

The HELP Guide for
Community Based
Rehabilitation Workers:
A Training Manual



Marian Loveday



Global-HELP Publications

Author

Marian Loveday

Physiotherapist

This training manual grew out of my work as the only physiotherapist working in a community of about 300,000 people. Given the overwhelming needs in this community, I determined my task to be passing on basic rehabilitation skills to people of the community. We defined the community we were working with as the community of disabled people, which included disabled adults and the mothers of disabled children. In each area in which we planned to work, a meeting was held with this community of disabled people. They chose from amongst themselves a person who would receive training and then work as a rehabilitation worker in that area. During my last years of work with the project, I completed a Masters degree in Maternal and Child Health, and for my thesis I completed a quantitative and qualitative evaluation of the rehabilitation project. I left the project in 1994 after ten years, and the work continued for a further ten years until the whole organization was forced to close due to a lack of donor funding.



In 1994, following political freedom in South Africa, my husband and I and our two small children moved to the Kalahari Desert near Botswana, where we lived in a rural area for six years. We lived at the Moffat Mission in Kuruman where my husband was the Director. Moffat Mission was David Livingstone's first home in Africa. There, I was employed by the newly established Northern Cape Department of Health as the District Health Manager of the Kalahari District. In this position, I was responsible for all the public health services within a defined geographical area which had three hospitals, fifteen primary health-care clinics, and seven mobile clinics.

Although we loved the Kalahari, our eldest daughter was diagnosed as having juvenile diabetes, and so for health and educational reasons, we left and moved to KwaZulu-Natal, another province in South Africa. During this time, I have been employed by Health Systems Trust, a non-governmental organisation, which strives to improve health services for all South Africans. Initially, I worked in a remote rural area supporting the local district health managers to implement an effective Primary Health Care system. More recently, I have moved into health systems and operational research focusing on TB and the interface between TB and HIV.

In the years since 1994, I have continued to draw on the wonderful memories of that time working with disabled children and their mothers, as well as the lessons that were learnt in providing good health for all the people of South Africa.

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Note from the Publisher

With the permission of the author, Marian Loveday, Global-HELP Organization is pleased to republish the book. We believe the principles presented are timeless and well-suited to guide management of disabled children worldwide. We thank Dr. Charlene Bulter for making this work available and for her guidance in preparing the material for this book.

Lynn Staheli, MD
President, Global HELP Organization
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Foreword

Charlene Butler, ED.D.

**Past President, American Academy
for Cerebral Palsy and Developmental Medicine**

In 1992, I traveled as a Fellow of the International Exchange of Experts and Information for the World Rehabilitation Fund. My task was to find and share innovative ideas for the care of disabled children. I visited programs and met with health-care professionals and special educators in 13 Mediterranean, African, and Southeast Asian countries. While in South Africa, I learned about the work of Marian Loveday. She had written and tested this curriculum and method for training community-based rehabilitation workers in extremely poor and uneducated communities. This manual is a valuable contribution to the field, I believe, in two ways.



In the obvious way, this is a training program that is notable for its well-chosen and well-written content, for its unusual training method that can reach even people who are not able to read, and for being evaluated for its effectiveness. Though developed for villagers in Africa, it can easily be modified for training use in communities anywhere.

In a less obvious — but equally important — way, Marian has captured the essence of some very complex disorders and issues and given us simple ways to talk about them with families and others who care for children with disabilities, such as teachers and aides of all kinds. Because of the elegantly simple explanations, the manual will be a helpful resource to health-care professionals in their offices, clinics, and hospitals at home as well as when working abroad seeing patients and families or for rehabilitation training.

INTRODUCTION

This training manual has grown out of my work as the physiotherapist for SACLA, a community based health project in some of the black townships and squatter camps of Cape Town. Given the overwhelming needs in this community (I am the only physiotherapist working in a community of about 300 000 people), I have seen my task to be one of passing on basic rehabilitation skills to people of the community.

The basic principles of my work are similar to those of other health care professionals in South Africa who, sensing the dire need for access to adequate health care, have begun to implement Community Health Worker (C.H.W.) projects, empowering communities to take responsibility for their own health, and decreasing dependency upon the medical 'experts' (SACLA itself employs 40 C.H.W.s). A program to train and supervise Community-Based Rehabilitation Workers (R.W.s) was thus initiated at SACLA in 1988.

Some of the fundamental concepts in community based rehabilitation are that the R.W.s live in the area in which they work, are chosen by the community in which they work, and are ultimately responsible to this community. For obvious reasons the community with whom we work is the "community of handicapped people." Accordingly, two meetings were held with the handicapped people and mothers of handicapped children in each of the areas in which we planned to work. At the first meeting we described the plan to train a R.W. in the area, and explained the kind of work that was involved. Questions and discussion followed. At the second meeting one person was selected by the group to be trained as a R.W. and employed by SACLA.

The only criteria that we stipulated for the selection of R.W.s was that the person should be able to write. This was important for two reasons:

- Much information is contained in the training course. It would be difficult for a person to remember it all if they were unable to keep notes.
- Record keeping is essential.

We did not lay down a minimal educational level. A couple of the R.W.s have a standard two level of education. As the course is run in the language of the area (Xhosa), English is not essential.

The training included an intensive four week course that covered the basic conditions, treatment and management of handicapped people. At the first training course in 1988 we trained three people, and at the second course in 1989 we trained a further five. These people work in five different communities. Six of the people selected to be trained are themselves mothers of handicapped children.

The manual you have before you is a refined version of these training courses in 1988 and 1989. It began out of my own need to organize and record the courses, but I was encouraged to publish it and make it available to other health workers.

One of my main reasons in doing so is that a number of people have expressed interest in the content and structure of the course. Further, I sometimes fear that there are many of us in South Africa who are aware of the desperate need for rehabilitation and are training or starting to think of training R.W.s. It seems a waste of energy and time for us all to come up with more or less the same content (and make the same mistakes!) It is my hope that this manual can provide a starting point for others who can put energy into areas that they feel are deficient or non-existent in this manual, thus enhancing all of our work.

Hopefully this first attempt and subsequent developments will enable us all to get a little closer to the goal which really should motivate our work in the next decade: "Health for all by the year 2000."

Let me say some things specific to the manual itself:

- This manual is designed for the *trainer* who is assumed to have adequate medical knowledge. The course itself may well need to be orally translated while teaching it.
- The sessions are in a systematic order rather than in the order in which they were taught. For example, the session on *Immunization* followed quite naturally after the session on *Polio*.
- Many of the sessions took longer than one time slot to complete. Some of them also took place with the help of local resource people and institutions (referred to by name). You will need to adapt the course to your local conditions.
- The course was taught mainly in dialogue form rather than as a series of lectures. To capture this, many of the sessions include questions and answers. Obviously these represent the crux of the matter being discussed and the answers are those that emerged after general discussion. Peripheral questions and answers have been excluded.
- The question and answer format also makes the input in any given session very flexible so that the two courses I have run have differed from each other. The participating R.W.s shape their own course through their level of interaction.
- The aims stated at the start of each sessions are the aims for the R.W.s and not for the trainer. They summarize what the trainer should have hoped to pass on by the end of the session.
- As mentioned above, the majority of the R.W.s are themselves mothers of hand-capped children. When addressing them, or another mother I have used the Xhosa form of address. For example, "Mama ka Simphiwe" is the mother of Simphiwe.
- Xhosa beliefs are often referred to. Because so many people believe them, we take them seriously, and encourage people to believe in them if they are not harmful. If they are harmful we encourage the R.W.s to listen to them and gently change them.

There are so many people who have been involved in this manual that in many ways it is more like a group effort. There are a few that I would like to thank by name though. Steve de Gruchy, my husband, for doing the editing and laying it all out on a computer programme that I could never have mastered. Keli Mbangata for doing the primary health care sessions and endless translations. Nomazizi Stuurman for her help with translation and being patient with me as I struggled to get this all together. Chip Snaddon for the wonderful illustrations. Nomisa Lawana, Tozama Ntshayi, Nosango Somwahla, Nozukile Mguda, Nowitness Mxi, Nokingrose Sitamama, and Eric Gqola - the R.W.s (and all the other mothers of handicapped children) who helped shape the course and this manual.

Sue Kramer, Di Hewitson, Kirstie Rendell, Jan Hollingshead, Sharalee Cuthbert, Birgit Schweizer (the whole thing!), Toni Tickton, Pam Hansford and Mary Reynolds for reading through different sessions, correcting and making suggestions for improvement. They should not, of course, be held responsible for any weaknesses or mistakes in the material.

Finally, I hope you can take this manual and put it to good use. Feel free to copy anything you want (not for profit). If you have any comments, criticisms, or suggested changes please don't hesitate to contact me.

I. HEALTH IN THE COMMUNITY



A Rehabilitation Worker doing home visits in the community.

I.1. HANDICAP AND THE COMMUNITY

Aims of this session:

1. To introduce the Rehabilitation Workers (R.W.s) to one another and have them relax together.
2. To understand the words "handicap", "community" and "education" and how these affect the work each R.W. will be doing.
3. To recognise that working in the community as R.W.s involves not only educating and treating handicapped people and their families, but the broader community as well.
4. To identify people from the community who need to be educated about handicap, the presence of handicapped people in their area and what can be done to minimize discrimination against handicapped people.

1. Welcome and introduction.

A. Introducing the rehabilitation workers.

After introductions and ice-breakers, established R.W.s described their work.



B. What does 'handicap' mean?

What kind of work do you think that you will be doing as R.W.s?

- *Working with handicapped children and adults.*
- *Working in the community.*
- *Teaching handicapped people and their families about handicap.*
- *Working out exercises for handicapped people.*

All of you are mothers. You all have normal children and a handicapped child. What does it mean if we say that a child has a handicap?

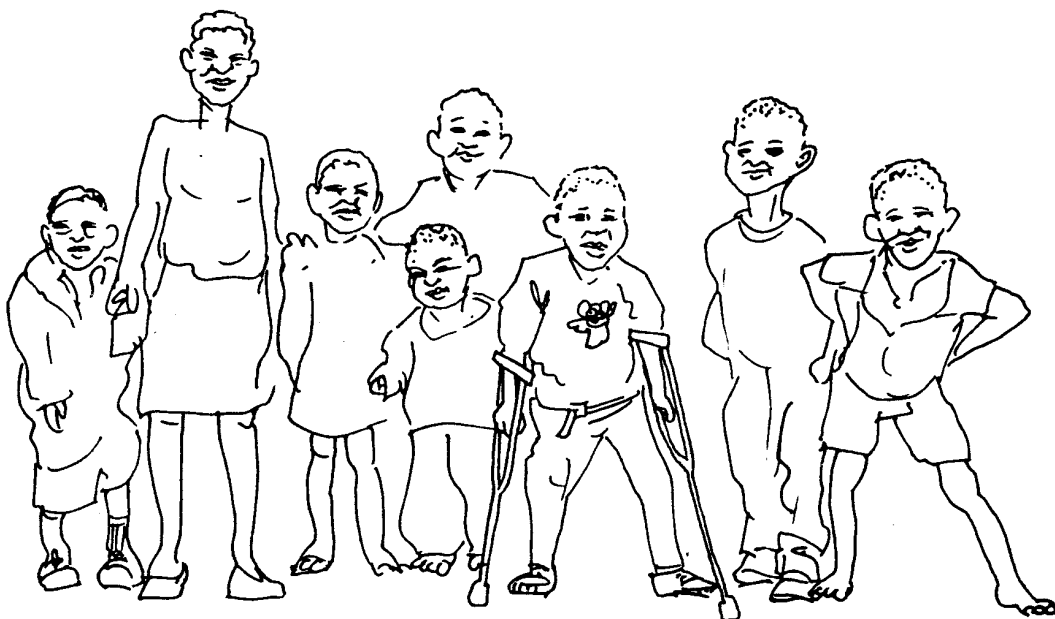
The child has a problem so that he is not normal.

What kind of problem may this be?

- *My child is blind.*
- *My child is very stiff and tight. He cannot move or talk.*
- *My child has polio, so he cannot walk around and can only crawl.*

There are in fact 4 main groups into which different handicaps fall. We have mentioned 3 of these:

- People who have problems with their sight.
- People who have problems with moving.
- People who have problems with speech and hearing.
- People who have problems with thinking and behaviour.



Is it only children that can be handicapped?

No, adults as well.

In fact, in communities such as Site B, KTC or New Crossroads, 1 out of every 10 people is handicapped. These may be children or adults.

2. Handicapped people in the community.

A. Who is the 'community'?

We keep talking about this word "community". What does this mean to you?

- * *It is the people around us.*
- * *We all live in the same place together and come from the same place. We all speak the same language and have the same faith and beliefs.*
- * *We share the same problems and worries: water, the bucket system, the wet and cold in winter and our children who get ill.*



You were each chosen by the community of handicapped people to be the R.W. in your community. You will be working with handicapped people and their families, developing training programmes and teaching handicapped people and their families how to carry these out. While we will pay you, you will really be responsible to the community of handicapped people.

B. Daily activities and handicapped people.

What are the activities that we do each day?

*eating and drinking * washing and bathing * going to the toilet * dressing *
listening to people * talking, sharing thoughts and feelings * making oneself un-
derstood by others * getting up from lying * moving around the home *
moving around the community * breastfeeding babies * children playing *
children going to school * reading, writing and counting * taking part in family
and community activities * doing daily household activities * working * using
money * using transport * getting married * having children and raising a
family*

Do your handicapped children get a chance to do some of the things in the list above?

- * *No, my child cannot do anything so I have to do all the above for him.*
- * *My boy with polio can do some of these things, but it takes him so long and I get impatient so I do almost everything for him.*

What do normal babies do?

They lie and cry. They are breastfed and they move and play.

So what must handicapped babies have the chance to do?

They also lie and cry and are breastfed. They must be given the chance to move and play. Extra time needs to be taken to help them do these things.

What do normal children do?

They play, talk, go to the toilet, wash themselves, run around and go to school.

So what must handicapped children have the chance to do?

They must be given the chance to do all of these things if possible.

Time will be needed to teach them to do these things. It will take longer to teach these children and we may need the use of some equipment.

What do we as normal adults do?

We look after ourselves, we look after the house and the children, we cook, talk and work.

What should handicapped adults have the chance to do?

To do as much of these things as possible, even if it takes longer.

Small adaptations may be needed in the house to assist in doing some of these things.



C. Attitudes to handicapped people.

How do you all feel about your handicapped children?

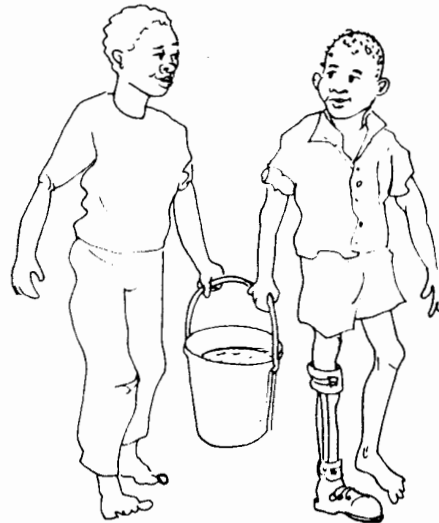
- * *I love my child so much, but I find that I get very tired looking after him. Also, I have never been able to go out and get a job, as I have to stay at home caring for him. The other very draining thing is that I can never leave him with anybody, as nobody else likes to change the nappy of a 4 year old boy.*
- * *My little boy with polio is so demanding, I seem to spend my day rushing around doing things for him as he cannot do them.*

How do people in the community see handicapped people?

They see them as someone who needs help and needs looking after. I think people in the community often feel sorry for handicapped people and their families.

Handicapped people have difficulties which prevent them from doing some of the activities that we do. Or they do activities in a different way. Society has come to look on handicapped people as being disadvantaged and not as equal to others who do not have disabilities.

Because of this they do not give the handicapped person the same opportunities that they give themselves. eg. handicapped people are not given the opportunity to go to school, get a job, or take part in family and community activities.



This is most unfair to handicapped people. It is true that some disabilities do stop people from doing certain things, but most handicapped people can do the same activities that other people do. Society's attitude has stopped disabled people from doing what they can do and prevented them from attempting to do things that they could learn to do.

What should handicapped people have the chance to learn how to do?

Maybe I should give my boy a chance to do the things that the other children do. He could dress himself, it's just that I get impatient with him, so I usually do it.

Handicapped people must be given the chance to learn how to do all the activities that we do. If they are not able to do these activities immediately, they may need some help in learning to do these things.

3. Education.

A. Who will you teach?

Who will you be working with as a R.W.?

We will be working with the handicapped people in our communities.

Is it just handicapped people we will be working with?

No we will have to work with the mothers and families as well.

Why?

Because they spend the most time with the child.

As R.W.s. a large amount of your work will involve teaching handicapped people and their families how to achieve certain activities, so that either the handicapped person is more independent or the activity is done in such a way so as to help the handicapped person and their family.

Do you think that people in the community understand handicap and how handicapped people should be treated in the community?

No. Everybody knows that there are handicapped people in the community, but nobody knows what help they need or how to help them.

Do you think that if people in the community understood about handicap and how to help someone with a handicap, it would be any use?

Yes, because in the areas we live the houses are so close that we are on top of one another and always helping each other out. If our neighbours also understood, they could help us.

To summarize:

Who are the people who need educating about handicaps?

- * *The handicapped person themselves.*
- * *Their family and mother in particular.*
- * *The communities in which we live.*

B. What will we teach?

Do you all understand what your child's problem is and what caused it?

I know my child had polio but I don't know why he got polio.

Polio can be prevented. Other handicaps can also be prevented. People need to know what caused the problem and how it can be prevented.

Do you know what problems your child might have in the future?

No.

Future problems can be avoided if you as the mother know what is likely to develop and how it can be prevented.

Do you feel confident that you know how to handle your child at home?

No.

If your child is handled correctly at home whilst you feed and dress and play with him, it will not be necessary for you to do specific exercises with him. It will also give him a chance to learn, to develop and hopefully to become more independent.



To summarize:

As R.W.s you are going to have to educate mothers and families of handicapped children and the community about a person's handicap:-

- * *what caused it*
- * *how it could have been prevented*
- * *what complications are likely to develop*
- * *how to avoid these complications*
- * *how to stop these complications from getting worse*

4. Working in the broader community.

A. Aims of our work.

Who do people in the community usually think will help them with their handicapped child?

The doctor.

Doctors will not spend enough time with you as mothers nor will they spend time in the community teaching about handicap, how it can be prevented and how the complications can be avoided.

It is you as R.W.s who are going to have to spend time with handicapped people in the community, teaching them, their families and the community.

In the long run we want the community as a whole to take responsibility for its handicapped people and give them the same opportunities as other people in the community.

However, community leaders, headmen or committees will not even think about handicapped people if we don't make them aware of such people and teach them about handicap and its problems.

Besides meeting the leaders in your communities there are also other people to meet who have contact with many people, who may know of handicapped people.

Who would these people be?

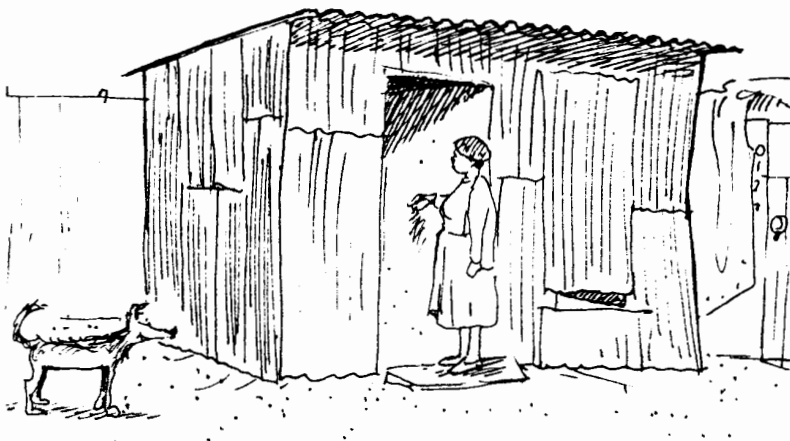
Ministers, creche teachers, teachers, social workers, traditional healers, members of the health committee, community health workers, nursing sisters.

With the people just mentioned, with community workers and with the community leaders, tell them how you hope to go about your work, and ask for their advice and suggestions.

B. Identifying handicapped people in the community.

How can you find handicapped people in the community?

- *Visit all the shacks in your area to identify all the handicapped people in the community.*
- *When you visit, ask not only if there is a handicapped person in that house, but also whether they know of handicapped people they can direct you to.*
- *Ask health officials if they have a list of handicapped people in your area. eg. in KTC at the Tembaletu school for the physically disabled.*
- *Visit schools and creches in your area and ask the teachers if any of the children are handicapped.*



When you find handicapped people, what must you do?

- Find out which handicapped people need help that you can offer.
- Discuss with the handicapped person and their mother their problems and together work out ways of tackling these.
- Check any appliances the person has, to ensure they are useful, appropriate, fit well and work.
- Draw in other people from the community who come into contact with the person, eg. school teacher, neighbour.
- Guide, encourage and assess the training that the mother or teacher is doing.
- Assess whether the handicapped person is getting better.
- Keep records.
- If necessary refer handicapped people to one of the hospitals, nutrition clinics or the orthopaedic workshop.

I.2. NUTRITION AND MALNUTRITION

Aims of this session:

1. To recognize the three different food groups and arrange the more common foods eaten into these groups.
2. To understand what a balanced diet is and why it is important.
3. To understand the three basic types of malnutrition.
4. To recognise when a child is malnourished and how the child should be treated.

1. Nutrition.

A. The three food groups.

What are the three food groups:

- *energy foods*
- *body builders*
- *protective foods*

Each person was asked to name 3 foods that they commonly eat and then say which food group they thought they were part of.

1. Energy foods.

Foods in this group contain fuel which gives energy for the day. If too much energy food is eaten the person will become fat or overweight. If a baby is given only energy foods, he will develop kwashiokor.

What are some examples of energy foods?

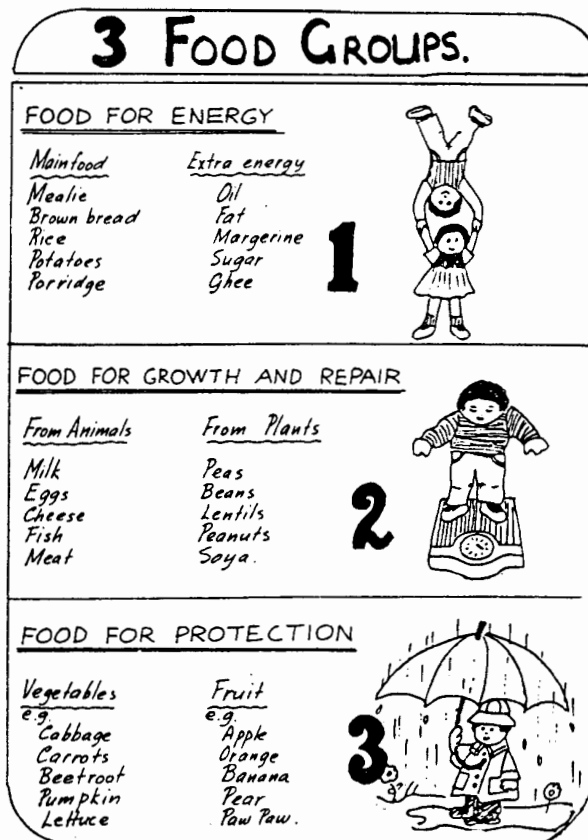
rice, bread (brown and white), cereals eg. oats, mealie meal, mealie rice, samp, maltabela porridge, oil, margarine, flour, mealies.

2. Body building foods.

Food in this group helps to build muscles, bones, teeth, and blood and keeps us strong. These foods tend to be more expensive than the other foods, but only a small bit of each one is needed, eg. one egg is sufficient at each meal. It is necessary to eat more than one body builder at a time.

What are some examples of body building food?

milk, eggs, beans, fish, meat, lentils, peanuts, peas, cheese.



3. Protective foods.

Foods from this group protect us from illnesses. All vegetables and all fruit fall in this group. When choosing either fruit or vegetables, choose those that are in season, are brightly coloured and look fresh. It is better to eat protective foods raw, so salads are better than cooked vegetables. Use different colour vegetables together.

What are some examples of protective foods?

Carrots, apples, cabbage, tomato, mango, paw-paw, pumpkin, onion, squash, oranges, peaches.

B. A balanced diet.

A balanced diet involves eating food from each of the 3 food groups. Correct eating does not necessarily cost more, but food needs to be selected daily from each of the 3 food groups.

Each person in turn planned a balanced meal. The whole group discussed each meal to ensure that all three different food groups were included.

At certain times in a person's life it is even more important than usual that they eat a balanced meal.

At what stage in a person's life would they really need a balanced diet?

- *While they are a child or a young person and still growing.*
- *If a person is very active doing manual labour on a construction site.*
- *When a woman is pregnant as she needs to nourish her growing baby.*
- *When a woman is breastfeeding.*
- *When a person is under pressure or an extra load.*

2. Malnutrition.

A. The causes of malnutrition.

What are the causes of malnutrition?

No money, overcrowding, unemployment, laziness - no energy to make food, poverty, sex.

Let's look at each of these in turn.

Why did you say that no money can cause malnutrition?

- *Without money it is not possible for a mother to buy food for her children, so they get hungry and then malnourished.*

How can overcrowding cause malnutrition?

- *There are so many people living close together that there is no room even for a small garden to grow vegetables, and the people living in these conditions are so poor, they cannot afford to buy vegetables.*
- *There may also be problems with limited access to toilets and running water, so the children may often be ill.*

How can unemployment cause malnutrition?

- *People who do not work do not have money. Without money a person cannot buy food. This is just the same as the first point that we discussed, under "no money."*

How can laziness - no energy to make food cause malnutrition?

- *The mother is too lazy to cook food for her family and this is why her children can be malnourished.*

When do you feel really tired?

- *Either late at night or when I am really hungry.*

Are there many mothers that you know of who will eat food if they can afford it, but not give it to their children?

- *No, nearly all mothers if they have a little food will give it to their children rather than themselves.*

Do you think that when you say that some mothers are too lazy to cook food for their families, that they are maybe malnourished themselves and too tired to rush round and look for food to cook for their children?

- * *Yes that's true. Maybe she is tired because she is weak from hunger.*

How can poverty cause malnutrition?

- * *This is the same as having no money or being unemployed.*

How can sex cause malnutrition?

- * *This is one of our traditional beliefs. If you have sex with a man, either your husband or another man, your child will become ill or malnourished. This was really a traditional method of contraception, that the midwives would tell us so that we wouldn't have one child on top of another one. We know now that this is not true, but older people in the community will always say that this is why your child is ill.*

Let's make a list then of the different reasons for malnutrition that we have been discussing, grouping together those which are basically the same.

Causes of malnutrition.

- * **Starvation**, a child who is getting no food will become malnourished.
- * **Poverty**, unemployment and no money all ensure that a mother cannot buy any food for her child, who will become malnourished.
- * **Ignorance**, about the different foods that a child needs and the value of breast feeding.
- * **Illness** over a long period of time so that the child becomes thin and malnourished.
- * **Overcrowding**, where contagious diseases are easily spread and there is limited running water and toilets.
- * **Depression**, the mother is depressed as she cannot feed herself and her child properly.
- * **Alcoholism**, where all available money in the house is spent on alcohol and not on food.

B. The three different types of malnutrition.

What are the three types of malnutrition:-

- *Underweight*
- *Kwashiorkor*
- *Marasmus*

Let's have a closer look at each one.

