back care for helpers

Helping someone who has a spinal cord injury to move on and off a wheelchair will put a strain on your back. You must know how to look after your own back and learn to lift properly.

Before helping him to move off the wheelchair you must:

- . Place the wheelchair in the correct position.
- . Check that there is nothing in the way to trip over.
- Stand with your feet apart either with one foot in front of the other foot or set astride, whichever makes it easier to move his weight.
- . Keep your back straight and do not twist to one side.
- . Bend your hips and knees before lifting and use your powerful leg muscles to take any weight.



Use a sliding board or a transfer belt (page 51) if possible to lessen the strain on your back when transferring him.

You must be aware that you can damage your back by not lifting properly. If you develop a pain in your back then you should not lift. You must ask other people to help so you can rest your back. If you have pain in the small of your back or pain in your buttocks and down either leg you must lie down in a comfortable position for short periods during the day. You should take short walks until the pain goes away. You must try to find out what caused the pain. Then you must change the way you lift to avoid problems in the future.

You must see a doctor if the pain does not go away within two to three weeks.

Before transferring a person from or onto a wheelchair:

- . Position the wheelchair in the correct place;
- . Check that the person will be in the right place at the end of the transfer
- . Make sure that there is nothing in the way.
- . Make sure that the place the person is moving to is safe to sit on and will not damage the paralysed parts of the body.
- . Remove or swing away the footplates of the wheelchair.
- . If possible remove the armrest from the wheelchair.
- . Make sure the wheelchair brakes are on and the front castors are facing forwards.

During the transfer:

. Make sure the person can return to the wheelchair if necessary.

After the transfer:

• A person who needs help to be transferred must not be left until he is sitting with support or is lying down.

How to move on and off a wheelchair

GRADE ONE

All those at Grade One will need help to move on and off the wheelchair.

Two helpers lifting a person on and off his wheelchair:

- One helper stands behind the wheelchair and crosses the person's arms holding onto the his outer forearm
- this helper grips the person's chest with her forearms - do not grab the person under his shoulders
- . the helper places her knee which is closest to the bed, onto the bed
- the second helper puts one arm under the person's thighs and her other arm below his knees and lifts the person's legs
- both helpers must lift at the same time.

Stand lift transfer when moving to his right:



. pull his buttocks forwards and

legs as you stand him

• turn him around to his right

. hold him close to you

at the same time push on his knees

with your knees to straighten his

. shuffle your feet to move his feet

upwards



- . Place his feet on floor
- hold his knees together with your knees
- lean him forwards so his chin is on your shoulder
- his arms hang down in front of him
- bend your hips and knees and keep your back straight
- . put your hands under his buttocks

- when he is turned prepare to lower him onto the bed
 hold his knees between your knees
- lower him by bending your hips and knees
- slide your right hand up to his upper back
- . make sure he is either sitting with support or lying down before letting him go.

The pictures show the person being transferred when the wheelchair is facing the seat so that it is clear how you hold the person. It is safer and easier to place the wheelchair beside the seat or bed when transferring him. Always sit him in a chair with a backrest and armrest so his body can be supported.



If he is able to move his shoulders his arms may be placed over your back. If he is unable to move his shoulders his arms should hang down in front of him and not over your back. Placing his arms over your back when he has no shoulder movement may damage his shoulder joints.



GRADE TWO

Transfer him by stand lift transfer. This is similar to moving a person at Grade One. The main difference is that his arms hang over your shoulders and down your back as the person probably has some shoulder movement.

Alternatively move him by using a sliding board and transfer belt. You may only need to keep his balance while the person slides sideways across the sliding board.

GRADE THREE

Learning to move using a sliding board with his feet up when moving to his right:



- . He pushes his left hand behind his left buttock
- he pushes his left buttock forwards
- . his right arm is hooked around the right push handle
- . he leans his head and shoulders backwards



- to push his trunk forwards he pushes on the inside of the left tyre with the back of his left hand
- he pulls forwards with his right wrist under his right thigh
- . he pushes his head and shoulders forwards



- . he holds onto the left push handle with his left wrist
- he pushes his right forearm under his right thigh



- he holds his right thigh while he pulls himself back with his left wrist, then his left elbow
- . he places his right foot on the bed
- the sliding board is placed under his right thigh
- . he straightens his right leg



. he lifts his left leg the same way as he lifted his right leg



- he leans forwards and puts his left hand close to his side and his right hand a little away from his body
- with his elbow straight he uses his shoulder movement to slide across the board.

The above drawings show the person transferring from a wheelchair without armrests. However the person can initially practise lifting his legs onto the bed with the armrests in. He can use the armrests to help pull himself forwards. When tranferring on and off a wheelchair the armrests should be removed if possible.

Learning to move with or without a sliding board with her feet down when moving to her left:



- . She removes or swings away the footplates
- . she places her feet on the floor
- she moves her buttocks forwards to sit on the front of the wheelchair
- if using a sliding board she puts it under her left buttock

GRADE FOUR



- she lifts her buttocks up and moves towards the bed
- . her feet stay on the floor



- she lifts her legs one at a time onto the bed
- she must support herself by holding onto her wheelchair with her left hand while lifting her legs with her right hand.

As for Grade Three but will most probably be able to do it without a sliding board.

GRADES FIVE AND SIX

People at Grades Five and Six will have no paralysis of their arms and hands. Moving on and off a wheelchair will be possible either using a feet down method or lifting the feet up first. The feet down method is usually preferred. These people will usually not need to use a sliding board.

It will also be possible for these people to transfer on and off a wheelchair with fixed armrests or with the large wheels at the front, without assistance. This transfer needs to be done quickly to be safe.

When moving to his right:



- . He lifts his buttocks forwards
- . he places his feet on the floor
- he places his right hand on the bed in front of himself
- . he places his left hand on the left tyre or armrest



- he lifts himself up to bring his buttocks forwards and off the wheelchair to clear the right large wheel
- . he turns his shoulders towards the right and quickly leans his head and shoulders forwards
- . leaning his head and shoulders forwards moves his buttocks back onto the bed.

People at Grades Five and Six can move on and off their wheelchair onto the floor.

Moving off a wheelchair onto the floor:



- . He leans to the right side while pulling out the cushion
- . he removes or swings away the footplates
- . he places the cushion on floor



- . he moves to the front of seat
- . he moves his feet forwards
- . he lifts himself up by pushing on the sides of his seat



. as his buttocks moves forwards off the edge of the seat he leans his head and shoulders backwards



. he lowers herself down onto the cushion.

Moving back onto the wheelchair from the floor:

. When lifting up to move back onto the wheelchair he must lean his head and shoulders backwards . he lifts by pushing on the sides of the seat



- . he pushes down on the side of the seat to lift his buttocks off the cushion
- when his buttocks are the same level as the seat he must bend his head and shoulders forwards to move his buttocks back onto the seat



he folds the cushion in half he places the cushion between the wheel and his thigh



he lifts his buttocks off the seat
the cushion unfolds
he lifts and wriggles to get the cushion in the correct place.

GRADE SIX

People at Grade Six will also be able to move on and off the floor a different and quicker way:



- . She removes or swings away the footplates
- she places her feet on the floor
 she moves her buttocks forwards
 she d forwards to lift her
- and to her left . she removes the cushion and places it on the floor
- . she bends forwards and puts





. she lowers her body to the floor.

To sit back on chair she must bend forwards while pushing down on the floor with her left hand and on the wheelchair with her right hand.

Moving onto and off a wheelchair without help takes a lot of practice.

3.7 Using Paralysed Hands

Splinting

People at Grade 1, 2 or 3 need to have their hands placed in a good position and wear hand splints. This is to prevent deformity. Some splints will help people at Grade 2 or 3 to do things.

GRADE ONE

People at Grade One will have no movements of their arms or hands. It is not essential for them to wear a splint. It is more important that the arms and hands are placed in a good position whether lying in bed or sitting in a wheelchair. This will prevent contractures and reduce swelling.



- . Place a small towel or rolled up bandage under the hands so they do not become too flat.
- . Support the arms on a pillow or on the wheelchair tray (page 46).
- . Do not let the arms hang down.
- . To prevent deformity it is also important that the arms and hands are moved every day (pages 29-31).
- . If the hands becomes swollen, the hands and arms should be raised (page 26).



People at Grade One will need to use a mouthstick to be able to do things (page 61).

GRADE TWO

People at Grade Two will be able to bend their elbows but will not have any wrist or hand movement. By wearing a splint to support their wrists they will be able to use their hands to do things like push a wheelchair, brush their teeth and hold a spoon.



A leather wrist extension splint will support their wrist.

This splint should have a leather pocket added to the strap crossing the palm of the hand. This pocket is used to hold cutlery and other items.

The person should wear this splint during the day so she can use her hands. She must make sure that the splint does not cause any pressure sores. How to make a wrist extension splint for the back of the forearm and hand.





- . Use three 2.5 cm wide leather straps one to wrap comfortably around the forearm, one to wrap comfortably around the wrist and one to wrap comfortably around the hand
- . The three straps are sewn on top of a 3.5 cm wide leather strap which runs from the knuckles to 2/3 length of forearm



. Sew a second 3.5 cm strap on top of the first



- . Slip a metal or aluminium bar between the two straps.
- . This splints fits on the back of the hand
- The metal or aluminium bar should be bent so that the wrist is bent backwards to approximately 30° .

How to make a wrist extension splint for the front of the forearm and hand.



- place the wet splint on the forearm and handmake sue that the hole for the thumb is big enough
- . bandage the splint onto the forearm and hand



- . remove the bandage and the splint from the forearm and hand
- . attach three velcro straps or buckles and straps to the splint - one over the forearm, one over the wrist and one over the hand
- . slip a metal or aluminium bar into the leather strip

leave the splint bandaged to the forearm and hand until the splint has almost driedthe splint must be almost dry to keep it's new shape



when the splint is dry the person can wear it.
The metal or aluminium should be bent so that the wrist is bent backwards to approximately 30°.

GRADE THREE

People at Grade Three will be able to bend their elbows. They will also be able to bend their wrists back. They will have very little or no active movement of the fingers and thumbs. However they will be able to open and close their fingers and hold things by moving their wrists.



. By dropping the wrist the fingers and thumb open.



. By bending the wrist backwards the fingers close and the thumb touches the side of the index finger.

It may take several weeks after an injury before the thumb touches the index finger. It is important that the joints of the hands are moved correctly (page 30).

If the thumb will not touch the side of the index finger then a thumb strap may be useful. This strap holds the thumb in the correct position. It only needs to be worn when the person is using her hands. After some time the thumb should be able to touch the side of the index finger without the splint. When this happens she will not have to wear the splint again.

How to make a thumb splint:



- . Sew a loop to go around base of thumb
- . the webbing must be long enough to wrap around wrist
- . sew two D-rings onto webbing so that they will be on the back of the wrist



The strap does up through the D-rings on the back of the wrist.