1. THE UNDERWEIGHT CHILD.

Underweight children are the most common of the malnourished children that we see.

• Causes

The child has something to eat, but not enough.

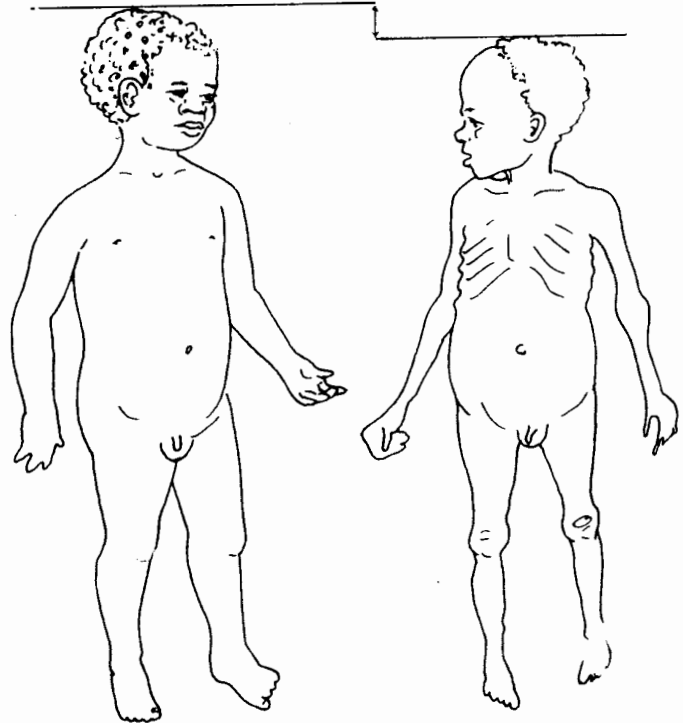
• Identification.

What does an underweight child look like?

- *The child has red lips, a swollen face, his hair is red.*
- *With an underweight child you don't actually see much. When the child is put on a scale, he is much less than he should be.*

This is a list of the things that you will notice with an underweight child:

- thin
- underweight
- thin upper arm
- loss of appetite
- very little energy and unable to play
- smaller than other children



• Treatment.

What do you think the treatment should be?

- *The child must get enough food and a balanced diet.*
- *The child must be protected from getting ill, so his immunization card should be checked and he should be checked for T.B.*

2.KWASHIOKOR

• Identification.

What does a child with kwashiokor look like?

- *Their mouth is red, the child is overweight, the child has a big head.*

Let's discuss each of these in turn.

- The mouth is red, the redness of the mouth is different to the redness of the mouths of people who drink.
- Cracked lips, are also present and like the redness of the mouth, they go away when the child is given proper food.
- The child is underweight although he looks swollen. The child may become swollen in as short a time as a week.
- The child has a big head, the head tends to look big, as the face is swollen and the cheeks are big.
- Sometimes the child is not strong enough to hold up his head so it flops, this also makes it look as if his head is big.



Let's make a list of what a child with kwashiokor looks like:

- *a red mouth with cracked lips*
- *swollen feet and hands*
- *moon face*
- *irritable and unsociable*
- *not playing*
- *soft and flabby muscles*
- *cracked and peeling skin with sores*
- *reddish hair*
- *loss of appetite*
- *thin upper arm*

• Causes.

What causes kwashiokor?

If the child is starving and gets no food at all.

Not really. Children with kwashiokor are usually given some food although it may not be very much. However they are usually given energy foods only, as these are the cheapest foods available.

Kwashiokor is most common when a mother stops breastfeeding her child as she has another child. So the children most commonly seen with kwashiokor are about 18 months old.

Why does this happen?

The breast milk provided the child with protective and body building foods so that when it is suddenly taken away all that the child gets is energy foods.

If the child gets energy foods only he will develop kwashiokor.

• Treatment.

What can we do for these children?

Give them food which is not only starch.

Are malnourished children usually well?

No, they are always getting sick.

We must try to protect them from illnesses which may be serious, so they must be sent for immunizations.

Let's make a list of how we would treat a child with kwashiokor.

- * The eating pattern of the child must be corrected, he should get food from all three food groups, not just starches.
- * If the child is not eating the child must be sent to hospital.
- * The immunization card must be checked.
- * The child should be referred to the TB clinic to check that he does not have TB.

3. MARASMUS

Marasmus is the third type of malnutrition.

• Identification.

What does a child with marasmus look like?

Like a child with kwashiorkor.

No, these children look different to children with kwashiorkor.

This is a list of what you will notice if you see a child with marasmus:

- very thin and underweight, skin and bones.
- wrinkled face like that of an old person.
- big belly
- always hungry.
- thin upper arm
- the head looks big in relation to the rest of the body
- brown sparse hair.



• Causes.

What do you think causes marasmus?

It is caused by starvation, the child has no food at all.

It is not as common in Cape Town as kwashiorkor is. In places like Mozambique and Ethiopia, which are disrupted by war so that there is no food available, it is more common.

• Treatment.

These are some of the ways to help a child with Marasmus.

- The child should get enough food and it should be a balanced diet.
- If some other illness is suspected the child should be referred to hospital.
- If TB is suspected, the child should also be referred to the TB clinic.
- Immunizations must be checked to ensure that the child will not get any diseases that can be prevented.

I.3. BREAST FEEDING

Aims of this session:

1. To learn why breast feeding is better than bottle feeding.
2. To learn how a mother can breast feed a handicapped child who has problems with breast feeding.

1. The importance of breast feeding.

A. The benefits of breast feeding.

Why do we breast feed our children?

- *Breast is clean.*
- *It is always ready.*
- *Breast is good.*
- *Breast is traditional.*
- *Breast milk makes the child grow faster and quicker.*

It also:-

- Is a time when the child feels close to the mother and feels loved.
- It is completely natural. Like animals, children know how to suck.
- It costs nothing.
- It is good and healthy.
- It provides the child with soldiers to fight against diseases.
- A child who is breast fed grows faster.



How many times a day should you breast feed your child?

Whenever the child is hungry and needs it.

For how long should you let your child drink at each breast?

The child should drink for 3-5 minutes each side. This will ensure that your child gets enough.

B. Problems with breast feeding.

Why do some people not breast feed?

- *Traditionally we believe a mother must not breast feed her child if she is sick as then she may be bewitched. The child will then suck the evil spirits from her mother.*
- *Because the mother or the child is ill.*
- *Because the mother has to go to work.*
- *If the nipple is cracked.*
- *If the mother has no milk.*
- *If the mother has nipples which are inverted.*

Let's look at each of these in turn:

- If the mother or those in her family think she is bewitched, she should go to a traditional healer to be healed. However, the baby must carry on drinking from her breast.
- If the mother is ill, she can carry on breast feeding. She will not pass on her illness to her child.
- If a mother is going to work and has to leave her baby at home. She can still breast feed the child, in the morning before she goes to work, and in the evening when she comes home. When she is not there, the child can drink expressed milk.
- If the child refuses to breast feed there is nothing that can be done. It is not a good idea to force a child.
- If the mother has cracked nipples, she must carry on, although it is painful.
- Even if the mother has a little milk, keep feeding the child, as a small amount of milk will protect and nourish the child. The more a child sucks the more milk will come.

2. Handicapped children and breast feeding.

Nomisa's child is severely handicapped. She has problems with feeding.

Was it easy for you to breast feed your child Nomisa?

No, not at all. She couldn't suck my breast and when she tried to swallow would just choke and vomit. I stopped breast feeding her and started feeding her baby formula out of a bottle.

This is a problem for all mothers with severely handicapped children and most mothers with cerebral palsied children.

Mothers stop breast feeding their children as their child has such difficulty sucking and swallowing. They then give their children baby formula, which is very expensive.

As we have discussed breast milk is very good for children. Maybe the mother could express milk and give it to her baby with a teaspoon. The problem is that it takes a lot of time and is a messy job to express milk.

(Positioning and how to breast feed and feed handicapped children is dealt with in the section on Feeding Brain Damaged Children (V.7.).

3. I.4. IMMUNIZATION

When should you start to give your child food?

From 4 months onwards.

What kinds of food should you start feeding your child?

Soft foods like bananas, mashed potatoe, runny pronutro and yogurt. He can also drink fruit juices.

How often should a child from 4 months onwards eat?

As often as 5 times a day, as they can only eat a little each time.

By 8 months to a year, the child should be eating the same food as the rest of the family even if it has to be mashed or mixed with liquids.

When do you wean a child?

- *6 months,*
- *a year,*
- *2 years.*

Everybody seems to have a different answer. In fact there is no specific time when you should wean your child. It is time to wean your child, when you as the mother feel ready and also when the child is ready.

You as the mother must be ready financially, emotionally and spiritually to wean your child. It is important not to wean your child for other reasons, if you are depressed or involved in quarrels. The child must also be ready to be weaned, she must be strong and not ill.

Is a child affected when it is weaned?

Yes, my children all seemed to miss it a lot. I had to comfort them, pick them up more often and keep them with me at the time that they were weaned. To keep the child strong and well, she must be given a balanced diet and milk.

One of the Rehabilitation Workers, Nomisa, has a child Zandile, who has problems with feeding and swallowing. She is 3.

What do you feed her?

It is very difficult to give her anything solid to eat, as she cannot swallow it. It is easier for her to drink or to eat food that has been mashed up and mixed with some liquid so that it is slightly runny.

Handicapped children need to have the nutrients contained in food which is still there even after it is mashed up. They need more than milk and powdered milk.

(See the session on Feeding children with cerebral palsy (IV. 7.)

I.4. IMMUNIZATION

Aims of this session:

1. To know how to find where immunizations are written down on the clinic card.
2. To understand what the different immunizations are for.
3. To recognise whether a child's immunizations are up to date.

Teaching aids:

1. Each R.W. had their youngest child's clinic card.

1. The clinic card.

What do you know about the pink clinic card?

It's for immunizations.

What are immunizations?

Injections.

Yes, injections to prevent certain severe illnesses. One of the immunizations is given as drops in the mouth and not as an injection.

What else do you know about this clinic card?

The growth of the child is measured inside the card.

How many times did you take your children to the clinic for immunizations?

Many times.

Can you remember when these were and what they were for?

- * *At birth for a BCG.*
- * *At 3 months, but I don't know what that was for.*
- * *Also at 4 and a half, 6 and 9 months, but I don't know what those were for either.*

What are the 6 diseases that children are immunized against?

TB, diphtheria, whooping cough, tetanus, polio and measles.

What are these different immunizations called?

- * *A BCG is to prevent TB.*
- * *DWT is to prevent diphtheria, whooping cough, and tetanus.*
- * *Polio immunization is to prevent polio.*
- * *Measles immunization is to prevent measles.*

Can you see why the DWT immunization is called DWT?

No.

What diseases is it used to prevent?

Diphtheria, whooping cough and tetanus.

The immunization is called DWT, taking the first letter of each of these 3 conditions. The D is for Diphtheria and the W is for Whooping cough.

What do you think the T is for?

Tetanus.

Do you know what boosters are?

No.

These are a bit like "top up" injections, to ensure the child does not get one of these diseases. Boosters are given when the child is 5 years old. Boosters are only for polio and DWT.

There are 2 boosters, the first at 18 months for polio and DWT (diphtheria, whooping cough, tetanus) the second at school going age for polio and for diphtheria and tetanus, no whooping cough.

What happens if you lose your clinic card?

They do all the immunizations again and give you a new card for your child.

This will not harm your child in any way.

2. Practical session.

Each R.W. had the pink card of their youngest child with them. It was explained where immunizations are found. To ensure that each R.W. understood the pink card, they checked their own child's pink card to ensure her immunizations were up to date. They also checked the cards of 2 other children to ensure their immunizations were up to date.

PRE-SCHOOL HEALTH RECORD VOORSKOLSE GEBOONDHEID REKORD				
PERSONAL DATA/PERSOONLIKE GEGEWENS				
Child's surname Kind se van		Tabata		
First name(s) Voornam				
Address Adres		110037 SGA C Kiliza		
Postal code/Postkode		Tel:		
CLASSIFICATION/KLASIFIKASIE				
Private Privaat	Medical scheme Mediese skema	Free patient Vry pasiënt		
CHILD'S FOLDER NUMBERS/KIND SE LÊER NOMMERS				
Hospital/Clinic/Health Centre Hospitaal/Kliniek/Sentrum		Number Nommer		
IMMUNISATIONS/IMMUNISASIES				
Age Ouderdom	Immunisation Immunisasie	Date administered Datum toegedien	Administered by Toegedien deur	Return date Terugkeersdatum
New born Pasgeborene	B.C.G.			
2 months 2 maande	Polio, D.P.T. "B.C.G.			
4 1/2 months 4 1/2 maande	Polio, D.P.T.			
6 months 6 maande	Polio, D.P.T.			
9-10 months 9-10 maande	MM, M, M, M			
18 months 18 maande	D.P.T. Polio			
5 years 5 jaar	D.T.			
School leaver Skoolleëner	B.C.G.			
Other Anders				

D-Diphtheria/Whoopingcough T-Tetanus/Elzem in die kook P-Whooping Cough/Kudhoes
*Only if no evidence of previous vaccination (scar or active vaccination).
*Slegs indien geen bewys van vorige immunisasie (litteken of aktiewe immunisasie).

The R.W.s found this confusing. It is necessary to know the child's age, then the list of immunizations has to be looked at. The date of each immunization is written down.

Then the R.W. has to work out if the immunizations are up to date or not. Most people struggled with this and we have had to do a follow up session on the pink card.

To make it easier to understand, we looked at this sheet.

IMMUNIZATION

Children should be immunized to protect them against certain diseases.

Breastfeeding provides the child with a natural immunity.

Immunizations must be done when the child is the right age.

Mothers have a right to ask about immunizations if they do not know or understand what they are all about.

MONTH.	1	3	4½	6	9	15	18
BCG	✓	✓					
D.W.T		✓	✓	✓			✓
Polio		✓	✓	✓			✓
Measles					✓	✓	

One thing which you will see fairly often as R.W.s, is that children with epilepsy or mental retardation should not get the whooping cough immunization, as it can affect them.

I.5. ORAL REHYDRATION

Aims of this session:

1. To understand the causes and effects of diarrhoea.
2. To see how diarrhoea can be prevented and treated.
3. To learn how to identify a dry or dehydrated child.

Teaching aids:

1. All the ingredients used to make a salt-sugar solution: salt, sugar, water, a litre bottle, and a teaspoon.

1. Diarrhoea.

What is diarrhoea?

It is a runny tummy.

Yes, your child has diarrhoea if she has more than one watery stool a day.

Is diarrhoea common?

I have 3 children and each one of them has had diarrhoea many times so I would think it is common.

Yes, it is common. At what time of year is it most common?

My boy seems to get diarrhoea most often when it is very hot.

A. The causes of diarrhoea.

Diarrhoea is caused by a germ, which likes to live in places which are overcrowded and dirty, especially if there are no toilets and people have to use the ground or buckets as their toilet.



If a person doesn't wash their hands after they go to the toilet and they touch food, the germ jumps onto the food and waits there until it is eaten. When the food is eaten the germ will enter the stomach, causing the stomach to become upset and get diarrhoea.

Flies, which are always present in large numbers in areas where rubbish lies around and in areas where there are not proper toilets, often cause the germs to spread by sitting first on rubbish or stools and then sitting on food. On their feet they carry germs to the food. When a person eats this food, the germ enters their stomach and causes diarrhoea.

These germs prefer the heat to the cold. Flies are also more common in the heat than the cold. This is why diarrhoea is more common when it is hot.

B. The prevention of diarrhoea.

Do you think it is possible to stop these germs from causing diarrhoea?

Yes, the germs enter people when the person eats food on which germs are sitting.

To prevent the germs from getting onto food, it is important

- to wash your hands after you have been to the toilet.
- to keep food and plates and cups covered so that flies are not able to transfer the germs.
- to wash fruit and vegetables before they are eaten.
- to try to keep things as clean as possible.

C. The dangers of diarrhoea.

What causes a child to become dry (dehydrated)?

If a child gets diarrhoea and vomiting or if a child bleeds a lot.

If a child loses blood this is very serious. The child will go into shock if a lot of blood is lost and can even die if the blood is not replaced.

The most common cause of a child becoming dry is diarrhoea and vomiting.

As the child becomes dry this can damage certain parts of the body. As R:Ws you will sometimes see babies who have started to fit as they have become dry as a result of diarrhoea. This in turn causes brain damage and any number of serious complications. A baby can also die as a result of being too dry.

What do you see in this picture?

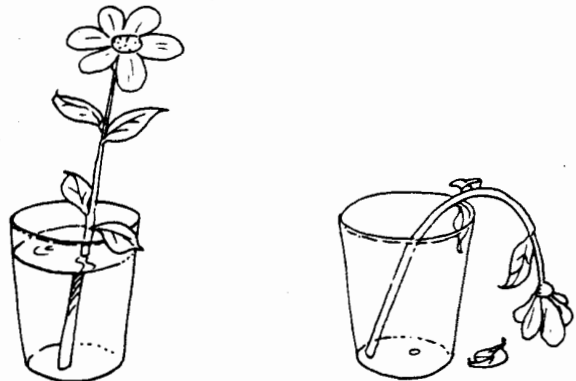
There is a flower that looks well and pretty and one which has wilted and looks dead.

What usually causes a flower to wilt?

No water.

Does the wilted flower have water in its glass?

No, none at all, whereas the flower that looks well has lots of water.



A child with diarrhoea is similar to a flower without water, the child will become listless and floppy and if the fluid is not replaced, may even die.

D. Learning how to identify a dry child.

Have any of your children ever been dry?

Yes, I have 3 children, each one of them has at different stages had diarrhoea and vomiting. One of them got so dry he had to go to hospital.

What did he look like? Does this picture remind you of your son when he was dry.

Yes it does. His eyes were sunken and his mouth was dry.

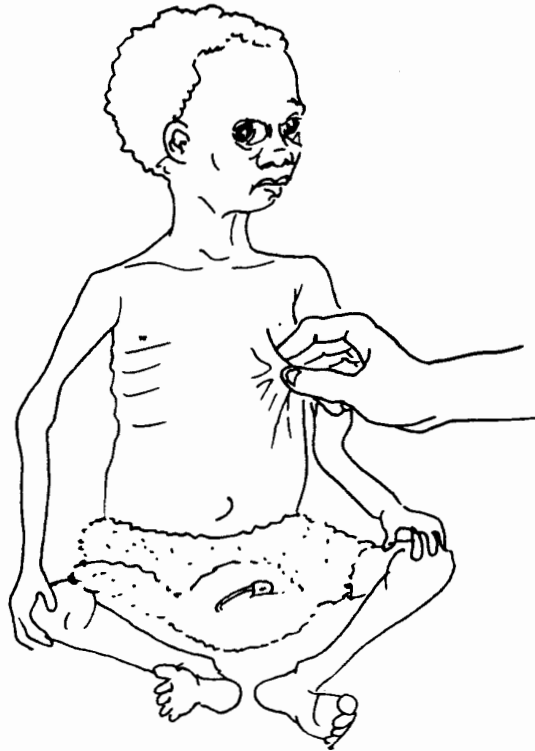
His skin was sticky and if I lifted it up with my fingers as in the picture, it almost seemed to stay there. The fold took time to disappear.

Did the fontanelle, this gap on the top front part of the head sink?

Yes, it seemed to go down.

These are the four signs most often seen in a child who is dehydrated:

- eyes sunken
- mouth and tongue dry
- skin sticky
- sunken fontanelle



My child who got diarrhoea stopped weeing is that not a common sign of dryness?

This happens if the child is very, very dry and so it is not that commonly seen.

2. Treating diarrhoea.

How is diarrhoea traditionally treated?

A child with diarrhoea is given enemas. This will increase the diarrhoea so that the spirit which is causing the diarrhoea is quickly removed from the body.

It makes sense that the cause of the diarrhoea should be removed from the body as quickly as possible. The danger of diarrhoea for a child though, is that through losing too much liquid, the child may become very ill and even die.

If a plant is wilted, what do we do for it?

Give it water and soon it will start to look better and stand up straight again.

A child is just like a plant, the child must be given water to replace the water that the child has just lost through the diarrhoea. The body itself will kill the germ that caused the diarrhoea, provided it gets enough water.

Enemas will actually cause the child to lose more water than she has already lost through the diarrhoea.

Diarrhoea is not fatal as long as the fluids are replaced by drinking more water.

A. The salt sugar drink.

Read this pamphlet called "Xa isisu somntwana sihambisa mnike lo mxube uza kumnceda" (How to help your child when he has diarrhoea.)



Now get into pairs and make the salt sugar drink using:

- 1 litre of water
 - 8 teaspoons sugar
 - 1/2 teaspoon salt.
-
- It is very important to wash your hands and the bottle.
 - If the water comes from a tap this is OK, but if it comes from a stream, it must be boiled.
 - Once you have made the solution, it must be covered.
 - A fresh solution must be made daily.

Having made the solution, each person tasted it.

How often should this drink be given to a child with diarrhoea?

It should be given to the child every time the child has a stool. The child should be given as much of the salt sugar solution as she has lost, between 1/2 and a 1 cup. For a big stool she should be given a larger drink of the salt sugar solution.

B. "How to make the salt-sugar rehydration drink". (A Xhosa song.)


We then learnt the song that the community health workers sing to teach mothers how to use the salt sugar drink.

Xa usenz umxube

Transkei health workers

$\text{♩} = 120$

d r a r d d r a r d



1. Ia u senz' um - xu - be Tha - ba th' i - li -
 2. I - ti - spune e - si - si - bho zo swe ki -
 3. Ga - le la na - na, Ga - le la na -
 4. Hlu - ku hla na - na, Hlu - ku hla na -

a d a r d d d r d t d



tha. Ga le - la na - na ga le - l' a - nan - zi.
 le. I ha - fu ye ti - spun - i ye ty - u - wa.
 na, Ga le - la na - na u sez' um - twa - na.
 na, Hlu ku - hla na - na u sez' um - twa - na.

° English translation of the song.

1. When you make the mixture: take a litre; pour mama, pour the water (into the litre).
2. 8 teaspoons sugar, 1/2 a teaspoon of salt.
3. Pour mama, pour mama, pour mama: give it to the child.
4. Shake mama, shake mama, shake mama: give it to the child.

C. Referring to a clinic or hospital.

The child with diarrhoea must be taken to a clinic or hospital for the following reasons:

- if there is blood or pus in the stools
- if the child has a high fever, more than 38,5 C
- if the child has stopped weeing
- if the child cannot drink as he is vomiting
- if the child has diarrhoea for more than 3 days

D. What to do if you see a child with diarrhoea. (Step by step)

1. Try and see the stool to check it has no blood. Ask the mother if the child has had any stools with blood.
2. Check the child is not dry using the 4 signs of dryness.
3. If the child is not dry advise the mother about the treatment and prevention of diarrhoea.
4. If the child is dry refer the child to a community health worker (CHW).
The CHWs see diarrhoea often and are experienced in assessing whether the child should go quickly to the clinic or hospital.

E. Diarrhoea and handicapped children.

Why do you think it is necessary for you as R.W.s to know about diarrhoea?

Handicapped children get diarrhoea. If we know what causes it we can discuss this with mothers whose children have diarrhoea so that they too can learn how to prevent it.

Is it easy to give a handicapped child water?

It depends on which child it is. In the case of the more severely handicapped children it is very difficult as they struggle to swallow.

What will happen if a child who struggles to swallow gets diarrhoea?

She will easily become dry and could die if the mother does not take her to hospital.

Do handicapped children often get diarrhoea?

Yes, it seems that my handicapped child has diarrhoea more often than my other children had.

Handicapped children seem to become ill and get diarrhoea and other problems more often than other children. They take longer to recover because they are not as strong as ordinary children.

II. NORMAL BODY FUNCTIONS



Mother carrying handicapped child and her younger sister.

II.1. THE SKELETON AND MOVEMENT

Aims of this session:

1. To understand the structure of the skeleton, and how the structure is well suited to the functions of the skeleton.
2. To understand the functions of the skeleton.
3. To understand what parts of the body are involved in normal movement and how their structures are well suited for their functions.

Teaching aids:

1. A real skeleton as well as a loose collection of the individual bones.
2. A diagram of the skeleton.

1. The functions of the skeleton.

A. To keep the body upright.

When you are building a shack, what do you start with?

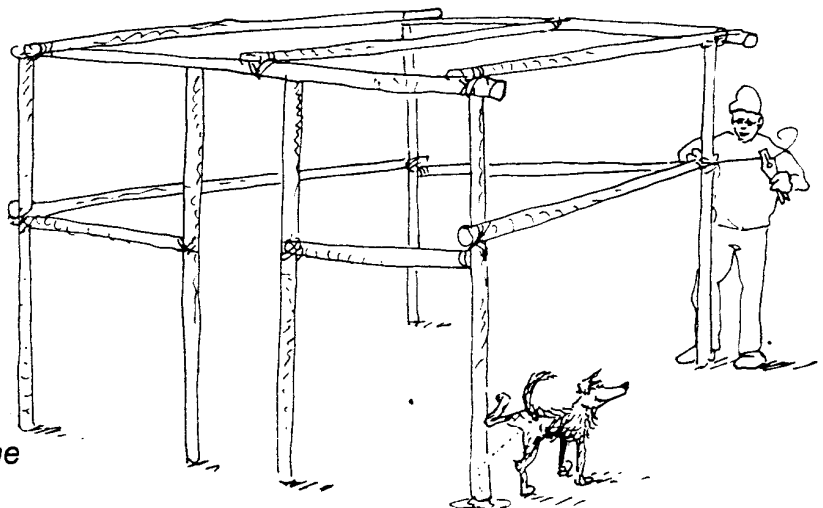
The poles.

What are these poles like?

They are strong. There is one at each corner of the shack. If it is a big shack there will be one or two poles in the middle of the shack.

Why are the poles needed?

They are needed to keep the shack upright. Without the poles the shack would collapse.



What makes up the skeleton?

Bones.

What are bones like?

They are hard and strong, just like the poles of a shack.

Why do we have a skeleton?

To keep the body upright and prevent it from collapsing into a heap.

Are the bones well built to keep the body upright?

Yes, because they are hard and strong.

The first function of the skeleton is to keep the body upright.

B. To provide a structure.

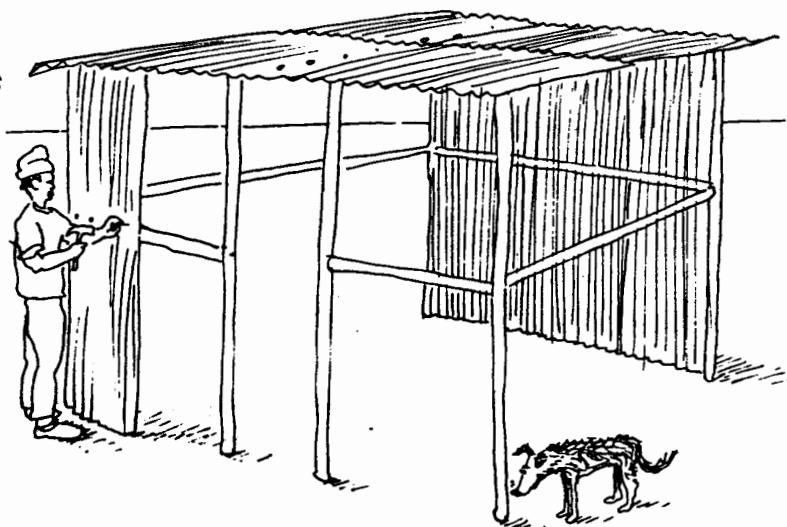
When you are building a shack, after you have put the poles into the ground, what do you do next?