- . place the loop over the thumb
- . the strap crosses the heel of hand and wraps around wrist
- . when the wrist is bent backwards the thumb is pulled towards the index finger
- . when the wrist is bent forwards the thumb moves away from the index finger.

GRADES TWO AND THREE

People at these Grades may not have good feeling in their hands. To protect their hands from being cut and injured when they push their wheelchair they must wear pushing gloves. These are leather gloves which are made to wrap around their hands.

Normal gloves may be used with the fingers cut off. Normal gloves will be harder to put on because these people have no finger movement. Cycling gloves may also be used.



Back view with pushing glove on.



Person using the pushing glove to hold a spoon.

See page 47 for pushing gloves used to push a wheelchair.

Doing things with paralysed hands

See WHO Training Package 14

GRADE ONE

The person will not be able to use his hands. To do some things for himself he will need to use a mouthstick. He should have several mouthsticks made in case he drops one. They should be placed on a stand on a table so he can reach them easily with his mouth.



. The person may drink without help by using a straw with the cup placed on her wheelchair table or an ordinary table.



GRADES TWO, THREE AND FOUR

The following are suggestions of ways which people at Grade Two, Three and Four can use their hands to do things for themselves.

Drinking

.



She holds a cup with two hands.



. She bends her wrist back to close her fingers and thumb to hold cup.



Eating



62

Attach a leather strap to the brush.His hand slips under the leather strap.This makes it easier to hold the brush.

Brushing teeth



- She uses two hands and her teeth to undo the toothpaste cap.She squeezes the toothpaste into
- her mouth.



Shaving

- . He holds the razor with two hands.
- . The razor may also be placed in a palmar cuff.



Writing

How to make a writing splint:



- . Take a length of 2.5 cm wide elastic
- . sew a loop to hold the pencil or pen



. sew a loop for the index

finger



. sew a loop for the thumb.

The pencil is placed in the pencil loop. The person then slips the index loop over his index finger and thumb loop over his thumb to hold the pencil while writing.

Cooking



- . Bowls with handles are easier to lift.
- . Large handles on pots make them easier to lift.

If she has no or little feeling in her hands she should not touch hot cooking equipment. If she does she is likely to burn her hands and cause a sore.

3.8 Washing

See WHO Training Package 14

Washing daily is an important part of living with a spinal cord injury. Keeping the body clean, particularly around the buttocks and genitals is necessary to prevent infection and pressure sores. The person must wash after defecating. People who have tetraplegia will require help and some equipment to wash themselves. Most people who have paraplegia will wash themselves without help but may require some equipment.

Different ways to wash

GRADES ONE, TWO AND THREE

If she is unable to sit on a commode, requires lots of assistance or does not have space to wash in her bathroom it may be easier to wash her on the bed.

- . Line the bed with towels to prevent the mattress and bedclothes from becoming wet.
- . If the mattress and bed clothes do become wet then they must be thoroughly dried before she sleeps in the bed.
- . She must be washed thoroughly when having a bed bath.

GRADES TWO, THREE, FOUR, FIVE AND SIX

If he is able to sit, a chair or a commode can be used for washing. A commode has a hole in the seat. This hole makes it easier to clean the buttocks and genitals (page 17).

If the wheelchair seat is adapted it is possible to use the wheelchair as a commode (page 17). However the wheelchair must be completely dry before using it as a wheelchair. In hot countries the wheelchair can be put in the sun to dry while he is dressing.

It is very important that he checks the temperature of the water before having a wash. Water which is too hot can cause burns to the skin.





Equipment for washing

The following are suggestions of equipment which people with spinal cord injury can use to wash themselves.



. A small scoop or saucepan may be used to pour water over his body.





- . A cotton or nylon rope can be threaded through a hole drilled in the soap.
- . The soap can then be hung around her neck while she is washing.



. Shampoo or soap in squeeze bottles may be easier to use.


- . A long handled bath sponge or brush can be used to wash the back, legs and arms.
- . A cotton webbing strap may be added to the end of the handle to wrap around her hand if she cannot hold it.





Tips for washing

- . Before starting to wash make sure everything that the person needs is within easy reach. He or his helper must be able to reach the water, soap, shampoo and towels easily.
- . Always check that the water is not too hot before washing. Hot water will burn and he will not be able to feel it on the paralysed parts of his body.
- . When using a sliding board to transfer on and off the commode or bench put a towel over the board. This will stop his naked skin from rubbing on the board and causing a sore.
- . When sitting on a commode, bench or in a bathtub, relieve pressure every 10 to 15 minutes.
- . If he has difficulty washing his buttocks and genitals properly while sitting he should do these areas back on the bed.



. To reach her feet she may be able to lean forwards while holding onto the backrest with her other arm. If she has good balance she can reach her feet by bending forwards until her chest rests on her thigh.



. If he has good balance and his spasms are not severe he can cross his legs. This will make it easier to wash under his thigh and to wash his foot.

- . All soap must be thoroughly rinsed off his body to avoid skin irritation.
- . Placing a towel over the seat of his wheelchair is an easy way for him to dry his back and buttocks.
- . Placing a towel on the floor or on the footrests is an easy way to dry his feet.
- . If he transfers back onto his bed for dressing, a towel over the bed can dry him further.
- . He must be completely dry so his skin does not break down.
- . After he washes but before he dresses is a convenient time to check his skin for any marks or sores (page 11).
- . His toenails should be trimmed regularly. A good time to do this is after a wash when the toenails will be easier to cut. This prevents them from becoming ingrown or too long and causing problems with footwear. Ingrown toenails may increase spasms (page 23-24) and cause dysreflexia (page 22).

3.9 Dressing

See WHO Training Package 14

Learning to put on and take off clothes after a spinal cord injury may take a long time. It will take many hours of practice.

Some people with tetraplegia will need help to dress and undress. Some people with tetraplegia may prefer to have another person dress and undress them even though they could do it themselves. It may be quicker for someone else to do it. Other people with tetraplegia may want to dress and undress themselves.

All people with paraplegia should be able to dress and undress without help.

Tips for dressing

- . Wear loose fitting clothes. Clothes should be at least one size larger than the clothes he normally wears. Loose clothing is easier to put on and take off.
- . Trousers should not have thick seams or pockets at the back. These may cause pressure sores when he is sitting down.
- . If his trousers have back pockets he must never put anything in them, such as coins or a comb. This will cause a pressure sore. Instead, he should use a waist bag or a bag attached to the wheelchair in which to carry things.

Equipment for dressing

. If he is unable to move his fingers loops sewn onto trousers, pants, zippers, socks and shoes may make it easier for him to pull his clothes on.





. An overhead strap or straps from the sides or foot of the bed may be useful during dressing.

How to dress and undress

There are many different ways to dress and undress. The following are examples of what may work. The person should try different ways to see what works best. For some people it will be easier to dress and undress in the wheelchair. For others it will be easier on the bed. Others will use both the wheelchair and the bed.

Putting on and taking off shirts and dresses

Over the head:



. He places the shirt face down with neckline nearest his knees



he holds the neckline of the shirt, lifts both arms up together and puts the neckline over his head





. he puts his arms in the sleeves one at a time - he may use his teeth to pull the sleeve over his hands



. he pulls the neckline down over his head



. he pulls each sleeve up his arms past his elbows



. he puts one hand underneath the front of the shirt and then pulls it down

. he pulls the back of the shirt down by leaning to one side and putting his hand underneath the back of the shirt.

To remove the shirt or dress:

- . She puts one hand inside the shirt and pushes off the opposite sleeve
- . she does the same to the other sleeve
- . she lifts the shirt over her head.



Around the back:

This way can be used to put on shirts and dresses which button up at the front. To use this way she must be able to lean forwards and sit up straight without support.



- . She holds the shirt by the collar with her right hand
- . she puts her left arm through the sleeve
- she pulls the sleeve up her arm and the collar around the back of her neck



. she lifts her right arm up and out to the side so that the sleeve slips onto her arm



- . she reaches behind with her right hand to find the other sleeve
- . she pushes her hand and arm into this sleeve



- . she does up the buttons.
- . She may use a button hook to do up and undo the buttons (page 70).

To remove these garments she reverses the way she put on the shirt.

Putting on clothes that wrap around the body:



- . She puts on her undergarments while sitting on the bed
- she drapes the clothes which wrap around her over the wheelchair



- she moves onto the wheelchairshe wraps the
- clothes around her body
- she must make sure there are no wrinkles on the parts of the clothes she is sitting on.

Putting on and taking off pants and trousers

To put on and take off pants and trousers the person must be able to sit in bed with the legs straight or on a wheelchair without support. Loops sewn onto pants and trousers may help those who have a weak grip (page 69).



To pull pants or trousers over her hips it will be easier in bed. However if she has good balance she can do this while sitting in a wheelchair.



It may be easier for her to pull up pants and trousers in bed if there is an overbed strap or straps attached to the side of the bed (page 38).

Pants and trousers can be removed by doing the reverse of putting them on.

Putting on and taking off socks and shoes

Socks:

Socks may be put on by either leaning forwards with legs straight in the bed, or by crossing one leg over the other, while either sitting on the bed or on a wheelchair. The person can use the same way in which trousers and pants are put on to put on socks (page 73).

It may be easier to pull socks on if a loop is sewn onto them (page 69).

Shoes:

Shoes may be put on the same way as socks.

It may help if a loop is attached to the rear of the shoe (page 69).

The laces should not be done up tightly. If the person is unable to do up laces, the laces can either be left loosely done up, or the person buys slip-on shoes or shoes with Velcro tabs.



3.10 Standing

Why stand ?

Standing is very important because it:

- . Straightens the person's hips and knees.
- . Keeps the person's feet in a good position.
- . Reduces the number and the strength of spasms the person may have.
- . Facilitates emptying of the person's bladder and bowels.

Who should stand ?

Everyone who has a spinal cord injury should stand. It will be difficult to stand those people at Grade One. People at Grades One, Two, Three and Four will only be able to stand in a standing frame. They will need at least two people to help them into the standing frame. People at these grades will only be able to stand. They will not be able to walk.

People at Grades Five and Six will start standing in a standing frame. After at least three to four weeks of standing in a standing frame they can practise walking between parallel bars while wearing callipers (pages 77-84).

When to start standing

GRADE ONE AND TWO

Start standing when the person is able to sit in wheelchair without feeling dizzy for up to seven hours. Usually about six weeks after getting out of bed.

GRADE THREE, FOUR AND FIVE

Start standing after four to six weeks of balancing exercises.

GRADE SIX

Start standing after two weeks of balancing exercises.

How long should the person stand ?

Stand for at least one hour two times a week as a minimum.

Some people like to stand. They may prefer to stand every day.

Not everyone wants to stand. Although they should be encouraged they should never be forced.

Standing in a standing frame

Before standing:

- . Remove or swing away the footrests
- . push the wheelchair up to the back of the standing frame
- . put the wheelchair brakes on
- . he must wear shoes
- . place his feet, with shoes on, flat on the floor
- . buckle the strap which goes behind his feet
- . buckle the strap which goes just below and in front of his knees.