The walls and roof are made, by attaching zincs to the poles. Then the inside is sorted out, the floor put down and the furniture brought in.

Why are poles needed?

Poles are needed to attach the walls and roof to.

The skeleton of the body, is like the poles of a shack, it is the starting point around which everything else is attached to and fits inside.



The second function of the skeleton is to provide a structure into which things fit or to which they can be attached.

C. To protect delicate organs and structures.

Why do we need strong poles for a shack?

So that the shack will be strong enough to keep out the wind and rain, and protect people and things.

Likewise, the skeleton also protects the important body organs.

Looking at the skeleton can you see all the different types of bones that make up the skeleton. The bones are of different shapes and sizes.

Look at the skull, what does it look like?

It is round and hollow.

What fits inside the hollow?

The brain.

So what is the skull for?

It is a protective cage for the brain.

Look at the ribs, look at the cage they make, what do they do?

They protect the heart and lungs.

Look at the pelvis, it also forms a hollow surrounded by bone, what is it for?

To protect the bladder, reproductive organs and developing baby (in women).

So we have 3 cages for protection, one on top of the other.

What keeps them one on top of the other?

The backbone, which is made up of many small bones.

These small bones are known as vertebrae. There are 33 vertebrae in all that make up the backbone. The bones are grouped into 5 different groups:

7 neck bones (cervical vertebrae)

5 upper back bones (thoracic vertebrae)

5 lower back bones (lumber vertebrae)

5 joined hip bones (sacrum)

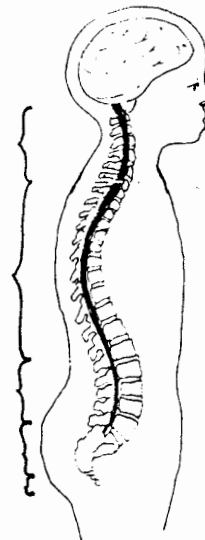
4 tailbones (coccyx)

7 neck bones

12 back bones

5 lower back bones

5 joined hip bones
4 tail bones

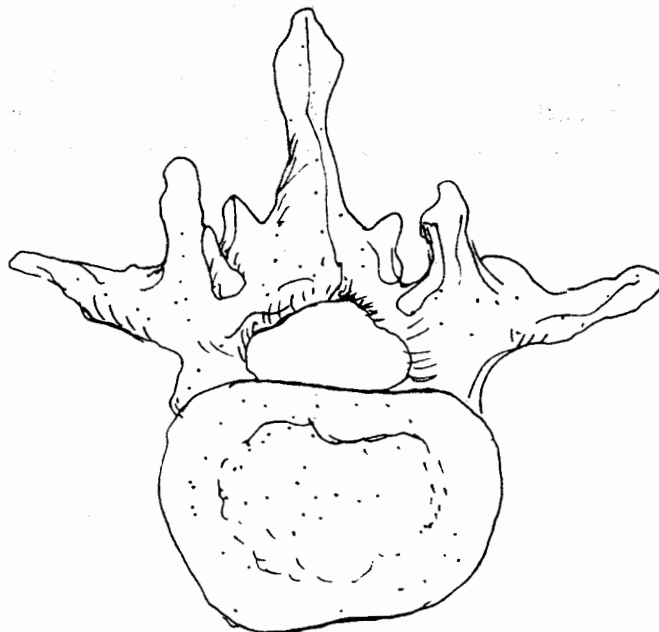


This is one of the bones of the back, a vertebra, what shape is it?

It is flat, fat, and short. So the backbone is formed by these 33 bones fitting 1 on top of the other.

When you kill a sheep and eat the small bones which make up the back, what is the soft juicy stuff that you suck out from the holes?

It is the nerves. Together these nerves make up the spinal cord. The spinal cord runs down the hole in the middle of the vertebrae. So the backbone is also for protection, the protection of the nerves of the spinal cord.



Why is it that the brain, heart, lungs, bladder, womb (in women) and spinal cord are so well protected by bone?

These organs are essential for life, and if they are damaged, life will be threatened.

Look at the bones that make up the skull, the pelvis and the backbone (the ribs are an exception).

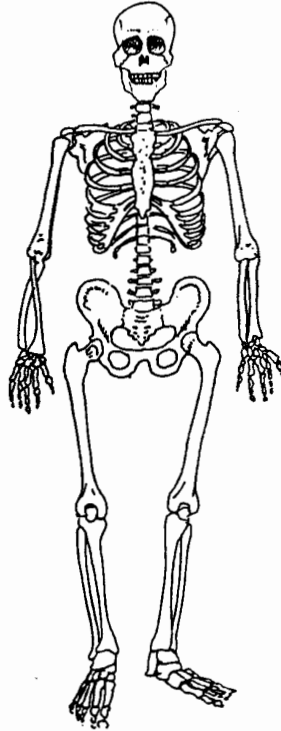
What is the shape of these bones?

They are thick, short and strong.

Being short, thick and strong do you think these bones are strong or will they break easily?

They are strong and difficult to break, so that they will protect the different organs well.

- skull - protecting the brain
- ribs - protecting the heart and lungs
- pelvis - protecting the bladder and womb
- backbone - protecting the spinal cord



As these bones are strong and difficult to break, damage to the structures inside these bones only results from powerful forces, such as motor car accidents, falling off a horse, bullet wounds, falling out a tree, stabbings.

So the third function of the skeleton is that of protection.

D. To allow free movement.

What is a big difference between a shack and a body?

A body should move, but a shack should not!

What do we mean by the word movement?

Getting from one place to another.

Think of a shack with one long pole in each corner, each pole going from the floor to the ceiling, and everything secured tightly. What difference would you expect to find in the body?

The body will be made up of shorter bones with joints so that it can move.

Yes, that's correct.

Looking at the picture of the skeleton, we have left out quite a bit of it. What have we left out?

The 4 limbs.

What are the limbs for?

For moving.

What is the shape of the bones of the arms and legs?

They are long and thin.

Are the bones heavy?

No. They are hard and strong, but they are also light.

This means that they are brittle and can break quite easily, rather like a china cup.

If they were heavy would they be easy to move?

No, but being light they are easy to move and can be picked up quite easily without the use of too much energy.

As they are long and thin, there is also room for muscle attachment.

What is there where 2 bones meet, like at the elbow?

There is a joint.

What happens at a joint?

Movement occurs.

Why are joints suitable for movement?

The joints are covered in a smooth material called cartilage, so that if movement occurs at the joint the movement is smooth.

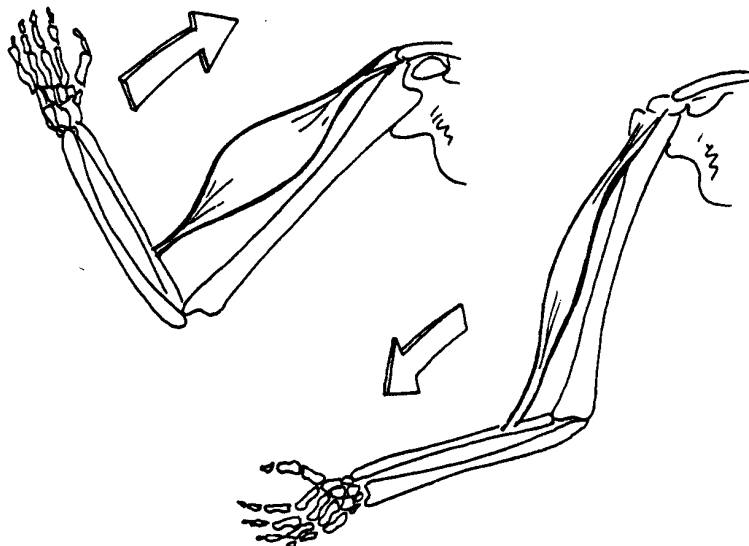
Also the joints are surrounded by a capsule, and there is liquid in the capsule. This is like motor car oil and lubricates the movement so that it is smooth.

What else is used in movement?

The muscles. These provide the energy or power for movement. The muscles are attached to the bones.

What causes us to get up and move or go from one place to another?

It is our brain. Because of a certain desire or need which must be fulfilled, the brain initiates the need for movement. For example: If I am hungry it is my brain which will tell me to get up and walk to the kitchen.



How does the message from the brain get to the muscles?

The nerves carry the message.

The muscles then perform the movement.

So necessary for movement are:

- bones
- joints
- muscles
- brain
- nerves

In what way are these different structures suited to movement?

- The *bones* are strong and light so they can move without too much energy being used.
- The *joints* are smooth enabling the bones to move easily on each other.
- The *muscles* do their work well for two reasons:
 - * there is a muscle or group of muscles for each movement.
 - * the size of the muscle is suited to the type of work it does. For example: small muscles perform small movements.
- The *brain* works very quickly co-ordinating the whole movement so that it is accurate and effective.
- The *nerves* conduct messages very quickly.

So the fourth function of the skeleton is to allow for free movement.

To summarize:

The four main functions of the skeleton.

1. Keeping the body upright - the bones are hard and strong.
2. Protection - the bones are hard, heavy, thick and strong.
3. Structure (the bodies framework onto which everything else is attached to or fits inside) - the bones are hard and strong and there is room for muscle attachment.
4. Movement - the bones of the arms and legs are long, strong and light.

2. The spinal cord.

A. A line of nerves.

What is the spinal cord?

The spinal cord is a line of nerves.

What protects the spinal cord?

The backbone made up of 33 short, strong vertebrae.

The vertebrae fit one on top of the other to form the backbone which protects the spinal cord. In between the different vertebrae are small holes. It is here that the nerves enter and leave the spinal cord.

When a sheep is slaughtered, do you see the nerves?

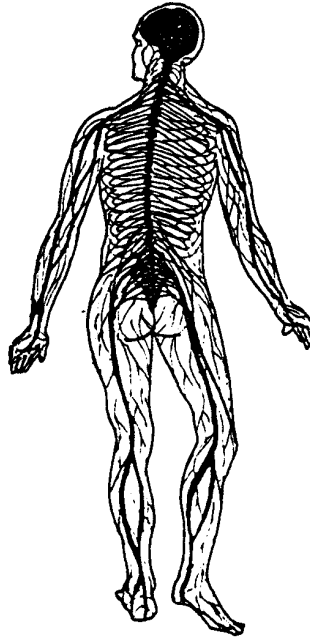
Yes, they are like thin pieces of white string.

What are nerves?

Nerves carry messages throughout the body.

They either carry messages:

- down from the brain to the rest of the body, or
- up from the body to the brain.



° From the brain to the body.

The nerves from the brain run down the spinal cord, and out through the holes to all the parts of the body.

What messages do they pass on to the different parts of the body?

They tell the body to move in an appropriate and controlled way.

° From the body to the brain.

The nerves from all parts of the body run towards the spinal cord. They enter the spinal cord through the holes. They then run up to the brain in the spinal cord. They pass on messages to the brain as to what the different parts of the body are feeling and what position they are in.

What are the different kinds of feelings that we experience?

- * *hot/cold*
- * *pressure/light touch*
- * *sharp/blunt*
- * *position sense.*

B. The nerves for the different parts of the body.

Between the neck bones the nerves going out of the spinal cord are those that control the movement of the arms and hands. The nerves going in between the neck bones are those that carry information about the feeling in the arms and hands.

Between the backbones of the chest nerves go in and out.

What area of the body are they concerned with?

The chest.

What kind of information are they passing on?

Information about the feelings and movement of the chest.

Between the lower backbones, the nerves going in and out control the movement and feeling of the bottom and the legs. Nerves from this area also control the bladder and bowels.

The joined bones at the bottom of the backbone and the tailbones form part of the pelvis. No nerves go in or out here.

C. An example.

Look at my hand. It is holding this handkerchief. Nerves in my hand close to the skin feel that there is something soft in my hand and that my hand is on the table.

Where do these nerves go?

They run up the arm and enter the spinal cord at the neck.

They go in the holes in between the neck bones and then run up to the brain where they tell the brain that something soft is in my hand and my hand is on the table.

My brain knows that it is a handkerchief and because my nose is running I must bend my arm and turn my hand so that I can blow my nose on the handkerchief. This message is carried from the brain down the spinal cord in a nerve. It leaves the spinal cord at one of the holes in between the neck bones. The nerve runs down the arm and tells the muscles there to move. They then move and take the handkerchief to my nose.

II.2. NORMAL MOVEMENT OF THE JOINTS

Aims of this session:

1. To understand the normal movement possible in the joints.
2. To recognise when movement is not normal.

Note:

The exercises in this session illustrate the normal movement possible for a person. It is important for a R.W. to know this. These exercises may, however, also be used for stiff joints. In this case they should be repeated ten to twenty times a day.

1. The arm.

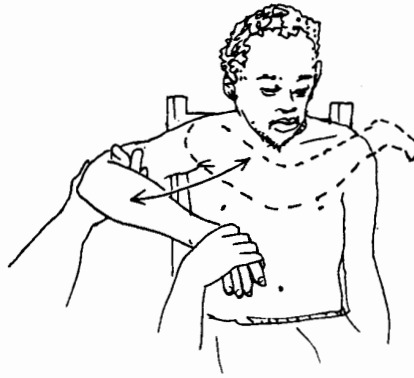
The person to whom the exercises are being done is sitting in a chair. The R.W. who is doing the exercises, faces the person in the chair.

A. The shoulder.

- Hold the hand and the elbow. Move the arm forwards, keep the hand facing the body, and lift it up so that the arm is lifted until it is next to the ear. Then put it down next to the side. The elbow is also bent and straightened.
- Holding the elbow and the hand, lift the arm away from the body out to the side. Put the arm down at the persons side.



- Holding the elbow bent and the hand so that the elbow and hand are level with the shoulder, move the shoulder so that the arm crosses the body at the level of the neck. Return to the starting position.



- Holding the elbow bent, hold the hand as well, move the forearm towards the stomach and away from the person, to turn the shoulder in and out.



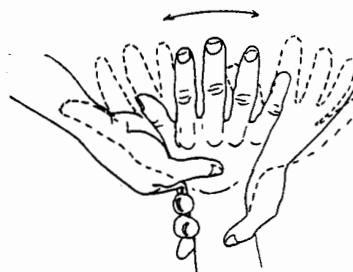
B. The elbow.

- Holding the elbow and the wrist, bend and straighten the elbow.
- Holding the elbow and the wrist, turn the forearm, to avoid stiffness at the elbow.



C. The wrist.

Hold the forearm near the wrist and the hand. Move the wrist backwards and forwards.

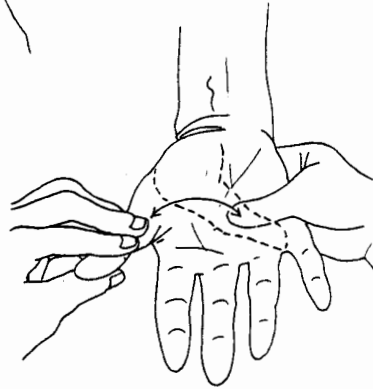
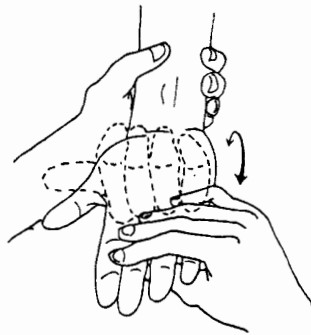


Hold the forearm near the wrist and the hand. Move the wrist from side to side.



D. The hand.

- Hold the palm of the hand and the fingers:
 - * Bend and straighten the fingers.
 - * Open and close the fingers.
- Hold the palm of the hand and the thumb:
 - * Bend and straighten the thumb.
 - * Move the thumb over to the base of the little finger and back.

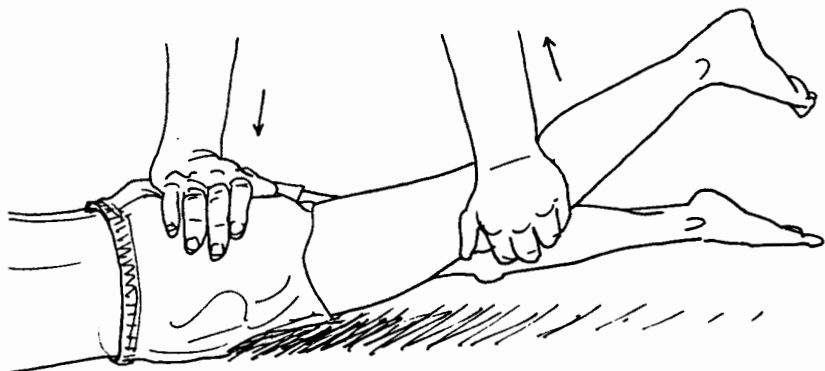
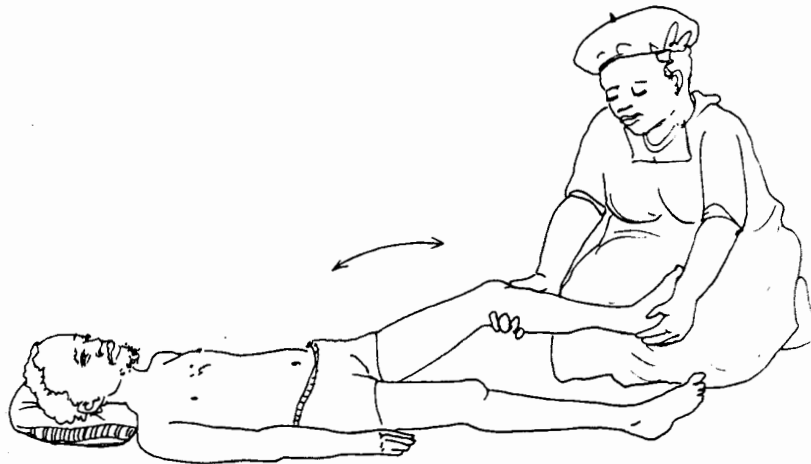


2. The leg.

The person lies on her back at all times except when specifically mentioned.

A. The hip.

- Hold the person's knee and foot. The knee must be supported and not allowed to fall straight as this can cause the person pain. Bend and straighten the hip and knee.
- Move the other leg out to the side. Hold the person's knee and foot. Move the leg out to the side and then back to the middle.
- Roll the leg inwards and then outwards as far as it will go.
- Lie the person on her tummy. The one hand must hold the pelvis down. With the other hand under the knee, lift up the leg, but keep the pelvis on the floor.

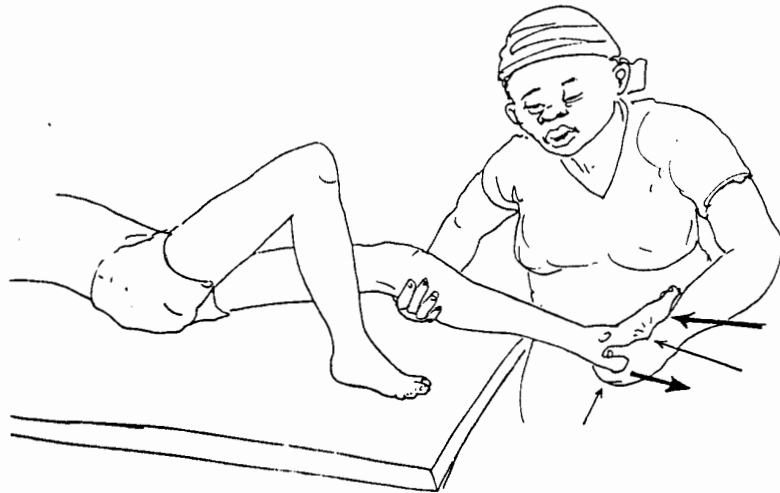


B. The knee.

- Hold the person's knee and foot. Bend and straighten the knee.

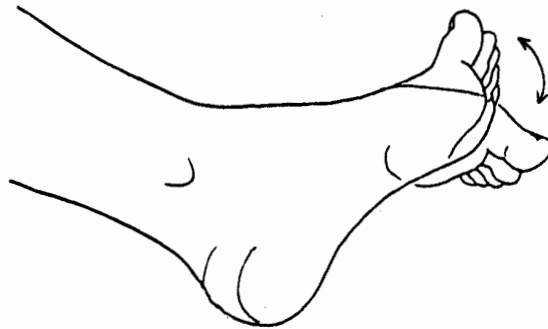
C. The ankle.

- Hold the person's knee to keep it straight and with your other hand grasp their heel so that their foot lies on your forearm. With this grasp you can bend the ankle up. To push the ankle down move your hand from their knee, to push down on the top of their foot.



D. The toes.

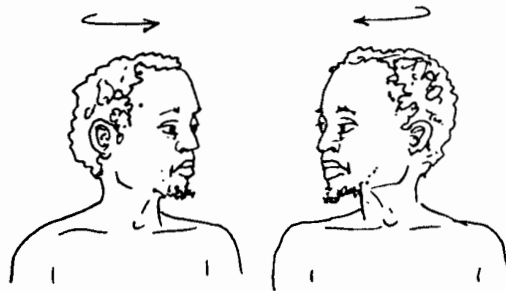
- Hold the ball of the foot. Bend and straighten the toes with your other hand.



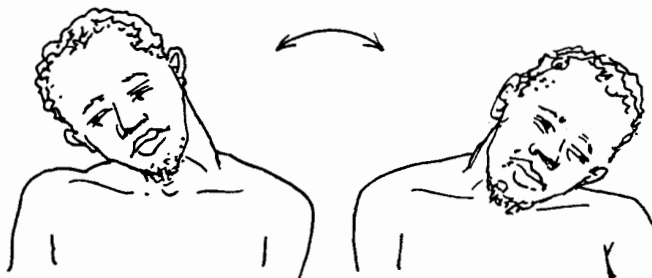
3. The neck and back.

A. The neck.

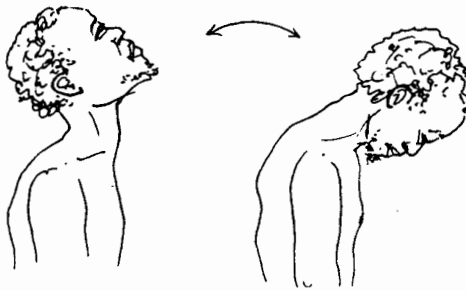
- Turn head to right and left.



- Move the head from side to side, to bring each ear in turn down to the shoulder.

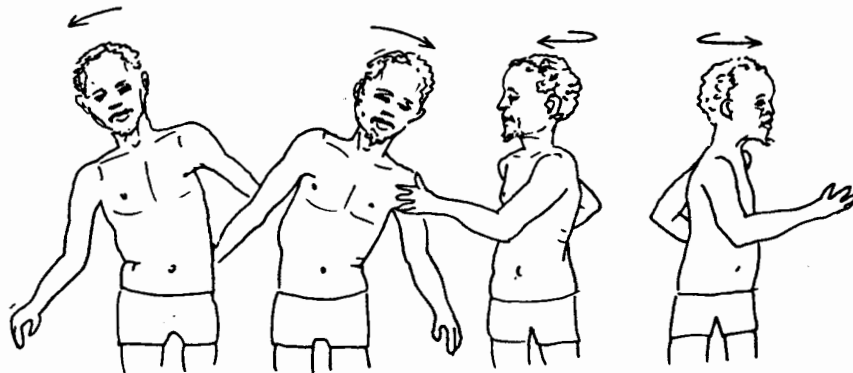
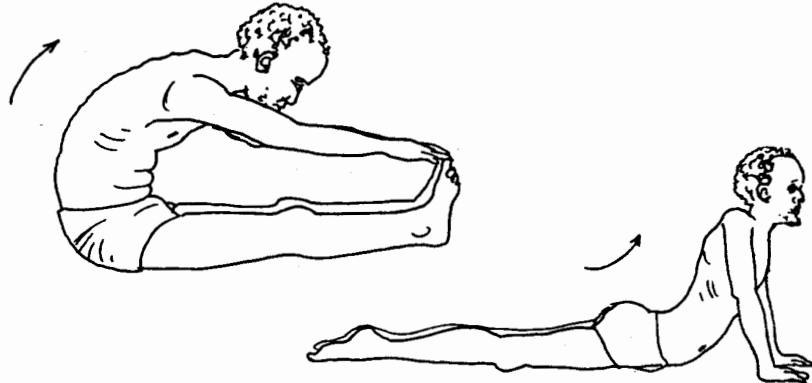


- Lift the head up and down.



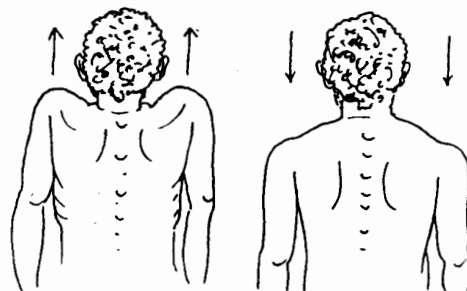
B. The trunk.

- Bend back.
- Bend forwards.
- Bend sideways.
- Twist.



C. Upper back (shoulder blades).

- Bring the shoulders forward and push them backwards.
- Lift up shoulder to your ears and push them down.



II.3. NORMAL DEVELOPMENT

Aims of this session:

1. Recognize the main motor and speech development milestones and when each step is reached.
2. To learn what is needed for a child to develop normally.
3. To understand what can slow development down.
4. To recognize the importance of R.W.s to know the normal pattern of speech and motor development.

Teaching aids:

1. Set of cards illustrating development.
2. Section from *Disabled Village Children* (by David Werner)

1. The necessity of development.

A. What is development?

What can a baby do when it is first born?

All it can do is to lie on its back or its tummy, drink from its mothers breast, cry if it is uncomfortable and wee and poo.

What does a baby grow into?

An adult.

What are the things that we as adults do each day?

We get up and wash, wash and dress the children, cook, eat, work, talk and walk.

The growth and changes that occur from when a child is first born, to when the child is an adult, are known as the development of the child.

Development is the changes that occur in the baby's body, mind and relationships, so that as he grows, he learns to stand upright, walk, talk to other people and do small precise movements with his hands.

Development is necessary for an adult to be able to live an independent life. If development did not occur the grown up adult would only be able to lie, sleep and cry and would need to be fed.

A child develops in 3 main areas:

- * Physical (body)
- * Mental (mind)
- * Social (communication)

B. The needs of a child for development.

What does a child need to develop normally?

- *Loving parents who play with and stimulate the child.*
- *Good food so that the child is strong.*
- *A house which is not too cold so that the child does not get sick.*
- *Stimulation from ordinary day to day interaction with people and things.*

What slows development down?

- *Malnutrition, disease, no stimulation, damaged brain, bones, nerves or muscles.*

2. Patterns of development.

A. Physical development.

We will be dealing mostly with the development of body control. We will discuss the average age when children start to do things, but this is just a guide line and the ages at which normal children develop different skills varies.

Sometimes a child may learn to sit or stand a couple of months earlier or later than is written here. This is no problem and no reason to worry. If however, the child sits a year later than is written here, there is something wrong.

Which part of his body, does the child learn to control first?

His head.

After a child has developed head control, he will develop trunk control.

How old is he when he develops head control?

3 months old.

And next?

He learns to roll at 5 months old.