To stand:

- . Lift him up from the wheelchair
- . lean him forward over the table of the standing frame
- . his chest should lie on a pillow on top of the table
- . his arms should hang down in front of the table
- . his legs must be straight
- . buckle the strap which goes behind his buttocks
- . lift his chest off the table so he is standing upright
- . he should help by pushing himself up with his arms
- . he should lean on his hands with his arms straight to stay upright.

If he becomes dizzy when he is standing he should:

- . Lean forward so his chest is on a pillow on top of the table and his arms hang down in front of the table
- . he should lean forward for two to three minutes
- . after this he should stand upright again
- . if he becomes dizzy again he should lean forward
- . if he continues to feel dizzy he should sit down in his chair
- . he should try to stand again later in the day or try again the next day.





3.11 Walking with Callipers

Only those people at Grade Five and Six or those with an incomplete spinal cord injury will be able to walk. They will need to wear callipers and use crutches. Callipers are made by orthotic technicians. Some will find walking in callipers and crutches takes too much effort and prefer to use a wheelchair. Some will walk for exercise but will use a wheelchair for moving around. Most people will use long leg callipers. Some people at Grade Six will use short leg callipers.

All walking must be taught in the parallel bars before practising with crutches. When the person is safe between the parallel bars, practise walking with one crutch and one of the bars. When the person is safe doing this, practise walking with two crutches.

If the person is going to walk with callipers and crutches everyday, then the callipers should be put on every morning when dressing. The callipers must be put on correctly. If the callipers are put on incorrectly, they will cause a pressure sore.

Begin by wearing the callipers for one hour a day, remove them and then check for any skin damage. Gradually build up the length of time the callipers are worn each day. By the end of four weeks the callipers should be worn all day as long as there are no skin problems. If the callipers cause a pressure sore or rub the skin then the orthotic technician needs to make adjustments to them so they fit correctly.

To learn to walk the person will need to do a lot of practice.

Standing between the parallel bars

- . At first the person will need to learn to stand with help from a wheelchair using the parallel bars.
- . Remove or swing away the footrests of the wheelchair, place the wheelchair at one end of the parallel bars and put on the wheelchair brakes
- . make sure that the callipers are on correctly and done up securely



- . stand in front of him and place your hands under his buttocks
- . he moves his buttocks forwards so that he is sitting on the front edge of his wheelchair
- . he leans forwards and places his hands on the parallel bars with his elbows raised high



- . he pushes down on the bars and lifts his body
- . you help by lifting under his hips
- . as he lifts himself up his feet will go back
- . you hold his hips forwards as he gets his balance
- . he must try to push his hips forwards to stop himself from falling forwards.



. Long leg callipers



short leg callipers

Before learning to walk

After standing between the parallel bars he must learn to balance. It will take time to balance on his legs which he is unable to feel. At first he will need help.

To learn to balance:

- . Push his hips forwards to stop him falling forwards
- . when ready he should lift one hand off a parallel bar and hold it out in front
- . he then tries to balance
- . he puts his arm down and lift up his other arm
- . he must learn to do this without any help.

Learning to walk with callipers

People at Grade Five and Six can learn to walk using a swing-to or a swing-through walk. Those with a Grade Six injury may also learn to use a four-point walk.

All walking must be practised between the parallel bars before practising with crutches.

At first he will need help when walking but eventually he must walk without help.

Swing-to walk:

If he requires help you should stand behind him and hold his hips.



- . He balances on his callipers and crutches
- . he moves the crutches forwards



- he leans forwards and pushes down on both crutches to lift his body
 - . as he pushes down he must lift his head up at the same time
 - . his feet will lift off the floor and move forwards



- his feet must land on the floor behind his hands
 his feet must not land in front of his hands or in front of the crutches
 he must find his balance by
- pushing his hips forwards
- . he moves the crutches forwards and repeats.

Swing-through walk:

Start in the same position as for swing-to walk.





. she lifts her head up high enough so that her legs swing forwards



- . her feet must land in front of the crutches
- . she pulls her shoulders back and pushes her hips forwards to stop herself falling forwards
- she pushes down on the crutches and leans her body forwards



- . as her body moves forwards she moves the crutches to the front
- . she then repeats the movements.

Four-point walk:

Only people at Grade Six will be able to do a four-point walk. Some of these people will wear long-leg callipers and some will wear short-leg callipers (page 77). A doctor or therapist will decide which type of callipers the person will wear.



She moves the left crutch forwards and keeps the right crutch close to her side



- she stands on her left leg while pushing down on the right crutchshe bends her head forwards
- . her right leg will lift off the floor and go forwards



. she stands on her right foot pushing her right hip forwards

She repeats these movements but with the opposite crutch and leg.

Standing up using crutches

When the person is able to walk confidently using crutches the next step is to practise standing up from a wheelchair using the crutches. At first he will need help but should eventually learn to stand without help. Before standing, remove or swing away the footplates, put the wheelchair brakes on and make sure the callipers are put on correctly.



- . He sits on the front edge of the wheelchair
- . he places the tips of the crutches on the floor behind the front edge of the seat
- . the crutches should be close to the wheelchair





- . while pushing down through the crutches he must lift his head and shoulders up and back
- . his body will lift up so his feet land on the floor close to the wheelchair
- he should pull his shoulders back to push his hips forwards
 the crutches are still behind him
- . as he balances he must move the crutches forwards to support himself before he walks.

Turning around while walking



Practise this first between the parallel bars.

- . She moves both hand forwards along the parallel bars
- . she leans forwards and pushes down on the parallel bars
- . at the same time she bends her head forwards
- . her buttocks and feet will lift up



while her feet are lifted up she must turn her shoulders in the direction she wants to turn
she repeats this until she has turned around

> . as she turns she needs to swap hands to hold the opposite parallel bars.



Walk backwards

Practise this first between the parallel bars.



- . He places the crutches in front of
- his feet close to his body
- . he pushes his weight backwards onto his heels



then he quickly lifts his weight up and bends his head and shoulders forwards to lift his buttocks up and backwards.

Going up steps

Using one crutch and a stair rail (using the stair rail on the right side):





- . He holds the stair rail with his right hand
- . he carries the right crutch in his left hand
- . he moves his right hand forwards on the rail
- . he places the left crutch on the next step up

Using two crutches to go up one step or a kerb:

- . he leans forwards and lifts his legs up onto the next step
- . as his feet land on the step he must move his head and shoulders backwards
- . he pushes his hips forwards and finds his balance.



. She puts both crutches on the step in front of her



. she leans forwards and lifts her buttocks and legs up onto the next step



. as her feet land on the step she moves her head and shoulders backwards so the her hips are forwards.

The width of the step or kerb needs to be wide enough for her to land on safely.

Going down steps

Until the person is confident about going down steps you should always stand one or two steps below ready to offer help if needed.

Going down steps forwards (using one crutch and a stair rail):

- . She holds onto the rail with her left hand
 - . she holds her left crutch in her right hand
 - . she places the right crutch on the edge of the step which her feet are on
 - she leans forwards and lifts herself up by pushing down
 - on the rail and the right crutch



as her feet swing through she lowers them onto the next step
as her feet land she pulls her head and shoulders backwards and pushes her hips forwards to keep her balance.

Going down steps backwards (using one crutch and a stair rail):



- . He holds onto the rail
- . he places the crutch on the edge of the step
 - which his feet are on

he leans forwards and lifts his butocks and legs up and backwards off the step



. he lowers his feet onto the step below

. as his feet land on the step he pulls his head and shoulders backwards and pushes his hips forwards to keep his balance.

The same techniques can be done using two crutches if the person has very good balance.

Sitting down from standing

Sitting down must first be practised between the parallel bars. At first the person will need help.

When the person is practising it is safer to have the back of the wheelchair leaning against a wall. This will stop the wheelchair tipping backwards.

The wheelchair footplates should be removed or swung away and the brakes should be put on.



He faces the wheelchair
he removes the crutches one at a time and holds onto the armrests or backrest of the wheelchair

. he turns his shoulders to his right and sits on his left hip





- . he turns himself around
- . his legs will cross
- he then pushes on the seat to lift his buttocks up and sit straight
 he bends his calipers at the knee joints and place his feet on the footplates.

He can stand from siting in a wheelchair by reversing this method of sitting down or by using the technique on page 80.

4 Sexual Issues Following a Spinal Cord Injury

4.1 Sexuality

In the early stages following a spinal cord injury a person may feel inadequate and insecure about his sexuality. The person may feel sexually unattractive. Other people may imply that they no longer find the person sexually attractive.

However with time, emotional support and opportunities the person may learn to feel good about himself and feel more sexually attractive. The person needs to feel good about himself before being sexually active. The person needs to feel good in order to be able to deal with the risk of possible rejection from other people. The person needs to approach sex with an open mind and a willingness to experiment.

Sex is not a purely physical act. It is affected by the feelings and thoughts of the couple. The person needs to be aware that the partner may be unsure and worried. The partner may not know what the person's emotional or sexual needs are. They both need to talk about their concerns and worries to each other. This will help their sexual contact to be mutually satisfying.

4.2 Physical Effects of a Spinal Cord Injury on Sexuality

Generally the person's desire for sex will not alter following a spinal cord injury. In many ways the person's body will still react in the same way. However the ability to move around during sex and to feel sensation in the genital area will be affected. How much this will be affected will depend on the person's level of injury and whether the damage to the spinal cord is complete or incomplete.

One man will have no erection of his penis. Another man will be able to make his penis erect but not keep it erect. Ejaculation of semen will probably be reduced. The feeling of orgasm will be absent or reduced. The fertility of men will be affected. This will make it difficult for men to father a child following a spinal cord injury.

A woman may have reduced lubrication of her vagina. The feeling of orgasm will be absent or reduced. However her fertility will be the same as before the spinal cord injury. If a woman was able to have a baby before the injury, she will still be able to become pregnant.

4.3 Things to Consider Before Sexual Intercourse

- . The person must empty the bladder to prevent any accidents from happening.
- . In preparing for intercourse the person should stop drinking a few hours before hand.

Men who wear an indwelling catheter should:

- . Disconnect the catheter from the leg bag
- . plug the end of the catheter
- . fold the catheter back on the erect penis and hold the catheter down with a condom.

Men who wear a urinal sheath should:

- . Remove the sheath
- . put on a clean condom before intercourse.

Women who wear an indwelling catheter should:

. Disconnect the catheter from the leg bag

. plug the end of the catheter

. fold the catheter back and tape the end of the catheter to the lower abdomen or groin area;

4.4 Things to Consider During Sexual Intercourse

If the person wishes to continue being sexually active then the person must be willing to experiment to see what will work best for them.

It may be that touching the penis will make it erect. It may be that the woman needs to use a lubricant to lubricate her dry vagina. It may be that the couple has to look at other ways to satisfy each other.

The partner that is not paralysed may have to take the more dominant role.

4.5 Safe Sex

It is just as important that the person practises safe sex as it is for anyone else. The person must discuss and practice safe sex with the partner even though their relationship may be long term. Venereal diseases and AIDS are transmitted through sexual contact. The male partner should wear a condom. It is the safest form of protection during intercourse.