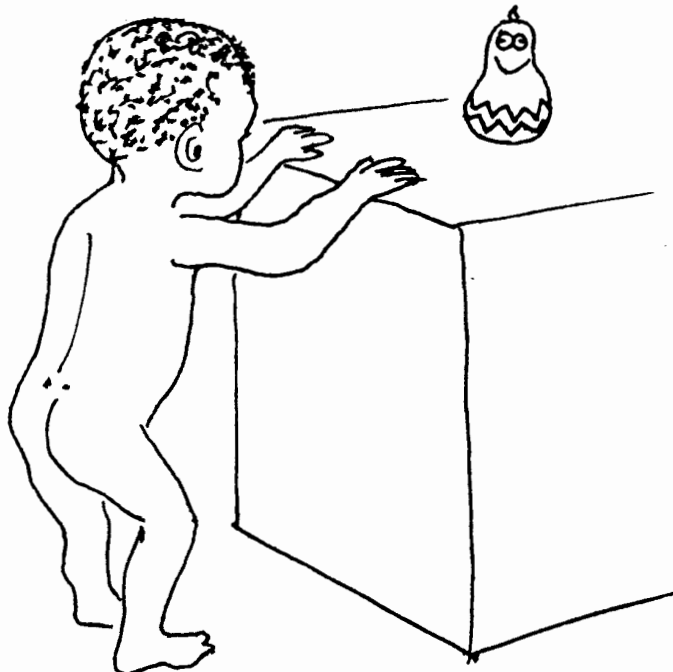
He learns to sit at 6 months old. To start with he sits very briefly and falls over easily, but then he is able to sit for longer and is more stable.

What does he do then?

He pulls himself up to standing using the edge of a bed or a chair at 9 months old.

When does he start to walk?

At 12 months he starts to walk holding onto the furniture.



At 1 year 3 months he starts to walk by himself.

At 2 he learns to run.

Children learn how to move their head and body before their arms and legs. After this they learn how to move and control smaller movements such as the hands and fingers.



B. Development of speech.

Does a child learn to speak overnight?

No. Its like the development of movement that we have just spoken about. It takes a long time.

What does the child learn to say first?

"Mama" and "Tata"

How old is the child when he starts to say these couple of words?

1 year old.

What does he learn to say next?

He will put two words together, like "mama iza" and "hamba tata." ("Go away," and "Come here")

He is 2 years old when he learns to do this.

What is next?

At 3 years old he can say short sentences, "ndiyafuna isonka," "ndiyafuna umcamu." ("I want bread." I want to wee.)"

C. Summary.

Development of the control of big movements.

Head control - 3 months

Rolling - 5 months

Sitting - 6 months

Standing - 9 months pulling up holding onto furniture

- 12 months walking holding onto furniture

Walking - 1 year 3 months

Running - 2 years.

Development of speech.

1 year - a few single words, "mama" and "tata"

2 years - 2 words together, "come here," "go away"

3 years - Short sentences, "I want bread."

Is development a slow or a quick process? Does the baby who is born today, walk tomorrow?

No, development is very slow. Looking at the normal pattern of development that we have just drawn up, it takes a year for a child to walk and 2 years for a child to learn to run.

Does a child ever learn to run before he can sit?

The baby learns different skills step by step in the order which we have drawn up above.

Some children may miss one step though and they may not crawl and will go from sitting to standing. There is nothing wrong with this.

3. Helping a child with delayed development.

A. Handicapped children have delayed development.

As R.Ws. you need to know the pattern of normal development and when each new stage is reached.

Delayed development is often the first and most clear indication that a child is handicapped. When working with children with delayed development:

- Work out at what stage of development the child is.
- Work out the next stage of development so that the child can learn new skills in the same order in which a child normally develops.

If a child's development is delayed, he needs stimulation and activities to help develop all the areas of his body and mind.

Children who have slow development need the same stimulation that any child needs.

They need extra help however to have activities adapted for them and will need to repeat the activity many times.

Activities will have to be adjusted for each child depending on his stage of development and specific disability.

For example: A blind child cannot see things which will make him want to reach for things and explore. He needs to be encouraged to use his senses of sound and touch to explore.



B. Suggestions for stimulating handicapped children.

- Children must be in a *normal and comfortable position* before they can move, play or learn.
- *Be patient and observant.* Children need to practise things again and again until they get them right.
- The first few times that a child does an activity, guide his movements with your hands, after he has learnt how to do it with you, he can do it by himself. Another way to teach a new activity is to get the child to imitate you. This can become a game.

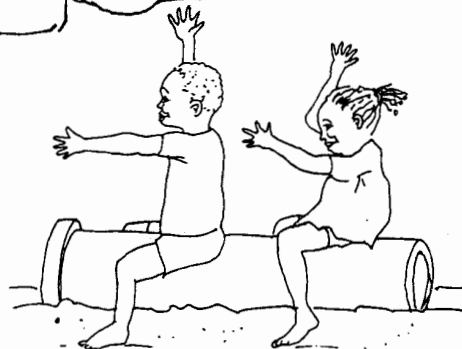


- *Be orderly and consistent.* Respond in a similar way to the child each time. Do things in the same order. Children are easily distracted so it is best to play with one toy at a time.
- *Use variety.* Repetition is important but the child will get bored so things need to be varied.
- *Be expressive.* Praise and encourage him often, giving him a hug if he achieves the activity. Speak clearly and simply to the child, explaining everything that you do with him.

- *Be practical.* Whenever possible choose skills and activities that will help the child to become more independent. If the child takes a long time to do something, don't take over, but help him so that he can learn to do it himself.



- *Make learning fun.* Children enjoy games far more than activities or exercises. Include learning activities in games; when the activity stops being fun, stop it for a while or change it. Encourage his brothers and sisters to play with him.



- *Encourage the child* to reach out or to go for what he wants. Don't always put what he wants into his hands.

We then read through the section in David Werner's *Disabled Village Children* (pp.302-316) which covers activities which encourage head control and learning to speak.

4. Revision of session.

To revise this session we used cards that Lies Hoogendoorn of the Child Health Unit (UCT and Red Cross Hospital) has drawn up. These cards include fine motor control, mental and social development. (See next page).




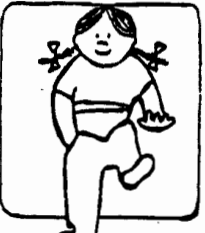
Working in pairs these 13 cards had to be put in the correct order in which a child develops. After putting the cards in the correct order, we discussed the different ages at which the child develops each of the skills represented on the cards.

Each person was then given a sheet of paper with all these cards arranged in the right order. Ages given for each of the skills represented on the cards.

smiles	- 2 months
sits	- 6 months
says "mama"	- 1 year
stands alone	- 1 year
walks	- 1 year 3 months
says single words	- 1 year, 6 months
toilet trained	- 2-3 years
kicks a ball	- 3-5 years
dresses, simple clothes	- 2 years,
undo buttons	- 4-5 years
stand on 1 leg	- 4 years
knows colours	- 4 years
draws a person	- 4 years

Limitations of this session.

We did not go through mental and social development in the same detail as the development of the body. Developmental problems in these areas of development are not always that easy to pick up because they need special testing. They may only become evident at school.

<p>Yintoni enokwenziwa ngumntwana wakho ?</p>		 Child Health Unit Development Clinic Cape Town	 Uyancuma
 Uyahlala	 Uthi mama	 Uzimela yedwa	 Uyahamba
 Uthetha izivakalisi	 Usebenzisa ipowu	 Ukhaba ibhola	 Uyazinxibela ijersey
 Uziqhubosha amaqhosha	 Uma ngomlenze omnye	 Uyayazi imibala	 Uzoba umntu

II.4. THE GROWTH AND WEIGHT OF CHILDREN

Aims of this session:

1. To understand the growth chart.
2. To learn how to plot a child's weight on the growth chart.
3. To recognise, with the help of the growth chart, whether the child is of average weight, underweight or overweight.

Teaching aids:

1. A balance scale and a standing scale
2. Growth charts.
3. A pink (clinic) card.

Reasons for this session.

Weighing was taught for two reasons:

- * as a screening technique to pick up handicapped children, (together with measuring head circumference and observing the development of the child.)
- * for follow up so that the R.W.s learn to expect that a handicapped child will not pick up weight and follow the normal curve on the growth chart.

At present the R.W.s do not have scales themselves, they refer the mother to a day hospital or a nutrition clinic to be weighed.

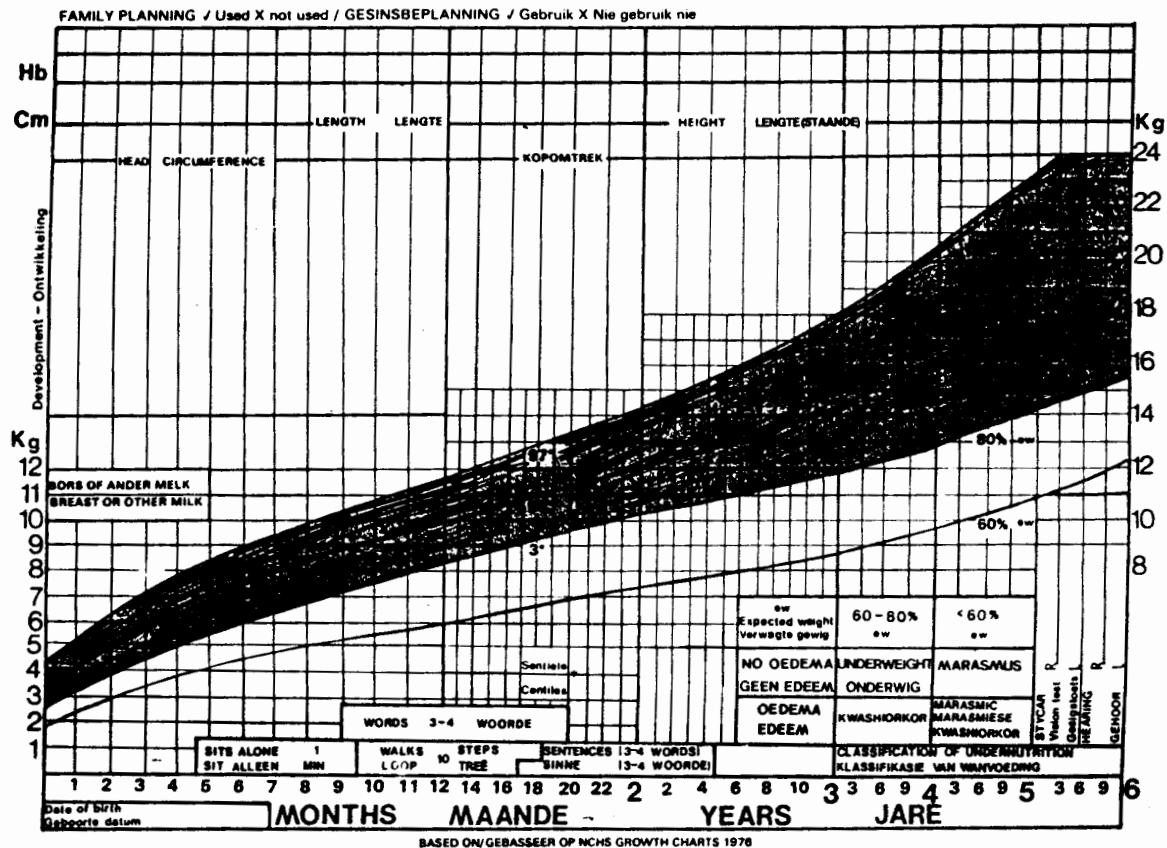
1. The growth chart.

A. Introducing the chart.

Do any of you know anything about the growth chart?

- * *I don't understand it at all.*
- * *I saw it used when my child was born and when I take my child to the clinic for immunizations or to see the doctor, I see that they use it there too.*
- * *I know that weights are plotted on it, but I don't know how.*

Let's look at the growth chart now. There is a lot of stuff written on it, but we are only going to look at a small bit of it. (See this on the next page.)



Running along the bottom of the chart is a thick line with numbers written on it. Underneath these numbers are the words "months" and the "years." The other two words here "maande" and "jare" are Afrikaans words for "months" and "years."

What do these numbers mean?

They represent the age of the child, either in months or years.

Point on this line to 2 months.

Point on this line to 2 years.

Point on this line to 2 years and 6 months.

Running up the page on the left is another line. On this line is Kg. What does Kg stand for?

It is used to weigh people or food.

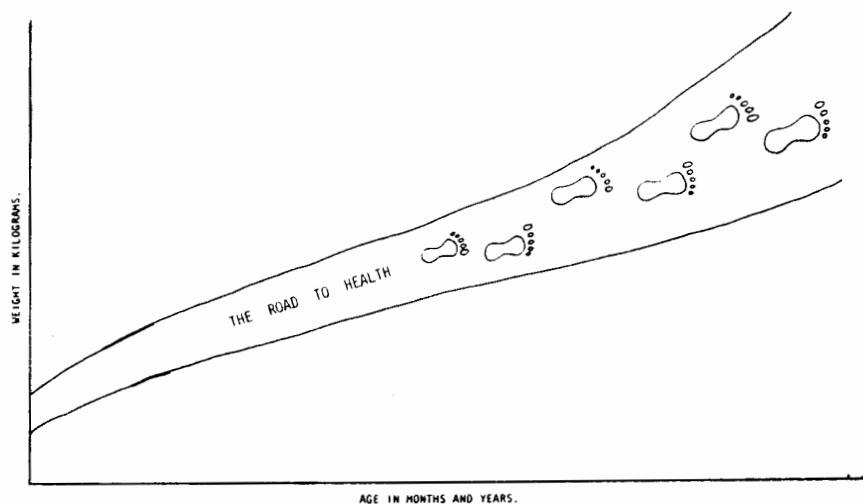
Yes, so the weight of the child, starting at the bottom of the page runs up the left hand side of the page getting bigger and bigger.

Point on this line to 1 kg.

Point on this line to 7 kg.

Point on this line to 18 kg.

B. The road to health.



In the middle of the page is a thick area which curves up the page. This is called "the road to health". If a child's weight falls somewhere in this area, their weight is normal for their age.

Why is the curve called the road to health?

If the child's weight falls on the road to health the child is less likely to get ill.

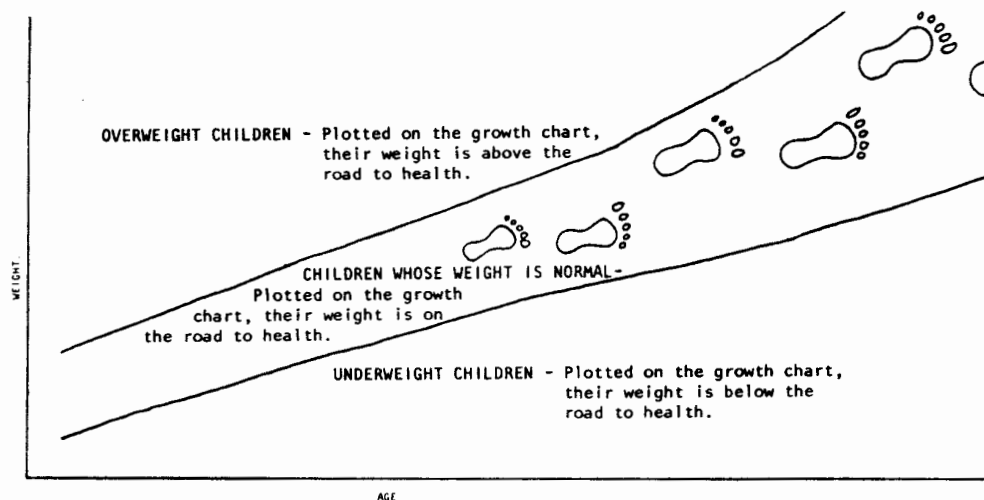
Yes, if a child's weight is normal, they are more likely to be healthy and will get sick less often.

What should happen to a child's weight as he gets older?

It should increase.

If a child is weighed and his weight is plotted on the growth chart, it should go up in steps staying on the grey area, the road of health.

Let's look at the 2 lines that form the border of the "road to health". These 2 lines represent the edges of the road to health or the boundaries of normal weight. If the child's weight falls outside this area, the child is no longer on the road to health.



If a child's weight falls above the area, the child is overweight. If the child's weight falls below the area, the child is undernourished.

Is it more common for children in the communities that you come from to be underweight or overweight?

Underweight, because people are so poor they cannot afford enough food or good food.

C. Average weight.

Now notice on the growth chart, the line in the middle, labelled 50* is the average weight for a child at any given age.

To work out the average weight for a child of 1 year old we find 1 year (or 12 months) and follow this line until it hits the line in the middle of the grey marked 50*. Where it hits this line we then follow the other line meeting here, which runs across the page. We follow this line until it hits the line with numbers representing weights marked on it. We then read, off this line, the weight of the child.

What is the reading on this line?

10kg.

This then is the average weight for a child of 1 year old.

Let's try another example.

What is the average weight for a child of 2 years old?

We would do this in the same way as we have just done for a child of 1 year old.

What is the average weight for a child of 2 years old?

12kg.

What is the average weight of a child of 2 years 6 months?

13kg.

3. Learning how to weigh children.

What are the two things we need to know to use the growth chart properly?

We need to know how much he weighs and how old he is.

How can we work out how much a child weighs?

Measure his weight on a scale.

A. The balance scale.

The use of a balance scale was then demonstrated:



- The scale was checked to ensure it was balanced before we started.
- The child was seated in the scale.
- The weights were moved, first the top one representing kilograms and then the lower one representing grams until the scale was perfectly balanced in the middle.
- When the scale was balanced, the weight was read and recorded.
- The mother was asked the birth date of the child.
- These 2 readings were then plotted on the growth chart to show whether the child was average or below average weight.

Each person in turn weighed a child, plotted where his weight fell on the growth chart and decided whether he was average or under weight.

B. The standing scale.

A much bigger child was put in the scale, but it was impossible to weigh him accurately as he moved constantly and his feet touched the table.

To weigh a bigger child, a standing up scale is used.

The standing up scale was then demonstrated:-

- The mother first stands on the scale and her weight is recorded.
- The mother then stands on the scale with her child in her arms and the weight is recorded.
- To work out the weight of the child, the first reading is subtracted from the second.

Using the standing scale is not as accurate as the balance scale.

C. The growth chart on the pink clinic card.

A pink clinic card was then examined to show where the growth chart is in relation to the child's name, mother's name and the record of immunizations. We also looked for the child's birth date.

3. The importance of the growth and weight of children.

A. The weight of handicapped children.

Why is this important for us as R.W.s?

I'm not sure because we are not going to be working at nutrition clinics.

Yes that is true, but what did you notice about the weight of the 3 of the children we weighed who were handicapped?

They were all underweight.

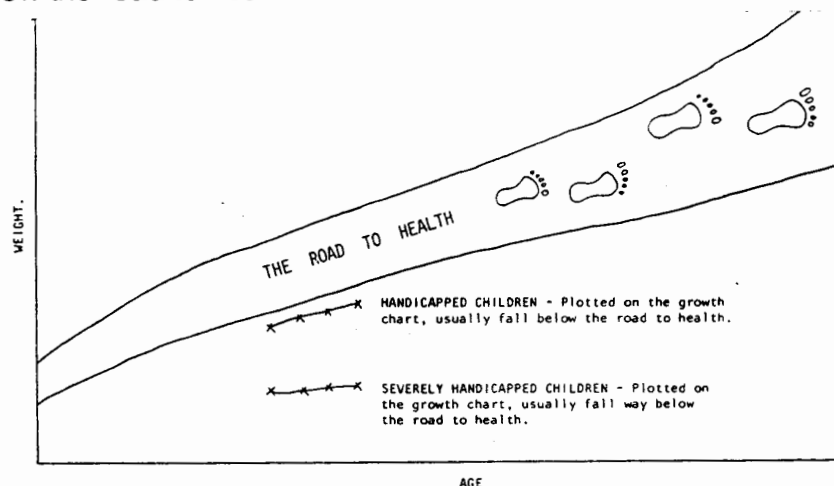
On the growth chart did their weight fall on the road to health?

No it fell below the road to health.

Most handicapped children are underweight, and fall underneath the road to health on the growth chart. If their weight is measured over a period of time, they will remain underneath the road to health.

Two factors influence the amount of weight a handicapped child will gain:

- the more severe the handicap of the child, the less weight he will gain so that his weight falls further and further below the road to health.
- if a child's feeding is affected, he will not gain weight easily and will fall further and further below the road to health.



Why do you think that most handicapped children are underweight?

- * *The mother may have no money to buy food to feed the child. She has no money as she has to stay and look after her child and cannot go out to work.*
- * *Feeding problems - It is so difficult to feed my child, as she keeps pushing the food out her mouth with her tongue.*

Are handicapped children sick more often than normal children?

My handicapped child has diarrhoea and also colds and coughs much more often than my other children.

This is often partly due to the fact that the child is underweight and so does not have the resistance to fight off germs and infections.

What can we do to help the mothers of these children?

- * *Show them how to feed their children correctly so that their feeding problem does not deteriorate further.*
- * *Teach them about nutrition, so that their child gets not only energy foods but body builders and protective foods as well.*
- * *Refer the mother to a social worker, to start applying for a grant so that with time the mother will have a small amount of money for food.*
- *

B. Weighing as a screening technique.

Handicapped children are often identified because they are underweight.

The other tests we use to work out whether a child is handicapped or not are:

- To measure the head circumference, to check whether the head is the right size. This we will look at in more detail in the session on Hydrocephalus (III.4)
- To check the development of the child, whether the child is developing normally or not. This we did in the previous session (II.3.).

C. Stunted growth.

Look at Nkosinathi who has cerebral palsy. How old do you think he is?

4 or 5.

He is in fact 7.

Does he seem tall or short for his age?

Nkosinathi is shorter than other 7 year olds usually are.

Handicapped children are usually shorter than normal children.

Look at Nkosinathi's legs. What do you think?

They are very thin. The muscles are very small.

Nkosinathi does not move normally or as much as a normal child, so his muscles are small.

Growth in handicapped children is often stunted as they have feeding problems. They cannot grow as they are not nourished properly.

In addition as the child does not move much or normally, not much blood goes to the bones or muscles so growth is inhibited.

Handicapped children are often stunted and short for their age.

III. CONDITIONS AND TREATMENT



Child with spastic quadriplegic cerebral palsy supported in a cardboard chair.

III.1. CEREBRAL PALSY IN CHILDREN

PLEASE NOTE.

There are five sessions under the general title "cerebral palsy in children". These are:

- a. Introduction to cerebral palsy in children.
- b. Children with spastic quadriplegic.
- c. Children with spastic hemiplegic.
- d. Hypotonic children.
- e. Children with athetoid cerebral palsy.

Each of the five individual sessions is named after its respective focus, but the use of the small letters in the numbering will serve to remind you that they are part of a broader whole.

Use of technical terms:

Please note that in these sessions we avoided the technical medical terms and used the following terms instead:

- * children with spastic quadraplegia or spastic hemiplegia - tight children.
- * children with hypotonia - floppy children.
- * children with athetoid cerebral palsy - children with strange, uncontrolled movements.

III.1.a INTRODUCTION TO CEREBRAL PALSY IN CHILDREN

Aims of this session:

1. To understand the causes of brain damage (cerebral palsy) in children.
2. To understand the effects of brain damage on children.
3. To learn how to help a severely brain damaged child.

1. The causes of cerebral palsy.

Cerebral palsy is a condition in which a child's brain is damaged before, during or shortly after birth. Although it is not possible to see the brain damage itself, we can see the results of brain damage on the child's movement, development and behaviour.

A. Before birth.

The following conditions may lead to brain damage in children before they are born:

- genetic conditions or congenital conditions, eg. Down's Syndrome.
- infections that the mother may have picked up during pregnancy, eg. German measles
- "poisons" that the mother may have taken while she was pregnant, eg. certain medicines, alcohol.
- malnutrition of the mother during pregnancy, if she is unable to afford a balanced diet.

B. During labour.

What may lead to brain damage during labour?

The brain needs a constant supply of oxygen.

If a child's brain does not get it for some time it will be damaged

- if the cord is in a knot.
- if labour takes a long time.
- if twins are born, the second twin may take much longer to be born.

C. After the child is born.

The following can lead to brain damage after the child is born:

- If a child fits regularly or for a long time brain damage will result. eg. If a child has a fever and develops a very high temperature, the brain which is sensitive to high temperatures, might react and the child may start fitting.
- If a child becomes dehydrated due to diarrhoea and vomiting, the brain is sensitive to a loss of water, can react and the child might start fitting. The child may then fit again and again and suffer brain damage.
- Injury to the head, a fall or motor car crash, can cause brain damage.
- Meningitis or encephalitis.
- Lack of oxygen to the brain.

D. What happens to a child who has cerebral palsy?

This is Noxolo, a mother from this area who has a child with brain damage.

Noxolo, what are the main problems that worry you about your child?

My child is unable to walk, she does not talk, she is very difficult to feed as she keeps vomiting and she is also tight.

Fundiswa also has a child with brain damage.

Fundiswa what problems do you have with your child?

My child cannot hear, cannot see and she fits often.

Brain damage causes many different problems that we notice if we look carefully at the child and ask the mother certain questions. These different problems are known as handicaps. A child who suffers from any one of these problems is known as a handicapped child.



What different problems or handicaps have you seen in children with brain damage?

Let's list these:

- * *doesn't move and behave like other children of the same age*
- * *has difficulties with feeding and problems with sucking, swallowing and chewing*
- * *doesn't move easily or much, feels tight and stiff and tense*
- * *doesn't move easily or much, feels floppy and heavy*
- * *quiet and slow to smile, babble and talk*
- * *doesn't seem to understand as quickly as other children*
- * *difficulties with seeing*
- * *difficulties with hearing*
- * *fits*
- * *mentally handicapped*

2. Different types of cerebral palsy.

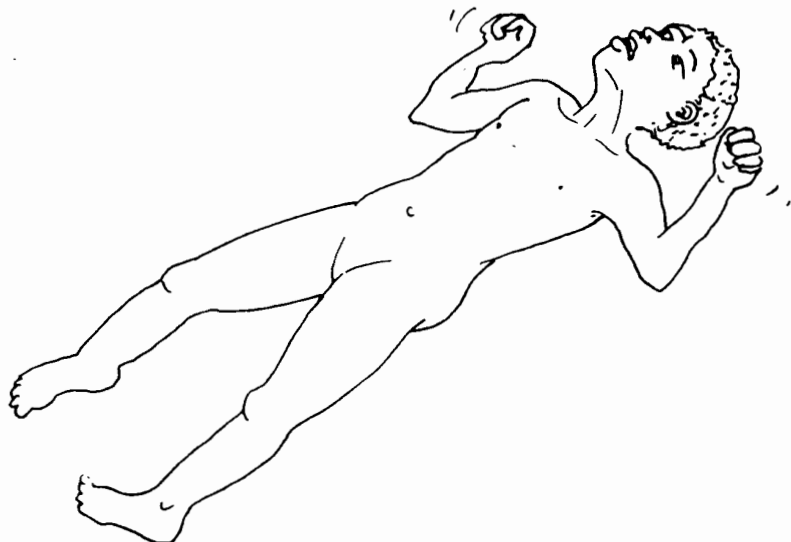
A. Tight children. (Spastic quadriplegic or spastic hemiplegic cerebral palsy)

Some children are very tight. The child's whole body, both arms and legs may be affected, or just a part of the body may be affected. It is difficult to move any part of their bodies.

If you try to straighten a part that is bent, or bend a part that is straight, it feels as if that part is fighting against you because it is tight and stiff. The child is unable to move easily.

Very few children are born tight. The tightness develops over the first few months or within the first couple of years. Usually a tight child adopts the following position:

- the child can't look at you easily.
- the head of the child pushes back.
- the shoulders pull back.
- the elbows and wrists are bent.
- the fingers are clasped tightly closed.
- the legs are straight and turned in.
- the feet point down.
- if the child starts to move the effort makes the tightness worse.