4.6 Specifics Issues for Women

Menstruation

A woman's menstrual periods may be absent for a few months after a spinal cord injury. Once the menstrual periods restart she should take her usual precautions.

She should use some type of sanitary pad or if available tampons. The pad must be changed every 4 hours. The pad should not be too thick and must not be placed too far back. If it is too thick or placed incorrectly then she might get a pressure sore from sitting on it.

It is important that the pads are changed regularly and that the genitals are kept clean to prevent infections.

Pregnancy and childbirth

Although it is possible for a woman with a spinal cord injury to become pregnant it is not recommended during the first two years following an injury. This is because her body needs to get used to having a spinal cord injury. Also her backbone and spinal cord need time to become stable and strong. She and her partner will have to consider some form of contraception if they wish to continue being sexually active during this period.

When she becomes pregnant, the pregnancy will usually be normal. There may be a problem with the bladder in the later months of the pregnancy. This is because the bladder will be pressed on by the growing baby in her womb. If she has a problem with her bladder, she may require an indwelling catheter to keep her bladder empty.

As she becomes heavier during her pregnancy it is essential that she continues to relieve pressure both in bed and on the wheelchair (pages 7-11). She must also manage her bladder and bowel (pages 12-19). She may need help with these and with moving on and off her wheelchair as she gets bigger.

She may have a normal delivery but probably will not be able to feel the contractions. It is usual for her to be watched closely by doctors because there is a risk of dysreflexia (page 22). The baby may have to be delivered by forceps. Some doctors feel it is safer to deliver a baby by a caesarean section. This may decrease the risk of dysreflexia and prevents the bladder from becoming damaged.

After the delivery she will be able to breast feed her baby in her chair or in bed. She may require assistance to do this, particularly if she has tetraplegia. She will also need to continue to relieve pressure (pages 7-11) and to re-establish her bowel and bladder routine (pages 12-11).

She will need to experiment with ways to carry her baby and ways to change her baby's nappy.

She must also be willing to ask for help when she needs it.

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5. Children with Spinal Cord Injuries

Do what other children are doing

Children who are paralysed should only be expected to do what is normal for their age. Do not try to teach them to do things that other children of their age cannot do. They will find it too difficult and become frustrated. As the child grows he will need to learn how to do things for himself like washing and dressing. He will also need to play with other children and to go to school.

Moving on and off the wheelchair

When he is learning to move on and off a wheelchair he may have difficulty. This is because he is small and still growing. Because he is small his arms are short. This may make it difficult to transfer. This will get easier as he grows and with practice.

Keeping the back straight as the child grows

If his back is not straight it will become more crooked as he grows. This must be prevented. The child's back must be supported by a block-leather or plastic brace. The brace is made by an orthotic technician. The child must be sent to see an orthotic technician by a doctor or therapist. The brace should be changed at least once a year. If the child grows very quickly the brace should be changed more often. A poorly fitting brace will cause pressure sores.

When standing:

- . The brace can be joined to callipers.
- . He should stand as often as possible.
- . Standing is the best position for his backbone to grow straight and to keep his legs straight.
- . The orthotic technician will make the callipers (page 77).
- . The callipers should be changed at least once a year.
- . If he grows quickly the callipers should be changed more often.
- . If he is able he can learn to walk with crutches.





- . Some children will not be able to stand or walk with crutches.
- . These children can stand in a wheeled frame.
- They must wear their brace and their callipers.

Using a trolley:

Rather than standing he can move around on a trolley.

- . He lies on his abdomen and pushes the large wheels.
- . He does not wear the brace.
- . He must be careful not to get pressure sores on the front of his body by changing his position regularly.



In a wheelchair:

- . He will need to sit in a wheelchair or chair for part of the day.
- . A wheelchair will be the easiest way for him to push himself around.
- . However sitting for a long time is not good for his backbone.
- . He must only sit in his wheelchair for two to four hours at a time.
- . When he is in his wheelchair he must wear his brace.
- . He must sit up straight in his wheelchair.



A child's skin is vulnerable to injury and pressure sores. He must relieve his pressure regularly (pages 7-11). He must be careful when playing, moving on and off his wheelchair, trolley or standing frame and when doing things for himself.

Children need to be kept active. They need to play with other children and to go to school. They need to be involved in doing things around the house and in the compound. See "Promoting the Development of Infants and Young Children with Spina Bifida and Hydrocephalus" (page 101) for more suggestions on working with children who are paralysed.

6. Incomplete Spinal Cord Injuries

If the person has some feeling or voluntary movement below the damaged segments, the spinal cord injury is said to be incomplete. There are many different types of incomplete lesions. Some may be more paralysed in the arms than the legs. Some may have more feeling on one side and more movement on the other side. Some may have more feeling and little movement while others may have more movement and less feeling, below the level of damage.

Much of the training in this book is appropriate for people with an incomplete spinal cord injury. They might show a mixture of problems. This will make it difficult to know what grade they are at. It is best to see what the person is having difficulty doing and work on ways to overcome these difficulties.

During bedrest

Take care to keep the backbone still while it is mending. Spinal shock often wears off sooner and therefore spasms will occur at an early stage. The spasms are often very strong.

Managing spasms:

It is important to try and disrupt what the spasm is doing.

First look at what the spasm is doing to the body.