We will be looking at stiff children in more detail in the sessions on Spastic Quadraplegic children (III.1.b.) and Spastic Hemiplegic children (III.1.c.).

B. Floppy children. (Hypotonic cerebral palsy)

A floppy child feels heavy and may feel as if he wants to slide through your arms. The arms and legs feel heavy, loose and floppy. They can be moved easily, but the child itself has difficulty moving them as they feel so heavy and the muscles are underdeveloped.

These children are slow to develop, have poor head, trunk and limb control. They seem to be clumsy. They also have poor balance, so they take longer than normal to learn to stand up and walk. They are slow to use their hands because the muscles are underdeveloped and have limited control.

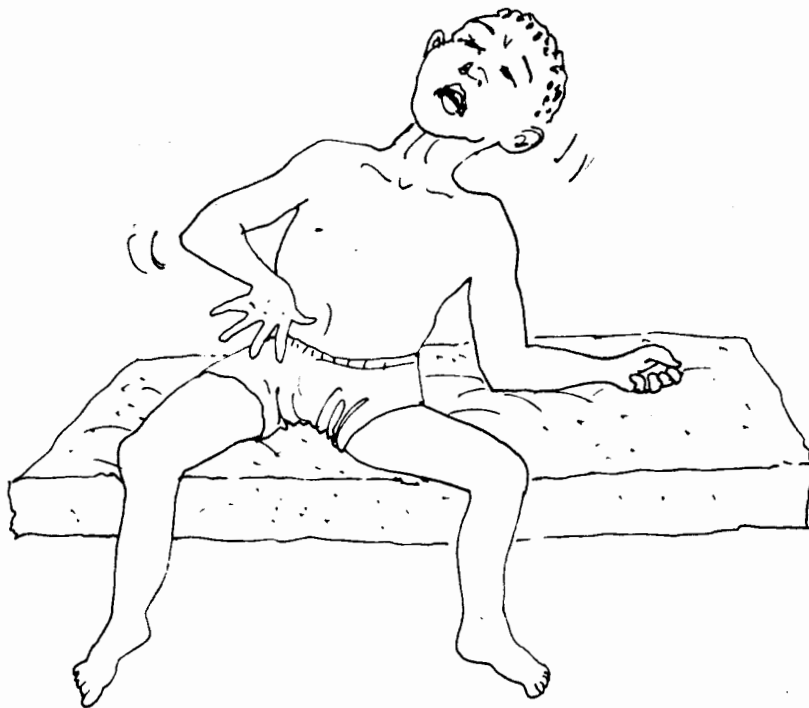
We will be looking at floppy children in more detail in the session on Hypotonic children (III.1.d).

C. Children with uncontrolled movements. (Athetoid cerebral palsy)

These children are often initially floppy. When they try to move, speak or are excited they become tight.

In these children uncontrolled movements interfere with the child's ability to move or to keep still. The child cannot sit or balance as they keep getting thrown off balance by sudden movements.

They cannot feed themselves as their arms move suddenly in awkward movements. They are unable to stand up as their legs are constantly moving. They are slow to use their hands because the jerky movements get worse with effort.



We will be looking at children with uncontrolled movements in more detail in the session on Athetoid cerebral palsy. (III.1.e).

All these children - from all three categories - are going to grow up and develop into adults with cerebral palsy.

3. Severely Handicapped Children.

A severely handicapped child is, as the name suggests, severely handicapped. These children are usually very tight and have other associated problems, for example, with feeding. They may also be blind and deaf.

A handicapped child in a family affects the family in many ways. A severely handicapped child is a tremendous burden on the whole family, but particularly on the mother. Often the mother will be depressed and need support. Supporting the mother can at times be more important than the treatment of the child.

As R.W.s do you think there are any ways in which you can help the mother?

Friendship, assistance and suggestions about the management of the child.

- make special seating and equipment which can make things easier at home for the child.
- teach the family about the condition and prognosis of the child.
- encourage mothers to take turns in looking after their own and a couple of other handicapped children so that they can each have some free time.
- set up a day care centre so that the mother can have a few hours break each day.

With a severely handicapped child treatment and exercises are not going to improve the condition of the child.

In working with a severely handicapped child we have four goals. This is usually unrewarding work as change is slow and of small degrees, so try to remember these goals:

1. The mothers of these children need help to work out the best way of caring for the child and not to think too much about curing the child.
2. The child needs to be physically comfortable, clean, safe and well-fed.
3. The mother must be shown how to position, handle and exercise the child so as to prevent further deformities and make caring easier. The mother needs to find ways of encouraging the rest of the family to care for, encourage and play with the handicapped child, as she would do for any other child.
4. Try to get the child to learn basic skills such as head and hand control.

As the rest of the sessions will show, however, there is a tremendous amount R.W.s can do to help children who are not so severely handicapped.

III.1.b CHILDREN WITH SPASTIC QUADRIPLEGIA

Aims of this session:

1. To recognize the problems of a child with spastic quadriplegia.
2. To identify the aims of working with such a child.
3. To learn how to help, play with and stimulate such a child.

1. Working with a child who has spastic quadriplegia.

A. Development of a tight child.

Can a child feed himself and go to the toilet himself when he is born?

No, he learns to do that as he gets older.

How does he learn, does he get it right the first time?

No, he has to practise again and again and he gets better at it with each try, until he eventually gets it right.

A child with cerebral palsy needs to be guided to do things for herself so that she learns how to do it as well as possible.

She has to practise much more often than a normal child before she will get it right. It takes much longer and much more effort for her to learn to do something.

A child learns a lot from looking around her and seeing what goes on, by watching other people and by listening to what they say to her.

Fundiswa, Noxolo in what position do your handicapped children spend most of their time?

Lying on their backs in the middle of the bed, as they cannot sit up.

Can a child see that much when she spends her day lying on her back in the middle of a bed?

No, she sees only what is over her head. She needs to sit up so that she can see as much as possible.

Can these children sit up by themselves?

Their mothers need to position them and support them with cushions or in a chair with straps so that they do not fall over.

They must be positioned so that their body is straight, their head in the middle, their legs open and the arms in as normal a position as possible. When the mother holds the child on her lap, she can help the child sit up and look around.



What is one of the first things that a child learns to control?

Her head.

Where does she learn to control her head?

She learns to control her head as she sits, by looking at her hands and at other people around her.

Sometimes the child may be too tight to sit immediately and will have to be rolled from side to side to make the stiffness less. Then she can be sat. If she lies on the bed only, she will only push her head back more.

What movements can we all do with our heads?

We can bend our heads down, lift them up and move them from side to side.

B. Examination of Nosipho, a tight child.

Nosipho is almost 3 years old. What do you expect a 3 year old to be doing?

Sitting up unsupported, playing with things - being interested in things and people, walking, running around and talking.

What does Nosipho look like lying here?

- * *Her head stays in one position.*
- * *She moves her arms, but only in jerky movements and her hands are kept tightly closed.*
- * *The right hand moves less than the left.*
- * *Her legs do not move and remain straight, close to each other and turned in, with the feet pointing down.*
- * *She only maintains the lying position.*
- * *She needs support for sitting and standing.*
- * *Her head flops down when she sits.*

The medical term for Nosipho's condition is spastic quadriplegia.

Mama ka Nosipho, what are your main problems with Nosipho?

Nosipho is very tight. She cannot sit up or hold her head up. Feeding her is very difficult as she pushes the food out of her mouth with her tongue and also vomits very easily. She is unable to talk.

Look at Nosipho, how old would you think she is from looking at her size?

- *She is very small for 3. I would have thought she was 1 and a half.*
- *She is so small because she is severely handicapped. Her growth has been handicapped as she doesn't move easily or much and because feeding her is so difficult.*

Try and move Nosipho's arms or legs, what do they feel like?

They are very tight and stiff and cannot be moved easily.

C. Nosipho's problems.

What do you think Nosipho's main problems are?

- *Her development is slow: she can't keep her head up or move it; her body is curled up tight; she cannot sit or stand unsupported.*
- *She is very tight and stiff. Her arms are clasped tightly to her chest and her hands are kept tightly closed. She doesn't use her hands. Her legs are straight and turn in.*
- *She cannot talk and feeding and swallowing are difficult for her.*
- *She is not toilet trained.*
- *Mother uses much more time caring for her, feeding and dressing her.*

2. Our aims in working with a tight child.

We must work with Nosipho's mother to establish aims and set goals for Nosipho. We must follow her mother's lead and find ways to help her to help Nosipho to do more and more.

There are four aims that we have:

1. To support the mother and help her handle the child so that she is helping the child do more in her daily activities.
2. To get the child upright. If the child is supported in an upright position, she can use her eyes and mouth and hands better.
3. To enable her to be more comfortable.
4. To prevent contractures and deformities from developing.

A. First Aim: To support the mother.

- We must listen to the mother, help her to define the problems and find ways of solving these.
- We can offer her friendship and encouragement, especially when change seems slow.
- We can ensure she understands her child's condition through discussion, explain the complications that are likely to develop, and how these can be avoided and what the future of her child is.
- We can help her handle the child more easily by seeing what works with the child, allowing the mother to feel what we do and then inviting her to demonstrate on the child (or ourselves). She needs a chance to feel and do for herself and will learn best through experience.



B. Second Aim: To encourage head, body and hand control.

When working with Nosipho move her slowly and handle her gently, encouraging her efforts to move. Encourage her to move her arms and legs independently. Encourage as much independence as possible, although this takes time and patience.

We will now spend some time looking at exercises for her head, her body, and her hands.

1. Encouraging head control.

Look at Nosipho sitting up. What do you notice about her head?

She is unable to hold her head upright in the midline, it keeps falling forward and to the right. If we put it in the middle it keeps falling to the same side. If we tilt her backwards, the head flops backwards and she is unable to bring it forward.

Put your hand behind Nosipho's head. What does she do?

Pushes back into my hand and her whole body seems to get more tight.

Where should I put my hands instead?

We do not want her to push back, we want her to be able to look forwards and move forwards.

We must rather put our hand on her breastbone. We can use this hand to lift her up and jiggle her loose.

What is the first thing that a baby learns to do in terms of her development?

She learns to hold her head up by moving it, especially when she uses her eyes.

"Mama ka Nosipho, what position is Nosipho usually in at home?"

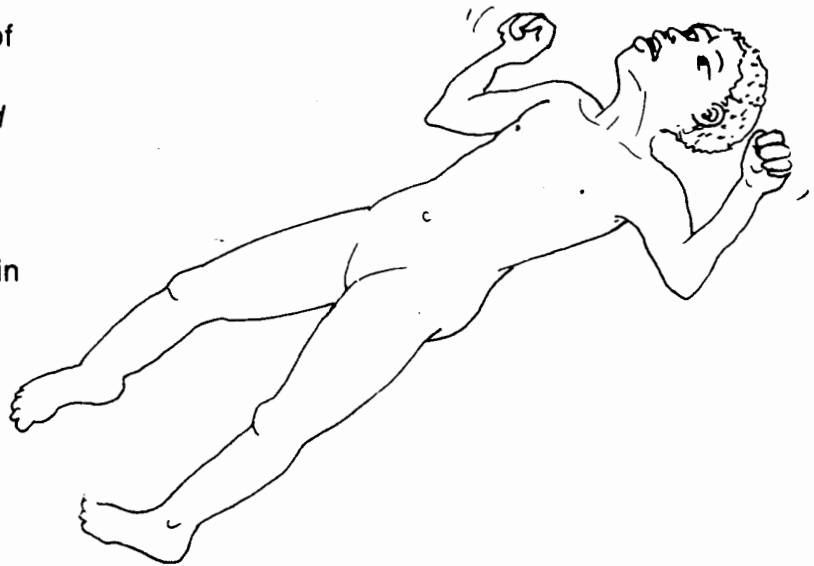
She usually lies on the bed on her back.

What does she do as she lies on her back?

She usually pushes back with her head.

What will help her when she is on her back?

She must always have a pillow under her head, to bring her head and her eyes forward.



What happens to Nosipho if we lie her on her tummy?

She pushes back and her whole body becomes very tight.

She carries on pushing until she has rolled over onto her back. This is the problem with putting a tight child who pushes back, onto her tummy, it encourages her to push backwards.

Nosipho will never learn to control her head lying on her tummy, as she pushes back in this position.

We must rather use other positions to encourage her to develop head control.

We must find ways of making eye contact and using our own voices, bodies and eyes to get her attention. We can help her learn to use her eyes and ears.

Do you think it is important that Nosipho learns to lift up her head?

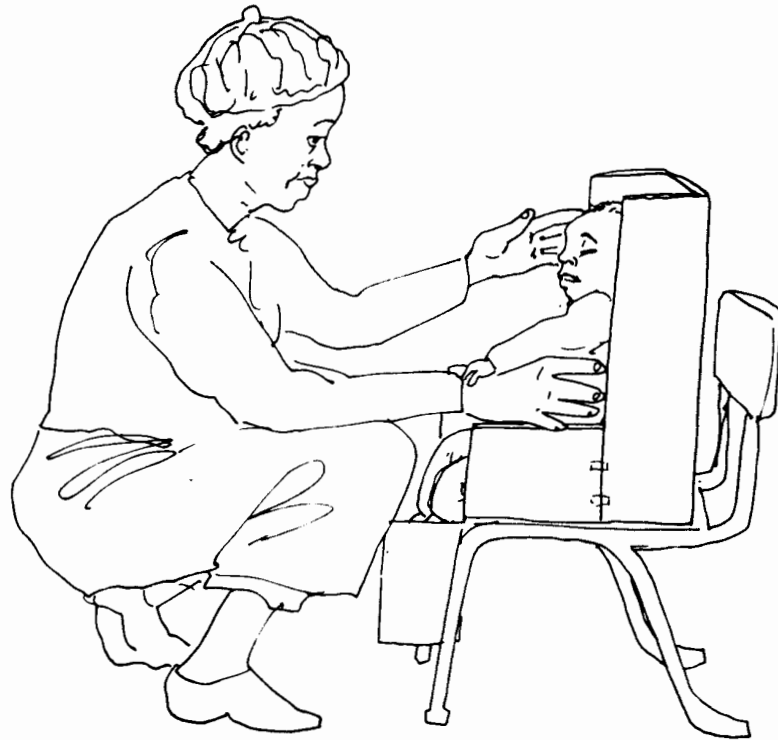
Yes, nothing else can develop until she has head control.

Is it easy to turn your head if it is falling forwards or it is falling to one side?

No, not at all. It is much easier to turn your head when it is held up and in the middle.

To encourage the child to develop head control, we need to keep straightening her head and putting it back in the midline. This is best done with traction and jaw control rather than pushing from behind. She will then learn the correct position for the head and how to hold it there.

Once the child has learnt how to hold her head in the middle, she needs to learn to move it from side to side. Then she needs to learn to move it into the middle herself.



This is Pindile. He is 2 years old. He has no problems and as you can see, is full of fun. How can we get Pindile to look to one side?

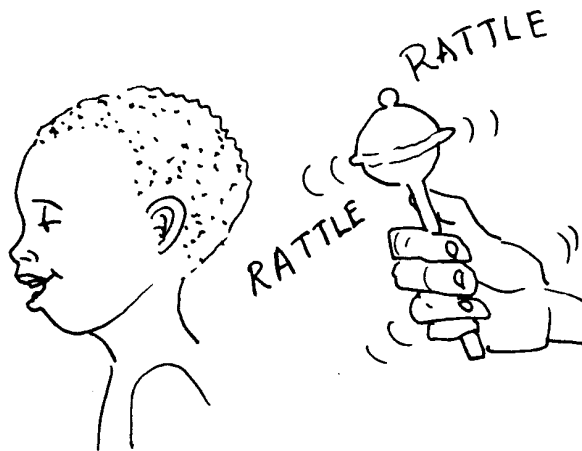
We could call him while we stood on the one side, or hold a toy on this side and shake the toy so he turns his head to look at it.

If we play a game like peek-a-boo (hiding behind our hands), it will be more fun for him and he will respond more quickly and enthusiastically.

How can we encourage Nosipho to move her head?

In a similar way to Pindile:

- *We could shake a rattle on one side.*
- *We could call her from one side.*
- *We could attract her attention using a rattle and then move the rattle so that she follows the rattle with her head.*
- *She will enjoy it more and respond better if we play games and tell stories that encourage her to take part, rather than just using a toy or words to tell her what to do.*



To which side does she seem to find it easier to turn her head?

She can turn her head to the left, but she struggles to turn her head to the right as her head usually falls to the right.

Which side must we encourage her to turn her head to?

To the left, but mostly to the right, as this is what she finds most difficult.

Does she respond as quickly as Pindile?

No, much more slowly, so we need to be patient and take time with her.

Do you think it is possible for her to learn how to do these things by herself?

No, she needs help to be put in a good starting position and then to be stimulated in this position.

Even when she is put in a good position, she may need help to maintain this position. If we use our hands to guide hers, so that her efforts are successful, she will learn best and want to do more.

Would this game work if the child could not see?

No, we would have to use a toy that rattles or makes a noise.

It is more difficult to stimulate and play with a child who cannot see. We have to use our voices more and describe things for them, paint pictures with words, so they can hear and learn to understand.

We must also open their hands and guide them to feel different things and then describe in words what they are doing and feeling. They will then start to learn through experience, like other children.

Brain damaged children that are blind and deaf are usually far behind in their development as they are so difficult to stimulate. There is no reason for them to do anything else other than remain lying all day.

We will have to teach them everything with our hands.

Mama ka Nosipho are you busy at home with Nosipho?

Yes, very busy as I have to do everything for Nosipho and because she is so tight and stiff things take a long time. Feeding itself takes me ages and by the time we are finished, Nosipho is in such a mess because she vomits, that I have to change her.

Do you have an extra half an hour a day to do a set of exercises with Nosipho?

No, not at all, it would be really difficult to find such time. I seem to struggle so much anyway just to keep going from day to day. I never seem to have time to spend with the other children.

How could we try to include "exercises" in the daily routine of the mother and child so that they help the child and mother to do better in their daily activities.

The mother spends time with the child when she feeds, dresses, washes or carries the child. We could try and include the essential exercises in this time that the mother already spends with the child.

In fact if the mother feeds, dresses and carries the child in the correct way, she will not really need to do extra exercises, as these will be exercises in themselves. These activities if done correctly, will be more beneficial, as they will make her more active, rather than have somebody do everything for her.

We have given Mama ka Nosipho a cardboard chair for her to use at home. Nosipho can be strapped into this chair so that she can sit up without the support of her mother.

If she is sitting instead of lying, she can respond to movement and noises in the room. She can lift up her head and see what is going on around her.

Where in the room should we put her chair?

Nosipho finds it most difficult to turn her head to the right. We should put the chair in a place where all the activity in the room happens on the right side of her, so that she is encouraged to turn her head to the right.

How does Nosipho's mother hold her when she is sitting down?

With her head resting on her chest.

Will Nosipho learn to control her head if she is sitting on her mothers lap and her head is resting on her mothers chest?

No, not at all. She can only learn to control her head if she holds her head up herself, when her head is not being held up by her mother's chest.



As Nosipho is sitting here and we are trying to get her to move her head, what is the rest of her body doing?

Her arms are crossing in front of her body and her hands are clasped closed. Her legs are straight and close to each other with the feet pointing down.

We want to find ways to get the two legs to do different things. We can carry her holding one knee bent and allowing the other to hang down.

We can work in different positions for head control, so that different parts of the body are in different positions.

What other positions could we work in to encourage Nosipho to develop head control?

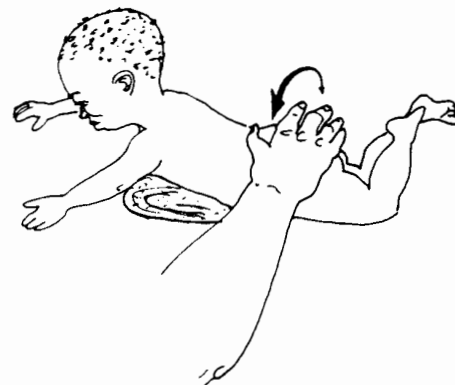
Lying on her stomach.



Yes, but as we've already discussed she spends most of the day lying down; and she pushes back when she is lain on her stomach.

She would benefit from lying on her stomach as she can learn to pick up her head in this position. When she is on her stomach put a pillow under her arms and chest, then press down on her bottom rocking it from side to side to make the stiffness less.

When you pick her up and put her down move her slowly otherwise she will become tight again. At other times we can swing her around and move her more quickly. But this will also make her tighter.

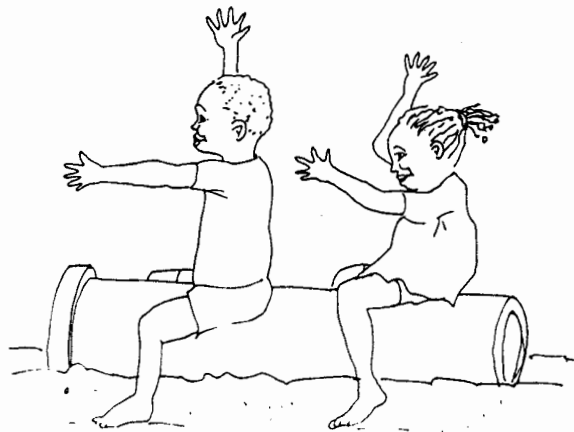


Some positions to use.**1. Sitting astride.**

This position is used to reduce the tightness in her legs. The tightness is greatest when the legs are straight and together. By sitting astride, her legs are then bent and opened. This will break the pattern and reduce the tightness.

Instead of sitting her on her mother's lap with her legs together, she can sit with her legs apart, one on either side of her mother's leg. If she is looking out, either we could stimulate her, or get one of her brothers or sisters to encourage her to lift her head up and move it around. If she is looking towards her mother, her mother can stimulate her. If her mother holds the top of Nosipho's arms bringing her shoulders forward, head control will be more easily encouraged.

We could also sit her astride some paint tins or a bucket. Then she can take weight through her feet on the floor and her feet cannot point down and turn in. Head control can be encouraged whether she faces the person holding her, or someone else.

**2. Kneeling.**

We could work kneeling her in front of a box. Her mother facing her, can hold her arms on top of the box and even keep the hands open flat on the box. She can attract Nosipho's attention using her voice and toys, to get her to lift up and move her head. Holding Nosipho at the hips, we can keep straightening and returning her head to the middle and also encourage her to keep her back straight and her bottom in.

**3. Standing.**

We can work standing her in front of a box. Just as when she is kneeling, her mother can hold her arms on top of the box and using her voice and toys get her to lift up and move her head.

Holding Nosipho at the hips and breastbone, we can keep her head in the middle, her back and legs straight, and her bottom in. While we encourage head control we will

What position does Nosipho like to keep her legs in?

She likes to keep them straight, close to one another, with the feet pointing down.

When we stand Nosipho up, we must keep her legs straight but also keep them apart, with the feet flat on the floor to break the tight pattern that she likes to keep them in.

2. Encouraging body control.

After a normal child has developed head control, she learns to control her body, she learns to roll, sit, crawl and stand. Many of the exercises and positions that we used to encourage the child to develop head control can also be used to encourage the child to develop control of their body. These exercises must be done with less support for the body, so that the child learns to control her body herself.

1. Lying

Let's look at Pindile again.

How can you encourage him to turn over?

If he is lying on his back, we can hold a toy out of his reach on the side. He will then roll over to reach for the toy. If he is lying on his tummy we can hold a toy above and to the side of him. He will then look up and in trying to reach for it, will roll over.

Working with Nosipho we can do exactly the same, but she will take much longer to react than Pindile, so we need to encourage her more, and patiently wait for her response.

To help her respond better we could give her a pillow under her head if she is on her back and a pillow under her tummy if she is on her tummy.

To help her roll over we can bend one leg for her to help her to roll over from the hips. We are not doing it *for* her, but doing it *with* her, so she can learn to take part, do more and do better. This in turn helps her to want to do more.



2. Sitting

To encourage the child to develop body control in sitting on her mother's lap, the child must be held away from her mother's body so that she learns to keep her body upright herself.

Sitting on her mother's lap, the child can be encouraged to turn her head and body to look and reach for something that is held some distance away from her. This can also be done if she sits over a bucket or paint tin.

Support in the front (breastbone) can be used to help her lift herself up and to twist her slightly which will loosen tight muscles and help her to gain control.

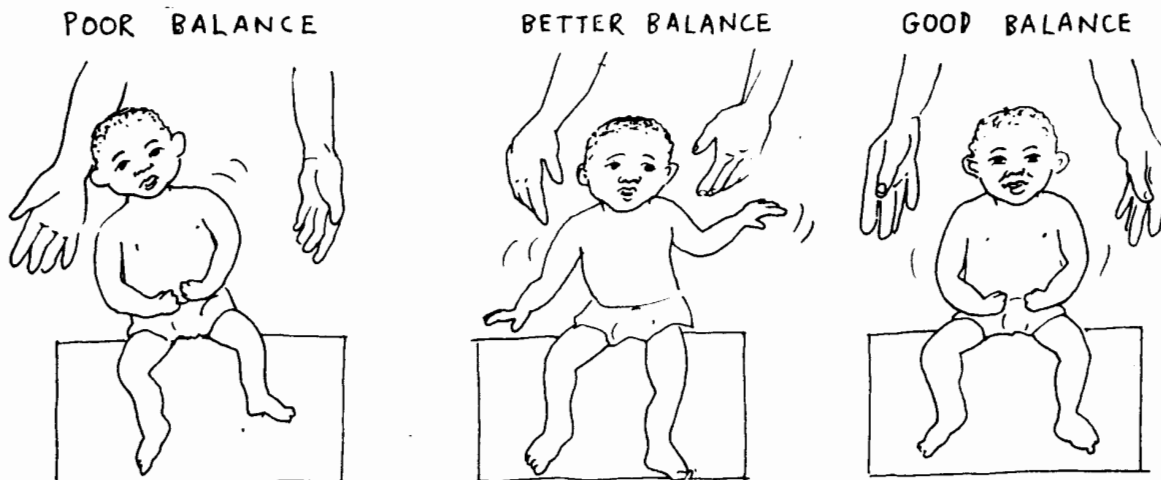


Body control and balance can be encouraged if the child tries to keep her balance and not fall over while her mother moves her legs up and down, pretending to be a horse.

Let's look at Pindile again.

What does he do if I suddenly push him to the one side?

He turns and puts his arm out to catch himself to avoid falling.



This is also something we can do with handicapped children, to encourage them to control their bodies, turn and protect themselves when falling. We can push them to each side, forwards or backwards and help them to catch themselves on their elbows and then on their arms we have prepared, reducing their tightness by stretching them out.

3. Kneeling and standing.

Playing with children in sitting or standing, first against a box and then with less support, will encourage them to shift their weight sideways in order to get balance and develop control of their bodies.

• 3. Encouraging hand control.

It is not always possible to teach a child with very tight hands to use their hands well. However we must make every effort to help her learn to reach forwards with her hands and arms so that she will be able to do more for herself, possibly able to feed herself, or help maintain a certain position.

Effort to use hands will make them tighter so we must always prepare them first by helping the muscles relax by stretching them out. Afterwards they must also be stretched out to encourage them to relax.

How does Nosipho usually hold her hands?

They are held tightly closed and are very stiff to open.

Will she learn to hold things in her hands if they are tightly closed?

No, they need to be less tight and open for Nosipho to learn to hold onto things.

In addition these children often do not feel that well or clearly. It's as if they are wearing thick gloves and feeling everything through these thick gloves.