- . If the legs are being pulled together then keep them well apart with a pillow.
- . If the legs are straightening then support the legs in a bent position for part of the day.
- . Passively moving the legs more than once a day will help to reduce the spasms (pages 29-31).
- . Encourage active movement where possible by encouraging him to help you move his legs.
- . The person must be encouraged to exercise (pages 33-36) and move the parts of the body which are not paralysed or which are partially paralysed

After the bedrest period

If the neck is involved the person may have to wear a collar to protect the newly healed bone when sitting in a wheelchair.

To learn to move the person must:

- . Sit in a wheelchair correctly (page 42).
- . Exercise in sitting (33-36).
- . Exercise in the kneeling position by crawling forwards, backwards and sideways
- exercises in the kneeling position will help the person to gain hip control.
- . Exercise in standing by moving their body weight from one leg to the other (pages 75-76).
- . Exercise by walking in a good position (pages 77-84)
 - while walking the person may need to wear callipers and use the parallel bars, crutches or walking sticks.

7. Living at Home

If the person is using a wheelchair her home and compound will need to be changed. She needs to be able to move around the home and compound using the wheelchair.

The following are suggestions of some things which may need to be changed.

The ground

The ground around the house should be level and firm so the person can move around easily using a wheelchair.

Ramps

- . A ramp should replace any steps into the house.
- . A ramp should be much wider than the wheelchair.
- It should have a level platform in front of the door to the house so the wheelchair does not roll backwards while the person is opening the door.
 The ramp should have a gradient not greater than
- 1:12. There should be a low border or rails on the sides
- of the ramp to stop the wheelchair from going over the edge of the ramp.



Doorways

- . Doorways should be at least five centimetres wider than the width of the wheelchair.
- . If the doorway has a raised sill then a small ramp over the sill is needed.
- . The door handles should be easy to turn.
- . Curtains may be easier to go through rather than a door

Bedroom

- . The bedroom needs to be large enough to move the wheelchair around.
- . The bed should be the same height as the seat of the wheelchair so it is easy to move on and off it.
- . A firm sponge foam mattress is essential to prevent pressure sores.
- . Clothes should be stored so that they are easy to reach.

Bathroom

- . The bathroom could be combined with the toilet if the room is large enough.
- . If using a commode the person can wash in the bedroom or in a screened off area of the compound.
- . Towels should be easy to reach.

Toilet

If using an existing toilet rather than a commode the toilet room needs to be large enough for the person to get into on a wheelchair.

- . The doorway needs to be wide. The door should swing outwards to allow more space. A curtain may be easier to open.
- There must be room to park her wheelchair beside the toilet. The toilet should be the same height as the wheelchair so it is easy to move on and of it.
- . Everything she needs should be in easy reach of the toilet - toilet paper, washing basin.
- She may need rails beside the toilet to help her with moving onto and off the toilet.
- . The toilet seat should be padded to reduce the risk of pressure sores.
- . A commode can be used in the bedroom or outside in a screened off area of the compound.



Floors and furniture

- . All the floors should be level and smooth.
- . All the loose mats or rugs should be removed.
- . All the furniture must be placed so the person can easily move around it.
- Tables should be high enough for the person to sit at while sitting in a wheelchair.
- . Shelves should be placed so they are within easy reach from the wheelchair.

Cooking





If cooking low down then a wall should be between . If cooking at a table make sure the table is high her and the fire to prevent her legs from being burnt. enough to get her legs under.

8. Keeping Active Following a Spinal Cord Injury

See WHO Training Packages 26, 27, 28, 29 and 30

People who have a spinal cord injury can learn to take part in family life, play, go to school, work and become involved with their community. They may require assistance or some equipment to do some of these activities.

The following pictures show the sorts of things people with a spinal cord injury can do. There are many more possibilities. With the support and encouragement of their families, friends and the community they will learn to do what they want to do.













































9. Summary of When to Ask for Help

The MLRW should ask for help if the person with spinal injuries:

- . Has spasms which are difficult to control (pages 23-24).
- . Develops a pressure sore or any other wound to the skin of the paralysed parts of the body (page 11).
- . Develops a urinary tract infection. The person may feel unwell, have difficulty urinating, have a high fever, and have urine which is cloudy or pink in colour (page 15).
- . Develops a sore on his penis (pages 14-15).
- . Bleeds from his anus. The bleeding may be due to a skin tear or haemorrhoids (page 19).
- . Has constipation which will not resolve after two to three days (page 19).
- . Has diarrhoea which lasts for more than two days (page 19).
- . Has haemorrhoids (page 19).
- . Has an anal skin tear that does not heal (page 19).
- . Develops high blood pressure with a pounding headache, sweating, shivering and a blotchy face dysreflexia (page 22).
- . Has long term pain (page 27).
- . Has localised swelling of either leg which is warm to touch deep vein thrombosis (page 26).
- . Fractures a bone (page 27).
- . Has joints which feel spongy when moved and which progressively become more difficult to move ossification (page 26).
- . Coughs up yellow or green phlegm a chest infection (pages 20-21).
- . Develops a contracture which is becoming tighter (page 32).
- . Is pregnant (page 87).
- . Is having a baby (page 87).



10. Further Reading and Acknowledgements

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"Training in the Community for People with Disabilities". Helander E, Mendis P, Nelson G, Goerdt A (1989) World Health Organisation, Distribution and Sales, 1211 Geneva 27, Switzerland.

The following Training Packages are referred to in this manual:

- 9. How to prevent deformities of the person's arms and legs.
- 10. How to prevent sores from pressure on the skin.
- 11. How to train the person to turn over and sit.
- 14. How to train the person to take care of himself or herself.
- 26. Play activities for a child who has a disability.
- 27. Schooling.
- 28. Social activities.
- 29. Household activities.
- 30. Job placement.

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