What do normal children of 1 or 2 usually do with their hands?

They are constantly reaching out to touch and grab things.

By doing this they are learning about the touch of different objects. They are also learning about how things work and different shapes and what fits together. Doing this is a large part of any child's learning experience.

Do you think there is anything that we can do for Nosipho?

We want to try to get her hands open so that the palms and the fingers can come into contact with different things.

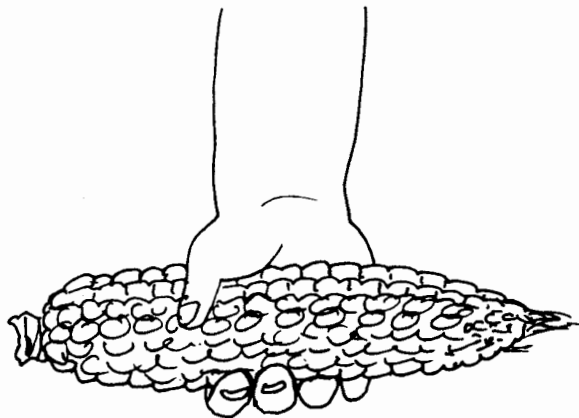
We need to repeat this again and again, not only because she will take time to learn, but because she doesn't feel so well.

Does a child crawl with her hands open or closed?

With them open, the palms and the fingers flat on the floor, so that she can take weight through her hands.

So will Nosipho be able to crawl?

No, not very easily.



Even a small thing like clasped hands can interfere with the child's development. As we work with Nosipho, we need to take things like this into account and work in positions that will improve this.

To encourage her to open her hands we can work in side sitting taking weight through one open hand.

C.Third Aim: To reduce tightness and make the child more comfortable.

I have found the following five positions the most effective in reducing the tightness not only for Nosipho, but also for other children. To reduce tightness we cannot focus on her hands only, we have to reduce the tightness in her whole body, arms and legs. By reducing the tightness in her body we are also making Nosipho more comfortable. To reduce the tightness:

- handle Nosipho carefully and gently as sudden movements will increase her tightness.
- move her slowly and encourage her efforts to move.
- encourage her to move her arms and legs independently.

1. Lying on her back.

When she lies on her back, she must have a pillow under her head, so that she can see you easily.

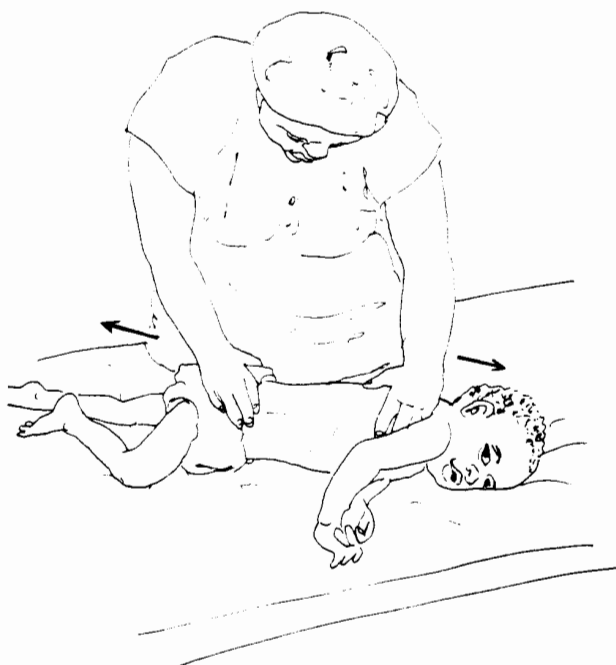
- Swing her legs slowly and gently from side to side.
- Curl the child in a ball and slowly roll her hips and legs from side to side.



2. Side lying

This is a very good position as tightness is reduced in side lying, her hands are free to move and she can see more than if she lies on her tummy.

- With both legs bent at 90 degrees, press down through her shoulders and hips to separate them, to make the sides longer.
- Separate the 2 legs so that the bottom one is straight and the top one is bent up. With one hand on her shoulder and one on her hip, gently separate them to make the sides longer.
- Gently pull the underneath leg to lengthen the underneath side.



- Rotate her body, by holding her at her shoulder and pelvis, and moving them backwards and forwards alternately.



- Once these exercises have been done her body will be less stiff. Then we can move onto working on her arm.

- Continue to gently rotate her body, start to move the uppermost arm forward bringing the whole shoulder forwards, until the whole arm is above her head, with the palm facing downwards and the fingers open.



- Then bend the elbow so that the open hand is on the bed and the child is taking weight through her open hand and arm. This should be done with each side in turn.



3. Sitting astride

By sitting astride her mother's leg or some paint tins, her pelvis is kept still.

To reduce the tightness in her body, we can gently rotate her at the shoulders so she faces in 1 direction and then the other.

As she turns to the one side, we can lift her arms slowly forwards, bringing the shoulder forwards, and up (one at a time), above her head with the palms facing inwards.

4. Side sitting.

In side sitting we can get Nosipho to take weight through her hand. This will make the tightness in her arm and hand less. If her hands are too tight to open, we will have to start with the previous exercises to reduce the tightness.

In side sitting we may have to keep the supporting arm straight and then bring weight onto that arm and hand. If the arm is not long enough to reach the ground, it will bend and get tight. It is easier to get the arm and back straight if we put the hand on a cushion, block or book.



5. Carrying.

When the mother carries the child, she must try to break the dominant patterns of movement. How do most Xhosa women carry their babies?

On their backs.

This is the perfect position for a child whose legs are usually straight, tight and together. Have the child sit astride as much as possible to break the tight pattern where the legs are usually straight and together.

D. Fourth Aim: To prevent contractures and deformities.

The most important thing in preventing contractures and deformities or preventing them from getting worse is to change positions frequently. We will reduce tightness in a child's body by moving her arms above her head, opening the hands, and standing her up daily.

In some cases there may be a need to stretch an individual muscle or joint. Certain muscles and joints tend to get stiff and contracted. We will deal with these on the session on contractures.

In examining Nosipho's problems which we had identified at the beginning of this session, and also the problems that her mother described, we have described ways of handling and treating that will:

- encourage her to experience different and better positions, move more easily and do more for herself.
- reduce her tightness and the complications that this can cause, allowing her to move freely.
- The problem of feeding her mother raised will be dealt with in another session.



In David Werner's book, *Disabled Village Children* from pages 302 - 316, are exercises that can easily be incorporated into handling by the mother as she performs her daily tasks. They include helping the child develop head, hand and body control.

III.1.c CHILDREN WITH SPASTIC HEMIPLEGIA

Aims of this session:

1. To learn to recognise a child with a hemiplegia.
2. To know how to:
 - a) reduce the tightness of the hemiplegic side.
 - b) improve movement of the hemiplegic side.
 - c) include the hemiplegic side in certain activities.
3. To recognise that the whole body is affected too.

1. Tightness on one side of the body.

A. Examination of a child with tightness on one side of his body.

This is Khanyiso, he was born in the Transkei.

What happened when Khanyiso was born Mama ka Khanyiso?

My pregnancy was normal, but labour was very long, two days. When Khanyiso was eventually born, the midwife pulled him out and he was fitting. After a while he stopped fitting. Since then he has been unable to move his left arm and leg properly.

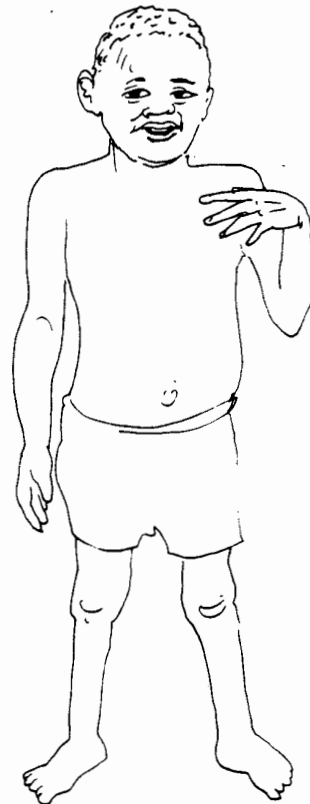
What problems do you have with Khanyiso?

I have two problems with Khanyiso,

- * *he cannot use his left arm and leg properly.*
- * *he has to have pills otherwise he will fit.*

How long has he had to take these pills for?

When he was born and he was fitting, as soon as I was strong enough I got up and took him to a hospital in the next village. I told them what had happened and they gave him some small white pills. Since then I have had to give him these small pills every day. If I run out of pills and don't give them to him for 2 or 3 days, he will fit again.



Have a look at Khanyiso. He is 4 years old.

What do you notice as you look at him?

He seems to be very like any child of 4, and is very active.

He is playing with the other children, talking and fighting with them.

What about his left arm and leg though?

He doesn't use his left arm as he plays. He keeps his arm close to his chest, with his wrist down. He limps quite badly. His right leg does most of the work and he seems to drag the left leg along behind him.

The medical term for Khanyiso's condition is spastic hemiplegia.

Let's play with Khanyiso and see if we can get him to use his left hand. Is it possible?

No, he doesn't want to use his left hand at all and it must be painful, because if you try to touch it, he screams and pulls it away.

What does his left hand feel like?

It is very tight and stiff. It is impossible to lift up the wrist. Straightening the fingers obviously causes him a lot of pain.

Do you think that Khanyiso can move and use his left arm and hand while they are so tight and stiff?

No, they are too tight and stiff.

The tightness must first be reduced in his arm and hand. Then we can try to get him to move his tight arm and hand, including it in a limited number of activities, together with the other hand. We hope this will encourage him to look after and not ignore it.

B. Reducing tightness.

When you look at Khanyiso, which part of him looks tight and stiff?

His arm and leg.

In fact it is the whole left side of his body that is tight, his neck and back too. To reduce the tightness effectively we have to reduce the tightness in his whole body, starting with the body and then moving onto his arm and leg.

Which is tighter Khanyiso's arm or leg?

His arm.

Where does he get pain?

In his elbow and wrist.

This is very common, not only in children who are hemiplegic, but also adults. Pain increases the tightness. The pain usually comes from the shoulder and can be made worse by pulling the child by his tight arm. This will tear some of the muscles in the shoulder and cause pain which the child will feel in his whole arm.

To avoid this we must warn the mother of the danger of pulling roughly on this shoulder and that it should be treated carefully.

We have 3 ways of reducing tightness:

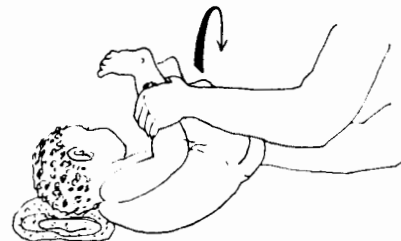
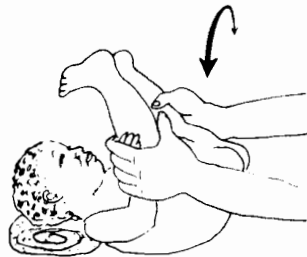
1. To stretch the tight muscles.
2. To take weight through the tight side of the body, the arm and leg.
3. To turn or rotate the body and the parts of the body that are tight.

2. Positions and methods for reducing tightness.

The following positions and methods make use of the three ways of reducing tightness.

A. Lying on his back.

Khanyiso must have a pillow under his head. Pull his hips down and curl him up. Swing his legs from side to side keeping his hips and knees together. This is to get the muscles of his neck and back to relax.



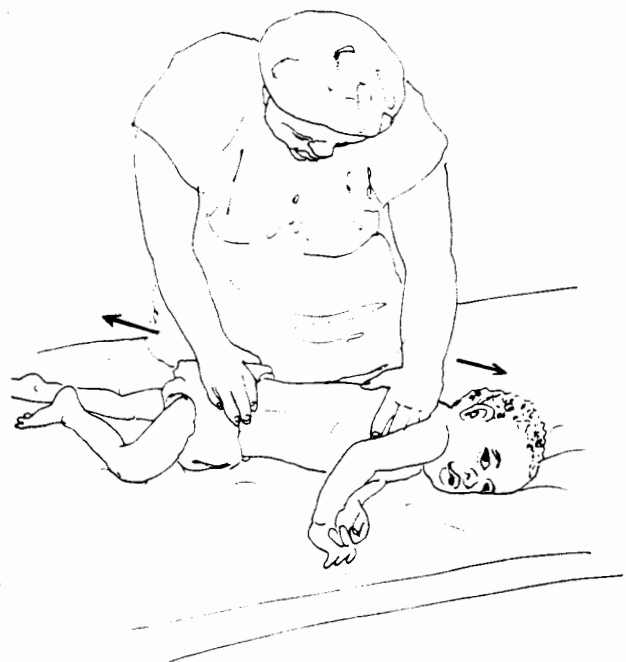
B. Lying on his side.

1. Lengthen the sides.

Although one side is obviously so much tighter than the other side this must be done to both sides. The side which is less tight, is also affected, because it has to do all the work and its movement is restricted by the tightness in the neck and back.

To lengthen the side and the tight muscles on this side, press down through the shoulders and hips and gradually move your hands away from each other.

Stretch out the bottom leg and gently pull it, release and pull again. Do this slowly a number of times.



• 2. Rotate the sides.

Hold the hip and shoulder and move them alternately backwards and forwards. This must be done slowly and the emphasis should be on moving both the shoulder and pelvis forwards and not backwards.

• 3. Moving the shoulder.

Holding the scapula (the flat bone that moves over the top of the rib cage) with one hand, and supporting the arm with your other arm, gently circulate the scapula moving it upwards and forwards and then returning it to the midline.

This must be done slowly and rhythmically for some time and after a while the shoulder and whole arm will get less tight. As the shoulder gets less tight, the arm can be moved forward and up. As long as there is no pain, the arm can be lifted up as high as the head.

What has happened to Khanyiso's arm and hand as I have been moving his body and shoulder?

His arm has straightened, his wrist is straight and his fingers have opened.



• 4. Weightbearing through the arm.

This can only be done if Khanyiso gets no pain in his arm or hand.

After doing the previous exercise the arm should no longer be tight so that it can be easily lifted forwards and upwards.

Bend the elbow so that the hand, with open fingers, can be laid flat on the bed.

The scapula must be held forwards, and weight can be brought through the hand and arm, by rocking his body forwards and backwards.

This is done most easily over a barrel.

Khanyiso can then play with something else with his other hand, as you help him to take weight through his tight arm.



C. Side sitting (weight bearing through the arm and hand).

• 1. Weight bearing through the tight side.

This can only be done after the tightness in the hand and arm are reduced, otherwise they will cause him a lot of pain.

Khanyiso must sit in side sitting, with the arm on the tight side straight, so that weight is taken through this side.

You will have to hold the shoulder forwards and the elbow straight.

Weight bearing through the arm and hand will further help to reduce the tightness in it.

This should never cause Khanyiso pain and if it does, must be stopped or the hand and arm turned in a bit.

He can then play with blocks or toys with his other hand.



• 2. Moving over the weight bearing arm.

Get Khanyiso to reach for a toy with his other hand, on the side of the tight arm, so that he turns and moves over this arm.

• 3. The "good" side.

It is also important to get weight bearing through the "good" side to emphasize that both sides are the same, reduce any tightness in this side, and give these muscles a chance to develop appropriately.

D. Sitting.

• 1. Sitting in a chair - clasping hands.

Look at Khanyiso as he is sitting now.

Where is his tight arm?

He has forgotten about it and it is falling off the side of the bed.

It is important to get Khanyiso to remember this arm and not to forget about it and let it flop everywhere. It will then get very sore. If he is sitting at a chair, he must keep this hand on his lap, preferably clasping his hands.

• 2. Sitting at a table.

Does Khanyiso ever sit at a table mama ka Khanyiso?

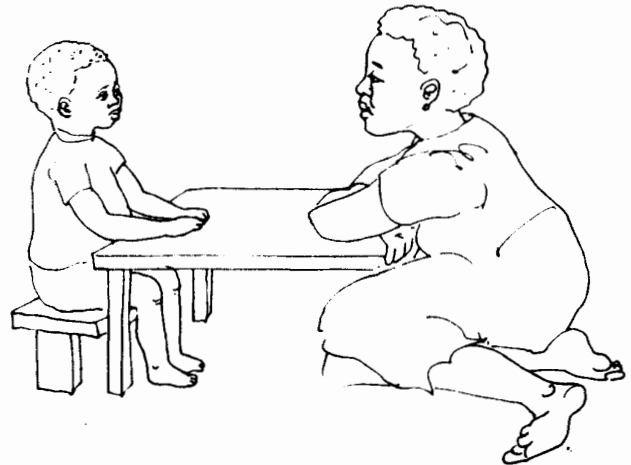
Yes, to eat.

Let's sit Khanyiso at the table.

Where is his arm?

It is under the table.

When Khanyiso eats, his tight arm should be put on top of the table, with the hand flat. In this way he cannot ignore it, and also it will be in a good position so less likely to get tight.



• 3. Drinking

While he is sitting at the table, he can also use the tight hand in a small way, to help him hold a cup and drink.

- He must clasp his hands.
- His mother can put a cup in between his clasped hands.
- Keeping his elbows on the table Khanyiso can lift the cup to his mouth.



E. Walking.

As you look at Khanyiso, what do you notice about his walking?

He limps.

If I lift up his stiff arm so that it is above his head, turned in, with the hand open and walk him lifting up this arm, what do you notice about his walking?

His walking is much better, he doesn't limp nearly so much.

How do you usually hold him when you walk with him mama ka Khanyiso?

I hold onto his good arm.

When you walk him, hold onto his tight hand and pull it up, so that it is above his head with the hand facing inwards, then he will not limp so much.

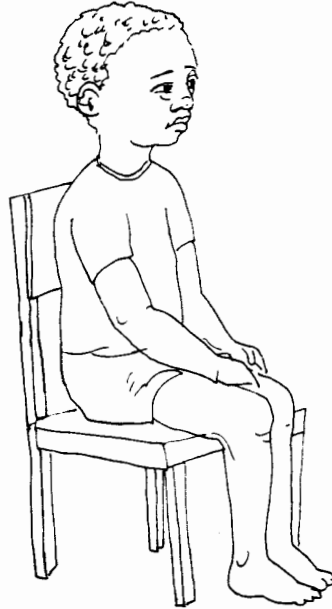


3. Including the tight side in activities.

The first three activities are similar to positions mentioned above, but are mentioned here again as ways of including the tight side in every-day activities.

A. Sitting on a chair.

Encourage him not to ignore his hand and let it fall at his side, but to keep it on his lap.



B. Sitting at a table.

His tight hand should be placed on the table with his hand open. He can be encouraged to open his fingers.

C. Walking.

Encourage his mother to hold his tight hand rather than his normal hand. When she holds this hand, she should lift it up so that the arm is straight up above the child's head and the palm faces towards the other arm. If she can lift the arm up, his walking will improve.

D. Playing.

Draw the face of his friend on the palm of his tight hand and encourage him to look at this, show it to his mother, kiss his friend and smack him. This will encourage him to touch and not ignore this tight hand.

Catching and throwing a ball, encourage him to use both hands.

Playing with blocks, encourage him to use both hands.



E. Dressing and washing.

Try to get him to do these things for himself, but to include his tight hand in these activities. If he finds it difficult to move his tight hand easily, movements can be done with both hands clasped together.

He can be taught to dress himself, by first dressing his tight side and then his normal side. This encourages him to be aware of and touch his tight side.



F. Eating and drinking.

When drinking he should hold his cup with his 2 hands clasped together. Then as he brings the cup to his mouth, his tight hand will be moving. When eating he should try to use his tight hand to feed himself.

Sometimes this hand will be too tight to hold a spoon, but can be used, if he is eating bread or an apple. If he is eating with his normal hand and is sitting at a table, he should have his tight hand on top of the table with his hand open.

What we have done in this session on children with hemiplegia, is to show how to reduce the tightness of the tight side and then how to include the tight arm and hand in daily tasks activities.

III.1.d. HYPOTONIC CHILDREN

Aims of this session:

1. To recognise a "floppy" child and try to understand the problems of low muscle tone and poor postural control.
2. To understand how the mother and family should be encouraged to help a "floppy" child.
3. To learn how to play with a "floppy" child and encourage her to be more active and move more easily.

1. Examination of a floppy child.

This is Amanda, she is 3 years old.

What is she doing at the moment?

She is sitting still at her mother's feet. She's been sitting there for a long time now. There is a toy just out of her reach, but she has not moved to try and get it, she just looks at it every now and then.

Is she moving her hands much?

No, they are just lying on her lap.

Let's ask Amanda's mother what her problems are with Amanda.

Mama ka Amanda, what problems do you have with Amanda?

She is such a lazy child this one. She just likes to sit still and look at the floor all day. She is 3 years old but she only sits, she doesn't talk and I still have to feed her.

Can she crawl and stand up?

She can crawl, but she crawls very seldom, only when she wants to, with her knees very wide apart. She can stand and can even walk a few steps, but she only does this every second day or so. She doesn't do anything that I tell her to do. I think she must be very stupid.



Children like Amanda we call floppy children.

The medical term is hypotonic cerebral palsy.

Sometimes cerebral palsy causes floppiness, not tightness. The floppiness usually affects the whole body and is not confined to one side of the body. Babies are often floppy when they are born and may tighten up later as they are handled and try to move.

A floppy child will have poor head, trunk and limb control. The parent's natural reaction will be to handle the child as an infant and be too protective of her. Uncontrolled movements and shakiness may appear later.

These children were called "lazy" in the past, but this unkind name is not used now as it implies that the child's chooses to be lazy, which is not true.

What do you think Amanda's problems are?

- *Her development is slow.*
- *She does not like to move.*
- *She is unable to feed or dress herself.*

2. Helping a floppy child.

What do you think we can do for Amanda?

We must play with her, encourage her to move as much as possible and encourage her to develop head, trunk and limb control.

A. Playing with Amanda.

Playing with Amanda needs a lot of patience as she tends not to respond and if she does respond, she takes a long time to respond.

When we play with her we need to be aware of these three things:

- She must be prepared for movement by making her floppy muscles more active, bouncing her on her bottom, tapping her chest and tummy muscles especially.
- She is reluctant to respond and needs a lot of stimulation before she will respond.
- She takes a long time to respond so we need to wait patiently for her to respond.

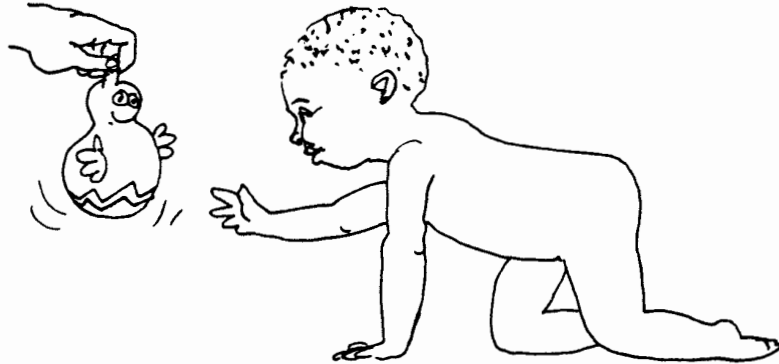
In what positions should we play with and stimulate Amanda?

If we play with her in a kneeling or a standing position it will help her to feel more comfortable in these positions so that hopefully she will get into these positions more easily.

The more positions that we can put her in to play with her, the better. Guide her hands to explore her body as you bounce her and play clapping games.

How can we encourage her to move?

Just as we would encourage any child to move, by holding a toy out of her reach, and encouraging her to reach for it.



Try to get Amanda to hug a big ball. With a small ball, hit it from hand to hand. Try this with any toy.

B. Stimulating floppy muscles.

Amanda will not learn to sit better by being supported or by being left to sit on the floor. Her body muscles need to be made more active so that her arms and legs become free to move.

She should rather sit on one of her father's legs, (not between his legs). He should then pat the child on the tummy and chest, or support her lightly on the chest and bounce her up and down.



Don't pick the child up by the arms, hold her around the chest to pick her up and put her down. This will leave her arms free to move and take part in balance activities. Do as much as possible to get eye contact.

In standing she can also be encouraged to take a few steps, first holding onto a bed or bench, but then without these.

To work for head control, roll a towel and put it under her arms, at the shoulder, this will encourage her to pick up her head and so strengthen her neck and back.

3. Teaching the mother to help.

A. These are some of the important things to teach the mother.

- Time must be taken to explain to her mother and her family that Amanda's slowness and lack of energy and movement is not her fault. Explain that her brain was damaged at the time she was born and that this is the cause of her problems.
- Her family must not fuss and protect her too much. The more support she is given, the less she will support and move herself. They must play with her, throw her in the air and treat her as much like an ordinary child as possible.
- The family, especially the other children, must play with her, encouraging her to play, move and make a noise. She will take time to respond. They must tease her gently into responding.
- When feeding her, her mother should put the food on the seat of a chair so that she has to stand up to eat or encourage her to sit at the table. She must not feed the child, but must encourage Amanda to help feed herself.



- In children who are more severe and more floppy, they will need to be secured before eating. The trunk must be supported by firmly securing the hips and the chest. Stretching the arms out on a high table will give the child maximum support. The child can then work for head control only while she is fed.

- When carrying the child, hold the hips and the knees bent. The head must be unsupported so that the child is stimulated to lift up his head.
- When the mother is dressing or washing Amanda, she must encourage Amanda to help.
- She must be encouraged to do more of the activities in which she starts to make sounds eg. bouncing, patting her tummy and her chest.

Although the mother and family should be encouraged to do these things, the R.W. must visit at least twice a week to see these children, play with them and support the mother.

B. Malnourished children.

The other children that we will see who are similar to these floppy children are children who are malnourished.

- They haven't had enough food so their muscles don't develop properly.
- They are weak and not interested in learning and playing and don't have the energy to move.
- They need extra stimulation and encouragement to move and play, and also enough food, a balanced diet. These children should recover completely.
- Their growth needs to be monitored at the clinic and the mother needs a lot of support.
- The mother may be very depressed as she cannot feed her child.



III.1.e. CHILDREN WITH ATHETOID CEREBRAL PALSY

Aims of this session:

1. To learn to recognise a child with strange uncontrolled movements.
2. To understand the aims of treating such a child.
3. To learn exercises to help treat such a child.

1. Examination of a child with strange uncontrolled movements.

This is Vuyiswa Bhenya and her mother. Let us watch Vuyiswa for a while. What do you notice?

Her arms, legs, head and body seem to move all the time.

The movements are writhing movements that have no pattern.

Feel Vuyiswa, is she tight or floppy?

She seems to be pushing back with her neck. At first she felt quite floppy, but when she started to move she felt tight.

There are many different types of children with uncontrolled movements. They are often floppy in the first year or two and become stiff when they try to move or speak or are excited.

In medical terms this is known as athetoid cerebral palsy.

Mama ka Vuyiswa, what are your problems with Vuyiswa?

Vuyiswa can do nothing at all. She cannot sit or stand or walk. She cannot talk or feed herself.

Do you sit her at home?

Yes, I tie her into a chair. I have to tie her in as otherwise the movement of her arms and legs and body throws her out of the chair.

Does she enjoy sitting up?

Yes very much. She seems to enjoy seeing what is going on and smiles a lot when she is sitting up.



With a child like Vuyiswa, who isn't tight, we don't have to do exercises to reduce tightness or stretch tight muscles. However, we do have to make sure that we put her in normal positions and move her arms and legs into normal positions so that she does not get tight. She could get tight if she spends her day in sitting and lying only.

Some of these children like to sit in odd ways, often like a frog, which can lead to a lot of tightness. They like to sit like this because they are trying to find a way to steady themselves and block the uncontrolled movements, but we need to check that it is not causing tightness.



2. Aims of treating children with strange uncontrolled movements.

What do you think Vuyiswa's problems are?

- *She cannot do anything except lie.*
- *She is unable to sit, stand talk or feed herself.*
- *Her development is slow.*
- *She will get tight and stiff if she lies all day.*

What do you think we should do with Vuyiswa?

- *We must sit her upright because her mother says she enjoys sitting and looking at what is going on around her.*
- *She should also kneel and stand up so that her legs and feet do not get tight and stiff.*

So the two main aims of our treatment are:

1. To encourage her development by finding ways to steady her head and her body.
2. To prevent her from getting stiff.

3. Exercises for a child who has these strange movements.

Let's sit Vuyiswa. What is the problem?

She is moving her arms so much that it is impossible to keep her balanced and upright.

When working with a child like Vuyiswa who has these uncontrolled movements we must handle her calmly and quietly as she is easily excited.

She unfortunately usually lies or sits in a position where the one side is in a different position to the other side. If her head goes to the one side, this influences the position of the limbs and the 2 sides will become more unlike each other.

We need to encourage her head to be in the midline, with her arms forward and to try and keep her hands and feet down on a surface. This will give her the chance to learn how to control her own body, without these moving arms and legs which keep throwing her off balance.

We can also work with Vuyiswa in a kneeling and standing position, as long as we can secure her hands and arms in front of her.

We have made backslabs for Vuyiswa's legs and arms which we bandage on, to keep them straight.

Do you use these at home Mama ka Vuyiswa?

Yes. It is so difficult to stand Vuyiswa up, but if the backslabs are on, they keep her arms and legs straight and then only 2 of us are needed to stand her up.

What are these backslabs made out of?

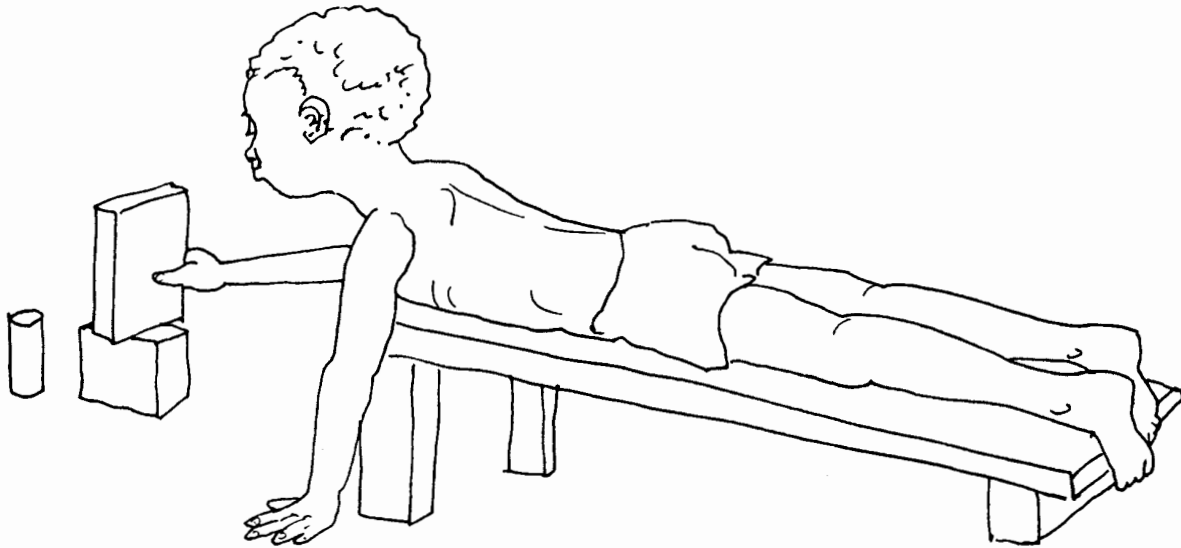
The grey sleeves that wine bottles come in at the bottle store.

They are cut to the right size. Two are put together and then placed inside a bandage. This is then strapped to the body with another bandage.



If Vuyiswa comes to the clinic we stand her up in the standing frame. She is then held fixed in a standing position and can use her hands to play with toys placed on the table in front of her.

Vuyiswa will also be able to play with toys put down in front of her. If she lies on her tummy on the ground tied to a board which is slightly tilted up.



Is it easy for Vuyiswa to feed herself?

No, it is very difficult because of the movements of her arms.

To help her to eat, we must secure her body, encourage her to be symmetrical (both sides the same) and get her to hold on with her hands, she will then be able to concentrate on head control and feeding. To help her we need to find ways for her to take some weight on her elbows and hands.

For eg. She can be helped from sitting on a barrel to sit down in side sitting on the floor.

Should we try and encourage Vuyiswa to feed herself?

Yes, for feeding we should try to sit her on our laps and hold her tight across her shoulders. We can then put the food into her hand and guide her hand to her mouth.

These children are often very clever and even if they can't talk, they want to learn to talk and do things. We need to teach them through talking and telling them stories and guiding their hands gently but firmly to touch, explore and do.

Will Vuyiswa always have these strange movements?

Yes, she will.

Children like Vuyiswa often don't do very well or get a lot better.

We need to persevere and keep working with her, and be around to support her mother.

III.2. DOWN'S SYNDROME

Aims of this session:

1. To learn to recognise a child with Down's syndrome.
2. To understand the problems a Down's syndrome child will have.
3. To learn what to explain to the parents so they can cope with these problems.

1. Identifying Down's syndrome.

A. Examination of two children with Down's syndrome.

We see many children at the clinic with Down's syndrome. Bathembu Dlakavu and Nelson Mgudiwa are two of these children. They are both here with their mothers today.

Mama ka Bathembu and Mama ka Nelson, how old are your boys?

Bathembu is 5.

Nelson is 4.

What would you expect a 4 and 5 year old to be doing?

They should be running around, feeding themselves, dressing themselves and talking.

Spend 10 minutes playing with each of these children, and notice what they can or cannot do.

What can they both do?

Can Bathembu and Nelson do the same things?

No, Bathembu cannot do that much at all. All this time, he has been sitting rocking to and fro. He does not get up and cannot talk.

Nelson is slower than an ordinary child, but he is able to stand up and walk around. He is able to talk although it is not as much as a normal child of 4. He also plays with toys.

Can they feed themselves?

Bathembu not at all.

Nelson can eat a piece of bread or an apple himself, but cannot eat with a spoon.

Do you think these boys have developed normally?

No, their development is slow.

Why is their development slow?

They may have brain damage or they may be mentally handicapped.

In the case of Down's syndrome, it is as a result of mental handicap.

B. What is Down's syndrome?

Down's Syndrome is one of the most common causes of mental handicap or slowness. Down's Syndrome children are slower than others in learning to use their bodies and their minds.

Down's Syndrome is caused by a mistake in the chromosomes, in the pattern that is followed in making the child. As a result the baby does not develop normally in the womb.

The reason for the mistake in the chromosomes is unknown, but children with Down's syndrome are most commonly born to mothers under 20 or over 35 years in age.

Do you think that Bathembu and Nelson are mentally handicapped to the same extent?

No, Bathembu is more severely mentally handicapped than Nelson.

C. Recognising a child with Down's syndrome.

Do Nelson and Bathembu look like normal children?

No, not at all.

What are the first things you notice?

They sit with their mouths open and their tongues sticking out. They have narrow eyes and their fingers are short and stubby.

These are the most obvious signs of Down's syndrome.

What else is unusual about their heads and faces?

- * *They seem to be the right size, but the head and face seem to be flat and wide. The head is also flat at the back.*
- * *Their noses are so small that Bathembu's nose doesn't keep his glasses on and they keep falling right off his nose.*
- * *Their eyes slant upwards and keep shaking from side to side.*
- * *They both have small mouths which stay open and tongues which hang out.*

What is unusual about the rest of their bodies?

- * *Their arms and legs look short.*
- * *Both of them have very big first toes and there is a gap between the big toe and the other toes.*



Pick up one of their arms or legs, how do they feel?

They feel heavy, but they are not tight. They feel floppy.

This heavyness or floppiness is the opposite problem to that of tight or stiff muscles. These children can move easily, but because the muscles are so floppy it is difficult for them to take weight through their arms and legs, as they tend to collapse. This is part of the reason why they are slow to stand up and walk around.

Watch Nelson as he moves now, what happens when he takes weight through his elbows?

They bend much further back than our elbows bend back.

As he stands up, what happens to his knees?

They also bend back much more than our knees.

As he sits on the floor, watch his legs, what does he do?

He swivels his legs right around him until they are behind him.

Can you do this?

No, not at all.

In Down's syndrome children, the muscles are floppy and the joints may be loose and flexible.

Two other problems that are very common amongst Down's syndrome children, but which cannot be seen are heart problems and problems with their noses.

Often these children are born with a *hole in their heart*. This has to be fixed by doctors operating on the heart to close the hole. This will need no further attention or care in any way.

The other problem concerns their *noses*.

What do you notice as you look at both Bathembu's and Nelson's noses?

They have colds and both have runny noses.

Down's syndrome children seem to always have colds and runny noses. They also often get sinusitis (pain in the forehead or deep in the cheeks caused by phlegm gathering here.)

2. Caring for a child with Down's syndrome.

Down's Syndrome children are everyone's favourites as they look so sweet, are often funny and are very affectionate. As with any child or any handicapped child, they need a lot of love and attention.

The 3 main concerns in caring for a child with Down's syndrome are:

- * Help the child to develop his mental and physical abilities.
- * Protect the child from infectious diseases.
- * Prevent or correct deformities.

A. Help the child to develop his mental and physical abilities.

Mental handicap may be mild, moderate or severe. Bathembu is severely mentally handicapped, whereas Nelson is moderately mentally handicapped. In both of them, physical and mental development is slower than normal.

How do you think the parents of these children can help develop their mental and physical capabilities?

They must be very patient with their child, although it takes the child a long time to learn anything.



One of the most effective ways of teaching children with mental handicap to do things is to break tasks into small steps. The child must try to do one step at a time. If the child does something well, he must be encouraged and praised.

Let us look at this with the example of teaching him to put on a sock while getting dressed.

- Step 1: Pull the sock over the child's foot and half way up his leg. The child must pull it fully up the leg.
- Step 2: If he can do the first step, put the sock on his foot, right up to the heel. He must then pull it up his leg.
- Step 3: The next step would be to put it on his toes only and he must pull it over his foot and up his leg.
- Step 4: Give him the sock so that he himself, puts it on.

The parents must spend time with the child, stimulating, playing and talking to him, encouraging him to move and learn and praising him when he gets things right.

B. Protect the child against infectious diseases.

These children tend to get ill more often than other children.

Mama ka Bathembu and Mama ka Nelson, what illness do your boys most commonly get?

Chest infections.

Have any of you ever seen an adult with Down's syndrome?

No.

This is because they usually die of a chest infection before they are adults.

As soon as the baby gets a cough, sore ear or sore throat, take them to a health worker, so that the infection does not get worse and go into their chest.

Children with heart problems must not be allowed to get too tired by running around and playing too much.

Just as with all other children, encourage the mother to breast feed, to get the child immunized and to feed the child a balanced diet if she can afford it.

C. Prevent or correct deformities.

The most common deformity involves the big toe.

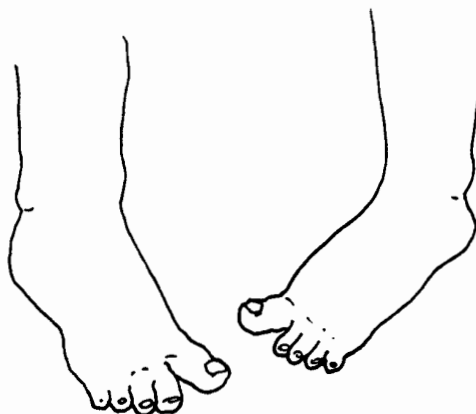
Does this big toe of Nelson's cause you any problems Mama ka Nelson?

It caused me no problems until I had to buy shoes for him. I can't find any shoe to fit him, as the toe just sticks out so much on the side. Now he just refuses to wear shoes.

The shoes that you bought for him, were they hard or soft?

They were hard.

They most probably caused him pain as they pushed hard on the toe that was sticking out. He may be happy to wear sandals or shoes that are open at the front, or shoes that are soft and will not press on his toe.



D. Prevention of Down's syndrome.

Down's syndrome is more common if the mother is over 35. Mothers over 35 should be warned of the possibility of this. If a mother has had a Down's syndrome child and is thinking of having another child she should be encouraged to go to a genetic counselling clinic at Red Cross Hospital. Here they can work out how likely it is that she will have another Down's syndrome child.

III.3. MENTAL HANDICAP

Aims of this session:

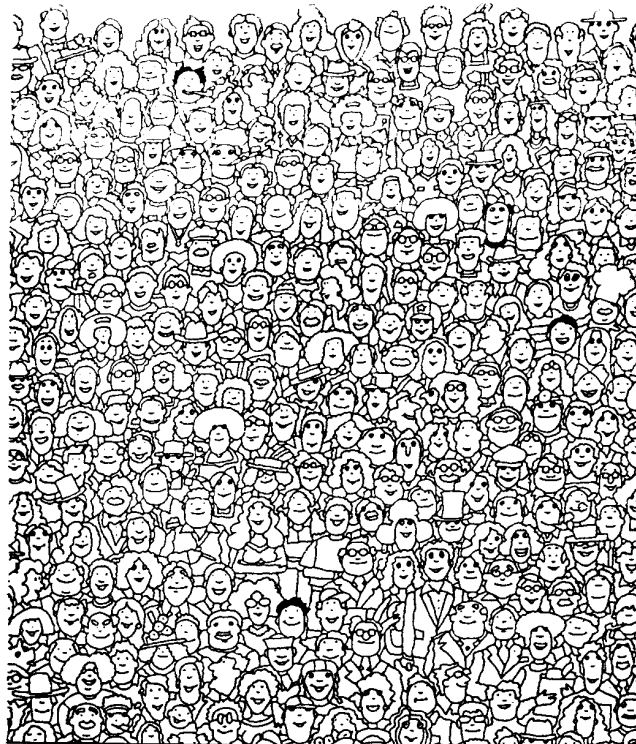
1. To understand the ways in which a mentally handicapped child may be affected.
2. To learn what can be done to help a mentally handicapped person.

1. The causes and effects of mental handicap.

A. Mental handicap in the community.

Do any of you know children or adults in your communities who are mentally handicapped?

- *Next door to me is a handicapped boy of 15. He spends his days wandering around from house to house. He doesn't have any friends and he hardly talks at all. He walks in a funny way with his toes pointing in and his arms held close next to his chest.*
- *My sister has a handicapped son. He seems to be quite normal as he can talk and do simple things around the house, but if he leaves his home he gets very easily lost and cannot find his way back. If he goes next door to the shop, he will forget what he is supposed to buy there, and leave the money on the counter.*



4 out of 1000 people in any community
are mentally handicapped.

- *I knew a little girl in the Transkei, she was in a serious condition. She couldn't sit and spent her day lying in the corner. She would make funny noises, but nothing her mother could understand. Over the years she has got worse and worse and now she is curled tight closed in a little ball and it is impossible to open her up and get her straight. It is very difficult for her mother to wash her.*
- *A child in my street is mentally handicapped. He doesn't talk. He sits on the floor and rocks to and fro all day. If he lies down he bangs his head on the floor again and again and again. He cannot sit still and is always moving and restless, as if he is not comfortable in any position.*
- *A young boy from my home town looks fine. He walks like one of us and works around the house helping his old mother. He used to have a job, but he was asked to leave as sometimes he gets really angry and fights with people, beating them up.*

Most of you seem to know of someone who is mentally handicapped, is that right?

Yes, but its not just one person, there are many handicapped people in our communities.

Mental handicap is quite common in our communities, one in every ten people is mentally handicapped.

B. The causes of mental handicap.

In most cases a mentally handicapped child has a damaged brain. We dealt with the different causes of brain damage in our session on "Brain Damage in Children." (Sessions III.1.a-e).

C. The effects of mental handicap.

Think of the people that you have just described to me. How are they different to other normal children?

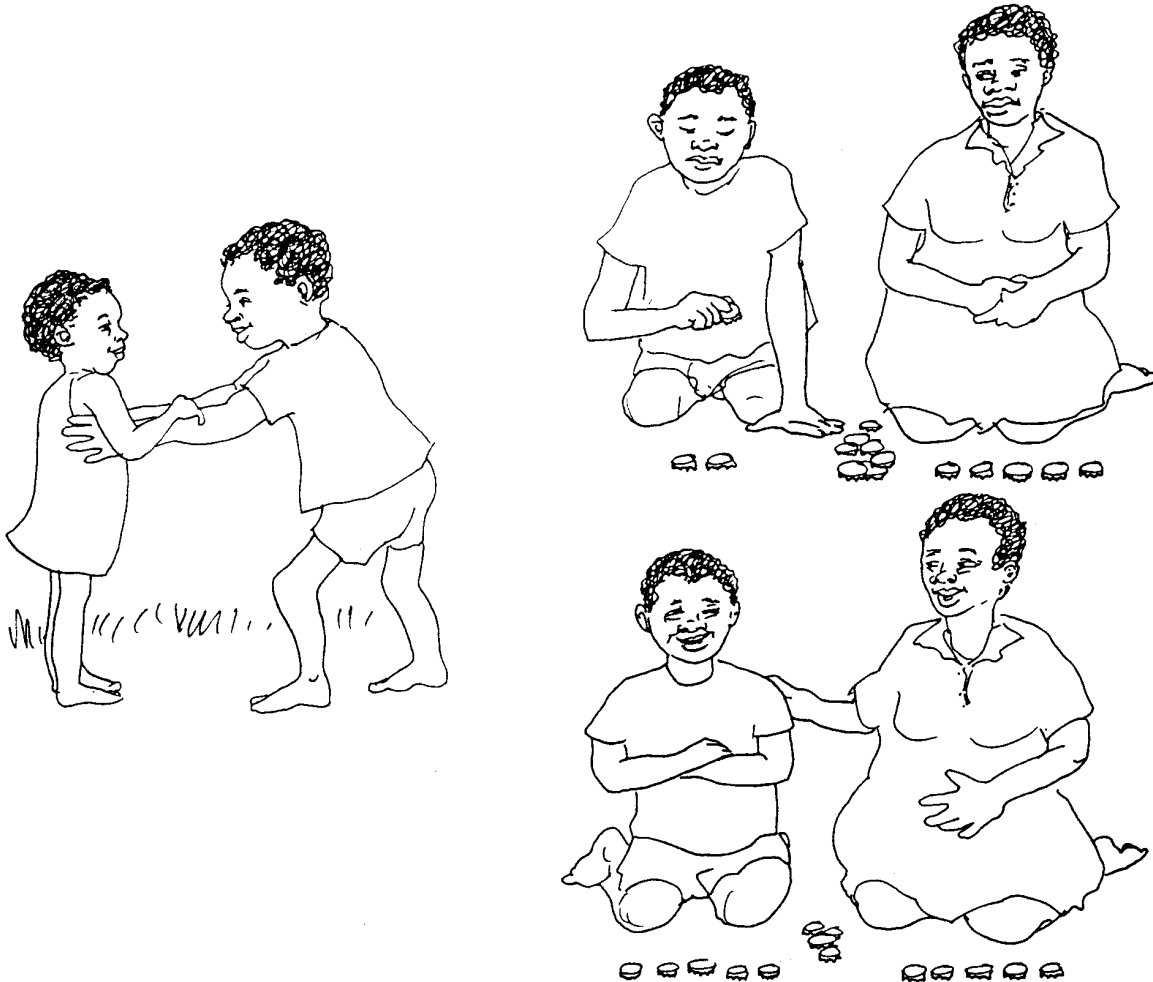
- They are unable to move properly:
 - * They may be tight, so that with time they become stiff and curled up in a little ball.
 - * They may have regular repetitive movements that they do again and again.
 - * They may be restless, constantly moving as if they are never comfortable.
- They have slow development, taking longer than usual to learn how to sit, get up, walk and talk.
- They are unable to think properly:
 - * They forget where they live or what they were supposed to buy at the shop.
 - * They do not manage at school as they seem to take a long time to understand and learn things.
- They are unable to talk, they make unusual noises that have no meaning.
- They have changes of mood, and may suddenly get angry and become violent.

Some of the people we talked about have problems with thinking only. These are the people we refer to in this session as having a mental handicap. Mentally handicapped people may, however, have many other handicaps, for example, blindness and stiffness.

2. Principles used to work with children with mental handicap.

A. Focus on the child's abilities.

No two mentally handicapped children are alike, so it is impossible to have one method for solving each problem. What will work with one child may not work with another child, so that another method needs to be tried. When working or handling mentally handicapped children, focus on what the child can do and not on what the child cannot do.



As an example of this, let's look at the fourth point we mentioned above. As a result of mental handicap, some children are unable to talk and can only make unusual noises that have no meaning.

We must not focus on the fact that the child cannot talk, but rather on the fact that the child can make noises. We must see these noises as something positive that the child can do and not see them as irritating.

These noises are positive because they can be used by the child to communicate in a way that can be understood. The child may learn to make different noises if he is hungry, thirsty or wants to go to the toilet.

As we talk to this child, we must talk properly and not make noises ourselves.

B. Breaking tasks into simple steps.

One of the most effective ways to work with children with a mental handicap, is to break any task that needs to be done into simple steps. Let's outline this teaching model:

1. Select the Task.

Discuss with the family and choose a task that is important to them, useful for the child and realistic.

2. Analyse the Task.

Divide the task into small parts, be clear about how each part will be taught, it needs to be repeated in exactly the same way each time, who will teach it and what the child must do for you to say the child has succeeded.

3. Teach the Task.

Use a relaxed, friendly approach, helping the child as much as is necessary with physical assistance, demonstrations, gestures and verbal assistance. Give the child the opportunity to practise again and again. Gradually reduce the assistance.

4. Reward the Success.

Reward the child each time he succeeds or makes a real effort to succeed. Use rewards that the child really enjoys.

5. Check Progress.

Check that the child can regularly perform the task correctly. If the child cannot perform the task, check if it is too difficult, or if parts of it are too difficult. Discuss with the family, the problems that the child is having. When the child succeeds regularly return to step 1 to select a new task.

Let us look at one aspect of **getting dressed - "putting on trousers"**, as an example of breaking a task into parts:-

Put the trousers on, until they are just below the waist. The child must pull them into his waist.

Put the trousers on until they are just below his bottom. He must pull them over his bottom and into his waist.



Put the trousers on to just above his knees. He must then pull them up his legs, over his bottom and into his waist.



Put his trousers over his feet only. He must then pull them over his knees, legs and bottom and into his waist.



Put one foot into the trousers, he must put the other foot in and pull them over his legs and bottom and into his waist.

Give him the trousers and he must put them on.

Lead him to the cupboard where his trousers are. He must take the trousers out of the cupboard and put them on.



Tell him to put his trousers on. He must go to the cupboard, find his trousers and put them on.

3. Working with a child with mental handicap.

To work out how we can help a mentally handicapped child, we mentioned five ways in which mental handicap affects a person. Let us examine each area and discuss ways of helping the person. As I mentioned above these will not necessarily work with each child. In this case alternative methods should be used.

A. Unable to move properly.

• 1. Tightness and stiffness.

We have discussed what to do for tightness and stiffness in many of the sessions we have done. Let's just outline some of the principles we should remember when working with a child who is tight and stiff.

What have we learnt to do for a child who is tight and stiff?

- *We can make the tightness less, but not the stiffness.*
- *The stiffness must be prevented.*
- *We have 3 ways of reducing the tightness:*
 - * *movement*
 - * *stretching*
 - * *rotation*
- *To reduce tightness, we must start reducing the tightness of the neck and body, before we try to reduce the tightness of the arm, hand or foot.*
- *If the child has pain, this will only make the stiffness more, so we must try not to cause the child pain.*

What joint is most likely to cause the child pain?

His shoulder, which would then make the whole arm, particularly the elbow and wrist painful.

Certain individual muscles tend to get tight and stiff. The method of stretching these is in the session on contractures. (IV.3).

Can you think of 1 or 2 muscles or joints which tend to get tight and stiff?

Ankle joint, because of tight calf muscles.

The muscles at the front of the knee and hip joint get tight from sitting too much. Eventually the knee and hip can no longer straighten so that the person cannot stand up straight.

• 2. Regular, repetitive movements.

One of you mentioned you knew a little boy who used to sit on the floor and rock forwards and backwards. If he lay on his tummy he would bash his head again and again on the floor.

Have any of you seen any other children who had unusual movements that they repeated again and again?

Yes, at the special care centre we saw a little boy who kept hitting his head with his hand.

Do you remember Bathembu with Down's syndrome? Did he do any movements like this?

Yes, he rocked to and fro, but he would also bend and straighten his second finger again and again as he sat on the floor.

Do ordinary people do these kind of movements?

No, not at all.

Do you think we should try to stop these children from doing these movements?

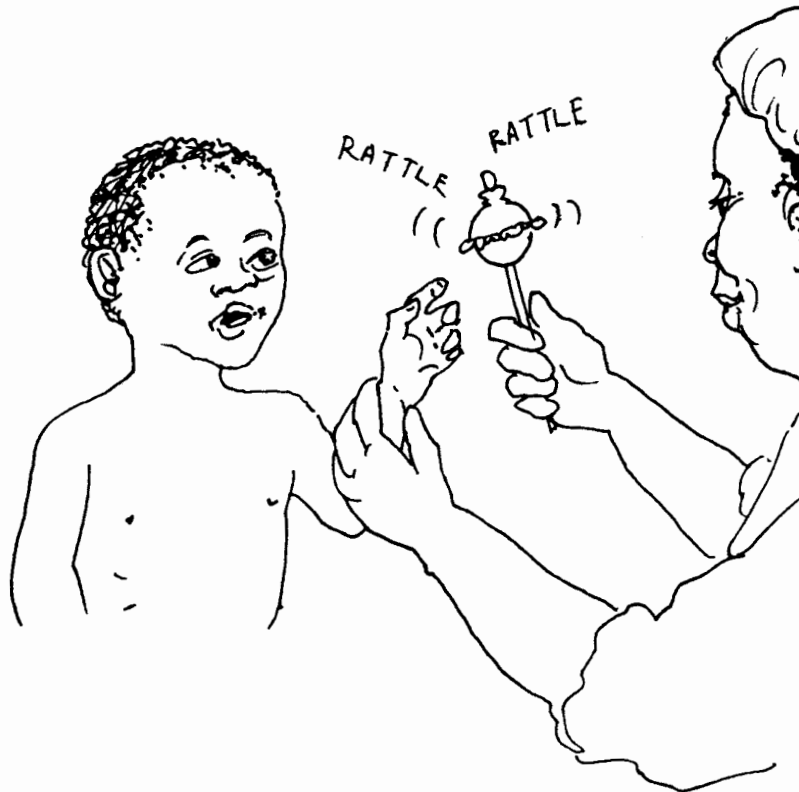
We must stop them, as otherwise they look so funny and other people can always tell that they are not normal.

How should we stop them?

At the special care centre a little boy was hitting his head with his hand. I saw the teacher in charge of the class, take hold of his hand and put it down on the table in front of him, so that he couldn't carry on hitting his head. As she was doing this she explained to him that he mustn't hit his head with his hand.

Did she just put his hand on the table, or did she put something in his hand?

She put a rattle into his hand to distract him so that he didn't want to hit his head anymore.



• 3. Restless movement.

What can we do for these children?

My neighbour had a child like this. The child was only ever quiet or still, when she was eating.

We need to try and find one or two things besides eating that a child like this enjoys doing, and then do these for a short time, so that he concentrates for a short while and is not restless for this short time. Hopefully the length of his concentration will increase so that he is quiet and not restless for longer and longer periods of time. With time we also hope that he will be happy to do more and more things.

B. Slow development.

In other sessions we have discussed what to do to help a child who is developing slowly. Do you think the same would apply for these children?

Yes.

What guidelines did we outline for working with children who develop slowly?

- We need to stimulate and play with them to encourage them to move and feel.
- We must be very patient as these children take a long time to respond and a long time until they learn anything.
- Work in different positions so that the child gets used to these and will feel more comfortable to get into these positions himself.
- The family, (particularly the mother and those who spend a lot of time with the child), must be encouraged to play with and stimulate the child as much as possible.

For children with mental handicap the teaching model that we have discussed in which tasks are broken down into steps, can be very helpful. As it takes these children so long to learn to do things, the parents must be encouraged to see that even the smallest thing learnt is an enormous step forward. The parents must try and focus on what the child can do and not on what he cannot do.



C. Unable to think properly.

Every child with mental handicap is different so it is impossible to describe one general way of helping each particular person. One of the ways in which children can be encouraged to develop concentration and their memory, is to break down tasks into steps. If the child succeeds in one of these steps he must be rewarded.

D. Unable to talk and makes unusual noises only.

We used this as an example when we were talking about the principles of working with mentally handicapped children.

Instead of being negative about the inability to talk, we must be positive about the ability to make noises.

E. Changes of mood.

What do I mean when I say that my mood changed?

Maybe you were very happy and then someone upset you, so you became very sad.

Does this happen to all of us?

Yes, of course.

This happens with mentally handicapped children too. They might be happy and then something makes them feel miserable or sad. Like ordinary children, they have to learn to express how they are feeling in a way that is acceptable to everybody around them.

Have any of you ever seen a child with mental handicap change his mood?

Yes, this boy who lived close to me used to be just fine. Suddenly he would get very angry and scream and throw himself on the floor and beat his hands and head on the floor.

It is not easy to know what to do with people who react in this way. But children with mental handicap need to learn how to express their feelings in a way that is acceptable to all of us.

Sometimes getting angry and misbehaving is the way in which the child demands attention. One of the possible ways of handling this is to ignore bad or unacceptable behaviour.

On the other hand, if the child or person behaves well, they must be affirmed, given positive attention and encouraged. By doing this you will be reinforcing or encouraging good behaviour. The child will then hopefully learn that to get positive attention he must behave well and not badly.

4. The mother and family of a handicapped child.

Who spends most time with the child?

The mother and the family.

The mother and the family, must be involved in any programme to teach the child to do anything. They must be encouraged to be patient, but keep trying to teach their child activities which could make him more independent.

The family and the mother in particular, must not only understand the problems of a mentally handicapped child, but must also accept the problems and complications that arise out of these.

Although the child needs help, often the mother and the rest of the family need help and support too. Having a mentally handicapped child in the family is exhausting and can also be very depressing, so the family must be supported and assisted in their management of the child.

What can be done to try and help the family, and the mother in particular?

- Often the mother is unable to go out to work as she has to stay at home to look after the child. The father may have left because of the difficulties of living with a mentally handicapped child. The family is very poor as a result. The mother should be referred to the nearest social worker for an application for a single care grant.
- There are very few schools for mentally handicapped children, but whenever possible the child's name should be entered on the waiting list for one of these schools.
- If there are many handicapped children in the same area, you as the R.W.s could start a support group so that the mothers of these children could get together once a week, to discuss their similar problems and the ways that they have coped.

I.1. HYDROCEPHALUS S

Aims of this session:

1. To understand hydrocephalus.
2. To learn how to judge whether a child is hydrocephalic.
3. To understand the main danger of hydrocephalus.
4. To learn how to teach the mother how to recognize and deal with a blocked shunt.
5. To recognize microcephalus.

Teaching aids:

1. A tape measure and head circumference chart.

1. Understanding hydrocephalus.

A. Examination of a boy with hydrocephalus.

This is Luzuko. He is 4 years old.

What is the first thing you notice as you look at Luzuko?

His head is enormous.

Have any of you ever seen a child with an unusually big head before?

- * *Yes, I knew a boy in the Transkei with a big head, but it wasn't nearly as big as Luzuko's head.*
- * *I know a girl in New Crossroads who has a big head.*

Luzuko is 4, what would you expect a child of 4 to be doing?

To be running around, playing with other children, to be eating by himself and to be dressing himself.

Let's ask Luzuko's mother if Luzuko can do all these things.

Mama ka Luzuko, does Luzuko run around, play, feed himself and dress himself?

- * *He is able to stand up and is just starting to take a few steps holding onto the furniture.*
- * *He can eat a piece of bread by himself, or an apple, but is not able to use a spoon and feed himself.*
- * *He is not able to dress himself.*

Are those children with large heads that you know in the Transkei and in New Crossroads, are they able to do these things?

- * *The boy in the Transkei was OK at first, but then he seemed to get worse and worse. He started having fits and then we all realised that he couldn't see. He also became very tight and then he died.*
- * *The girl in New Crossroads was able to do everything. She was just like a normal child.*

B. What is hydrocephalus?

What causes Luzuko to have a big head?

Water in the head.

Yes, that's right.

Do you think we all have water or fluid in our heads?

No.

Actually, we all *do* have some fluid in our heads. It is produced in the brain, and flows around the brain, but it keeps draining down out of the brain into the spinal cord. With Luzuko, there is a block so that it cannot leave the brain. So more and more fluid accumulates in the head.

When a baby is born are the bones in his head hard?

No, they are quite soft, and as the baby gets a bit older, they get harder.

The joints between the different skull bones are not fixed and can move slightly.

If more and more fluid keeps accumulating inside the head, what does it do?

It puts pressure on the structures surrounding it.

If the bones of the skull are soft and they can move, what will happen to them under this pressure?

The bones will flatten and move outwards so that the head is bigger and there is more room for the fluid. This is why Luzuko's head is so big.

Only a certain amount of movement is possible, and then the head can grow no bigger. If more fluid is being produced, pressure will continue to build up and push against the bones of the skull.

What is inside the skull?

The brain.

As more fluid is produced and the skull can no longer grow, pressure is exerted on the brain.

Is the brain hard so that it can withstand pressure?

No, it is soft so it can be easily damaged.

Hydrocephalus can cause brain damage if it is not treated immediately. Not all cases need treatment. Sometimes hospitals will not treat the baby if she is very badly affected early on.



C. Complications that can develop.

We have just discussed how the increased pressure in the skull, due to extra fluid, can cause brain damage. In the session we did on brain damage we discussed some of the results of brain damage.

How can brain damage affect a child?

The child may fit, be blind, deaf, tight and unable to move, unable to understand and difficult to feed.

Why do you think Luzuko is not walking around and feeding himself?

Maybe, his brain was damaged by too much pressure at some stage and this is why his development is slow.

Brain damage can cause a child to develop slowly.

Another possible reason for his slow development is that he spent a lot of time in hospital because of the hydrocephalus and during this time was not given the love, attention and stimulation he should have had from his mother.

This can happen with any child who spends a lot of time in hospital.

Remember the child that Nomazizi knew in the Transkei. Nomazizi said he started fitting, then they noticed he was blind and then his arms and legs and body became very tight. This little boy obviously became worse and worse as the pressure in his head got more and more. He may never have had an operation. He died as a result of the pressure of the extra fluid causing brain damage.

The most serious complication of hydrocephalus is brain damage. Children with hydrocephalus can do well, and be just like normal children if brain damage is avoided.

2. The treatment of hydrocephalus.

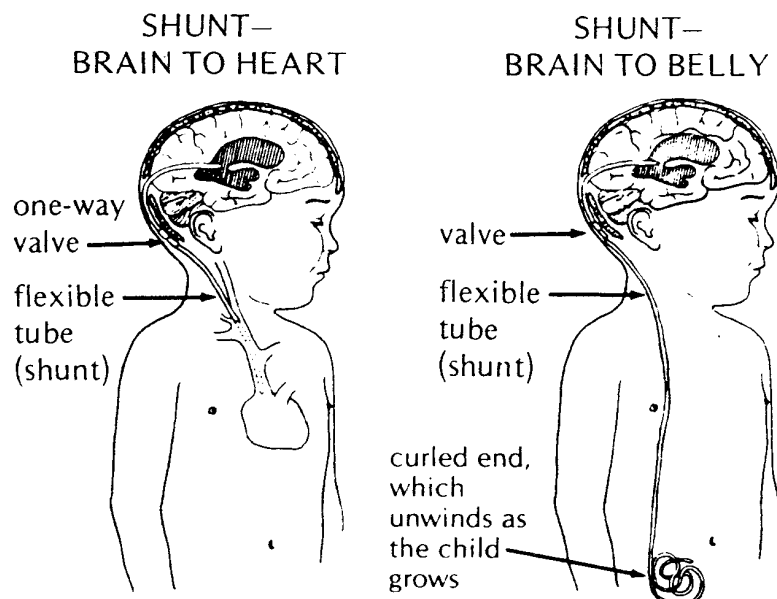
A. The shunt.

If more and more water is pouring into a plastic packet and the packet is about to burst, what can be done to stop it bursting?

A small hole can be made in it, so that it can run out and relieve the pressure.

How could the pressure in the head be released, as more and more fluid is produced?

A hole must be made in the head for the fluid to run out.



This could work, but the trouble with an open hole is that it can easily become infected and dirty.

So instead a tube runs from the liquid-filled hollow in the brain, either into the entrance of the heart or into the belly. The extra fluid in the brain can then drain out continually. This is known as a shunt.

Feel at the back of Luzuko's neck here, can you feel the pipe just under the skin?

Yes, it is just under the skin and feels quite hard.

B. The complication that can develop with a shunt.

Do you think there could be any problems with a small pipe?

It could get blocked.

What would happen then?

The pressure would start building up and could then damage the brain. It isn't possible to see the pipe, so the mother needs to be taught when to recognise that the shunt is blocked.

Signs of the shunt being blocked.

- The child may be uncomfortable and cry.
- The child may have a temperature.
- The head size may increase in a young child.
- The child may start vomiting the food or milk he has just drunk.
- The child may lose consciousness.
- The eyes may roll downwards.

If the shunt is blocked, the child needs to be taken to Red Cross Hospital as quickly as possible. The following can be done to help:

- Medicines may clear the bugs that are blocking the pipe.
- An operation may be needed to put a new pipe in.
- Sometimes the pipe just keeps on blocking and eventually the child dies.

3. Screening for hydrocephalus.

A. The three screening techniques.

If children with brain damage are discovered as early as possible, further damage be prevented from occurring.

In session II.4 (3.B) we mentioned the three screening techniques that you can use to pick up children who have problems early, so that they can be referred to the local day hospital or Red Cross Hospital before further brain damage occurs.

What are the three techniques?

- * *Measuring the weight*
- * *Measuring the development*
- * *Measuring the head size*

Which ones have we looked at in detail?

Measuring the weight and development.

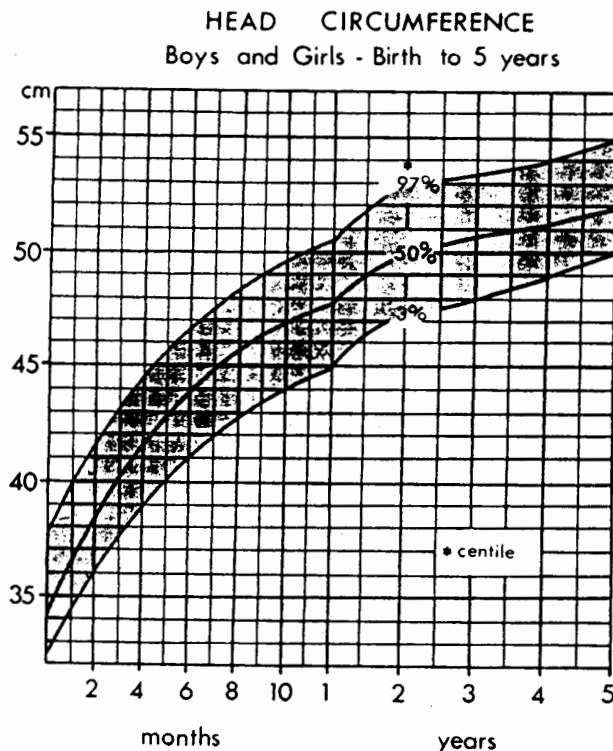
Which one do you think is important for hydrocephalus?

Measuring the head circumference.

B. Measuring the head circumference.

When we did the three screening techniques, we said we would look at the technique of measuring the head circumference in this session.

Each person was then given a tape measure and a head circumference chart. We all learnt how to measure a child's head, by measuring around the widest part of the head and then plotting this on the chart. To be of real value, this must be done regularly over a period of a few weeks or months.



We measured the heads of normal children and noticed that when we plotted these onto the graph they fell within the range of 'normal'.

Hydrocephalics were also measured and plotted onto the graph and they fell above the 'normal' range.

C. Microcephalus.

Do you think that some children would fall below the 'normal' range?

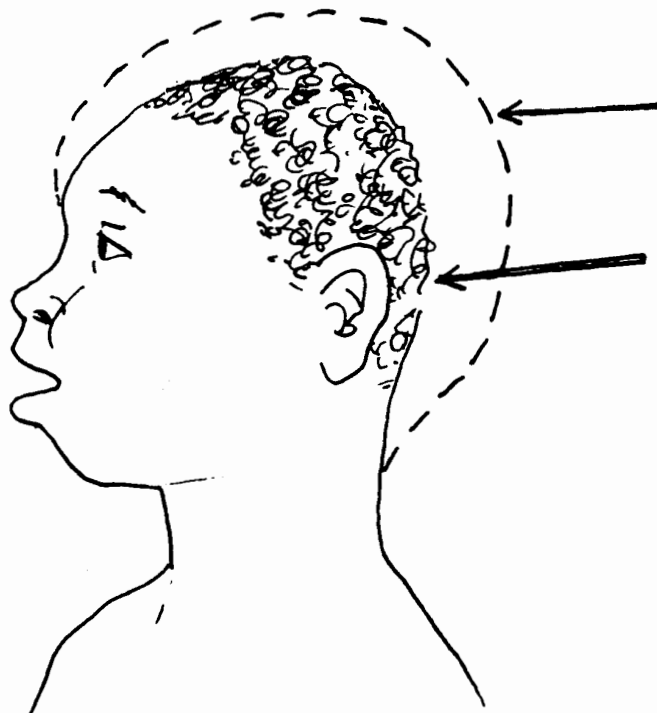
Yes, we often see children with small heads.

They have microcephalus.

Microcephalus is a condition in which the child's head is smaller than normal.

It is not a type of hydrocephalus, but we do need to learn about it, because the graph that shows up hydrocephalus also shows up microcephalus.

In fact, as you have noticed, we see more children with microcephalus than with hydrocephalus.



Children are born with microcephalus, and there are many causes for this. The problem is that due to the small head, the brain is damaged by the constant pressure of fluid against the brain. The child's health gets worse and worse.

These children usually present as spastic quadraplegics (Session III.1.b.). Many of them will also have feeding problems (Session IV.7).

D. Referral to a hospital.

You will often be the first person to pick up problems as you go around the community from house to house. Possibly you can also establish links with the creche teachers, so that you can go to the creches to check there are children there who may have these problems. Also if the teacher is worried about a child, she knows to approach you.

If you are concerned about a child because after 2 or 3 measurements over a period of time the head circumference is too big (hydrocephalus) or too small (microcephalus) when plotted on the head circumference chart, then refer the child to the local day hospital, or (if you are uncertain) tell the person who comes to supervise patients with you once a week, and together you can decide whether to refer them to hospital or not.

III.5. SPINA BIFIDA

Aims of this session:

1. To understand spina bifida and the problems which it can cause.
2. To learn how these problems can be avoided.

1. Examination of a child with spina bifida.

This is Thuleka, what do you notice as you look at her?

She seems to have a very big head. Her legs don't move and the feet are a funny shape.

Thuleka is 4, is she acting like a normal 4 year old?

No, not really, a 4 year old should be running around and playing, whereas she is just sitting still.

What about the nappy that she is wearing?

At 4 years old, she really shouldn't need a nappy.

What do you see on Thuleka's back?

Low down on her back, she has some big scars, they must be from an operation.

Thuleka was born with a condition known as spina bifida.

This is a problem which starts while the child is still developing in the mother's womb. The back bones do not form properly and do not close over the spinal cord.

At birth the spinal cord may bulge out as a dark sac filled with nerves and liquid. If the nerves bulge out into a sac like this they will be damaged. Sometimes, although there is no sac, the bones may not be properly closed, so the spinal cord is unprotected, and may be easily damaged.

Nobody knows what causes spina bifida, but 1 out of every 250 to 500 babies, is born with spina bifida.



1 out of every 4 children born with spina bifida dies in the first few weeks or months of life.

Let's ask Thuleka's mother: "What happened when Thuleka was born?"

She had this ugly looking sac at the bottom of her back. She was then taken straight away and operated on and the sac was cut away.

If a baby is born with this sac containing nerves and fluid, it must be operated on immediately. Otherwise the child might die.

2. The problems that are most likely to develop.

Let us now examine the problems that you noticed earlier when you looked at Thuleka.

A. Large head.

Hydrocephalus which means "water on the brain" develops in 4 out of 5 children with spina bifida. (See session III.4) The water that forms inside the head cannot drain normally into the spinal cord. It collects in the head and puts pressure on the brain and skull bones.

What happens if there is too much water inside the skull and it is putting pressure on the brain?

It can cause brain damage.

To avoid this an operation needs to be done as early as possible, and a shunt put in, to drain the extra fluid into the abdomen, so that it no longer pushes against the brain.

B. Legs that do not move.

Thuleka's legs and feet are paralysed, they cannot move. This happened because the nerves were damaged at birth. As they have never moved, they are also a strange shape.

What do the nerves in the lower area of the spinal cord do?

They carry messages about movement and feeling to and from the legs, bladder and bowel.

If a child is born with spina bifida low down on the back, what will happen to her?

She will be unable to move her legs, or only be able to move them a bit, but her body and arms will be able to move. Her bladder and bowel will also not work.

Thuleka's legs are unable to move, is there anything else wrong with them?

She cannot feel if we pinch them, or if we lift her foot up or down.

What nerves are present in the neck area of the spinal cord?

The nerves carrying messages to and from the arms, body and legs.

If a child is born with spina bifida at the base of her neck, what part of her body will be affected?

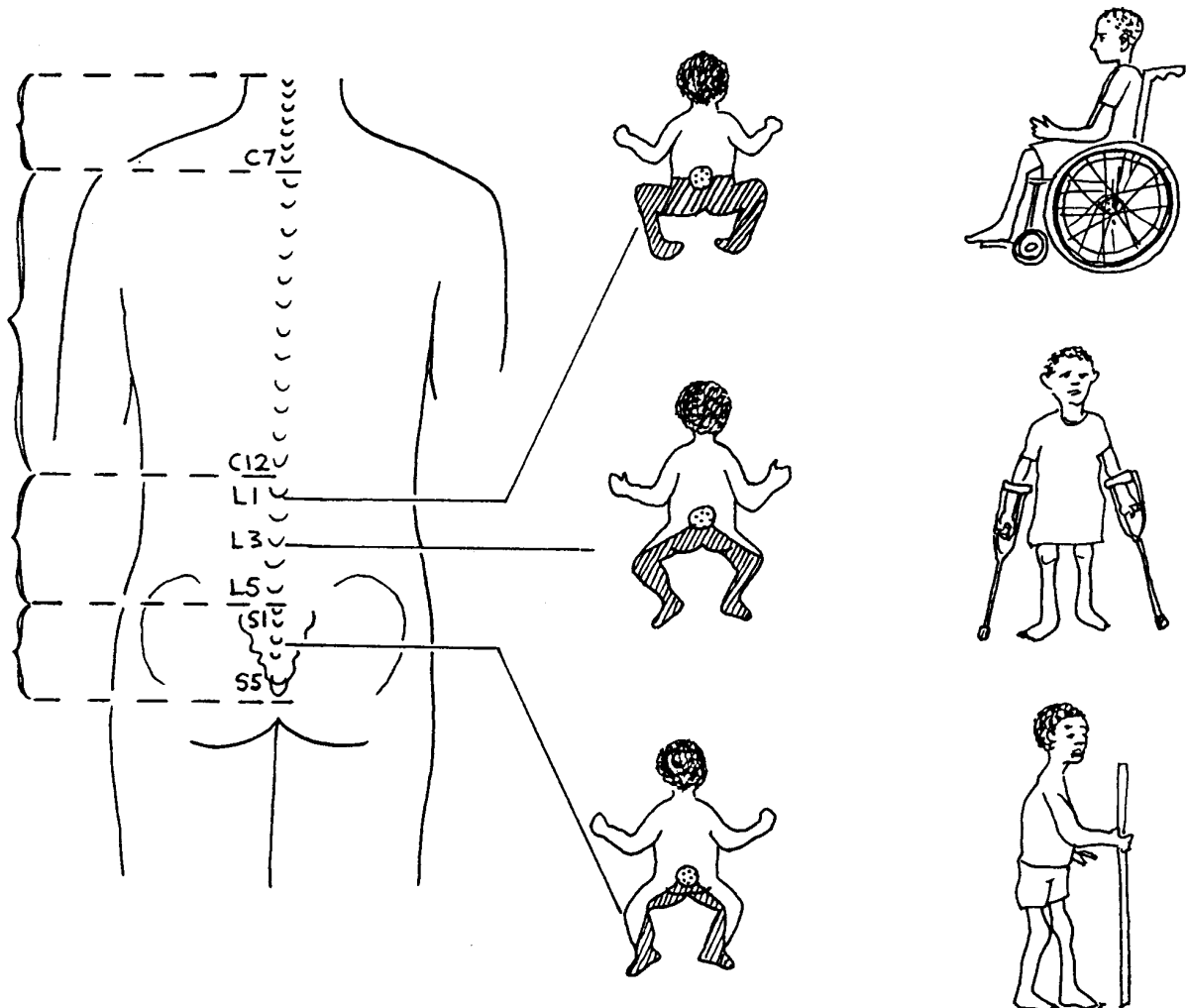
She will be unable to move her arms (or move them only a bit) or her body or her legs.

The higher up the spinal cord the problem is, the more nerves will be damaged and the less movement the child will have.

What are the chances that a child with spina bifida will walk?

This depends on how high up the spinal cord the problem is.

The lower down the spinal cord the problem is, the greater chance the child will have of walking. Some children may even be able to walk, go to school, learn to do many kinds of work and lead a full and happy life. The drawings below, show how likely it is that the child will walk, based on the level of the problem. The shaded areas show the parts of the body which are paralysed and have no feeling.



C. Deformed legs and feet.

What has caused the deformities we have seen in other children?

In the case of brain damaged children it is because the child cannot move and the muscles are so tight.

With spina bifida children like Thuleka deformities are caused by two reasons.

Firstly, like brain damaged children, some muscles are not working. But secondly, it is because she was born with two further problems with her legs: her hips were dislocated and she had club feet (feet that turn down and in).

As you look at Thuleka now, are her feet falling down and in and looking rather like clubs?

No.

Can you see the scars at the back of her ankles and on her feet? What do you think these are caused by?

It looks as if she had operations there.

Thuleka had operations to correct her feet so that she is now able to stand up on them.

D. Poor urine and bowel control.

We all noticed that Thuleka is wearing a nappy. Let's ask Thuleka's mother: How old is Thuleka?

She is 4.

Why is Thuleka still wearing a nappy?

She is not able to feel when she urinates or has a bowel action. So she keeps dirtying herself.

This happens because the nerves which should have been controlling the bladder and bowel, were also damaged in the sac at the time of birth.

3. Helping the child develop.

Should a child with spina bifida develop normally?

Yes, unless the child has brain damage as a result of the hydrocephalus.

Is it easy for Thuleka, with spina bifida to develop normally?

No, it is not so easy. She is unable to stand up and get around like other children.

How should her parents help her?

Her parents need to take this into account, she needs extra stimulation from her parents as she is unable to go and find something to stimulate herself. Her toys need to be put close to her and maybe the parents should encourage the other children to play with her or close to her.

Appliances may be needed to help her go through the same development as ordinary children, eg. calipers to enable her to stand up and walk around.

Although a child like Thuleka is paralysed from her waist down, she must be given the chance to develop her body, minds and social abilities as much as possible.

Depending on the level of the problem (higher up or lower down on the back) and the presence of brain damage (because of hydrocephalus), these children have the potential to live independent, meaningful lives.

As the child gets older many other problems, such as those listed below, can develop. These are a result of the problems that the child was born with.



If the parents really understand the child's condition, the problems that are likely to develop and how these can be prevented, the person can live a happy and fulfilled life, going to school, having a job and having a family.

The child must be encouraged to do as much as possible for herself, so that she becomes as independent as possible.

4. Further problems that develop.

A. Urinary infections and kidney damage.

Urinary infections occur because the bladder is often unable to empty completely. Many urinary infections lead to kidney damage. Kidney damage is very serious and can result in death.

If the child develops an infection, she must be taken to a doctor as soon as possible. To prevent infections and to help them clear as soon as possible, the child must drink as much liquid as possible. (An adult should drink 2 litres of water a day.)

B. Curve of the spine.

This occurs because muscles on one side of the vertebral column are weaker than those on the other side. So the spine is pulled towards one side. If you notice that the child's back is starting to curve, you must tell the mother to tell the doctor at the child's next appointment. The child may be given a hard plastic brace to keep her back straight. Although this is uncomfortable and it takes time for the child to get used to it, it is very important for the child to wear it.

C. Pressure sores.

Pressure sores tend to develop in children with spina bifida because their feeling below the level of the problem is reduced or not present at all. (See the session on pressure sores for details on how to care for and how to prevent pressure sores.)

D. Foot and leg injuries.

Do you think that children who walk but have no feeling in their feet or legs may have problems?

Yes, because the child cannot feel their legs and feet, it is easy for them to injure themselves by kicking a stone or bumping into a piece of zinc without even feeling it, and develop sores on these areas.

These can become severe if they are not treated and lead to bone infections, deformities and even loss of the feet.

The feet and legs must be checked everyday for sores or places where the shoes or calipers may be rubbing.

Who should check the child's legs and feet?

The parents must be taught to check, but the child needs to be taught to do it for herself.

The shoes and calipers must also be checked regularly to make sure they are not too small.

The child must be encouraged to keep walking although it is such hard work. If the child gets fat, it becomes even harder work.

What encourages a person to become fat?

If the person eats too much and if she eats too many sweet or fatty things, eg. sweets, cakes, fatty meat.

If it is not possible for the child to walk each day, she should stand up.

E. Hydrocephalus.

It is important to measure the distance around the head of child with spina bifida at birth and every week afterwards. If the head size increases faster than normal, or if the head swells a lot, the child probably has hydrocephalus. If the child has hydrocephalus, she will have an operation to insert a shunt. The parents must be taught how to recognise if the shunt is blocked. (See session III.4 on hydrocephalus).

F. Loss of bladder and bowel management.

See session IV.5 on this.

G. Contractures.

Children with spina bifida are often born with contractures, dislocated hips and club feet. However they also develop contractures either because of muscle imbalance or, less often, because of spasticity.

If the child's legs are paralysed, she tends to develop contractures in the feet, knees or hips, why is this?

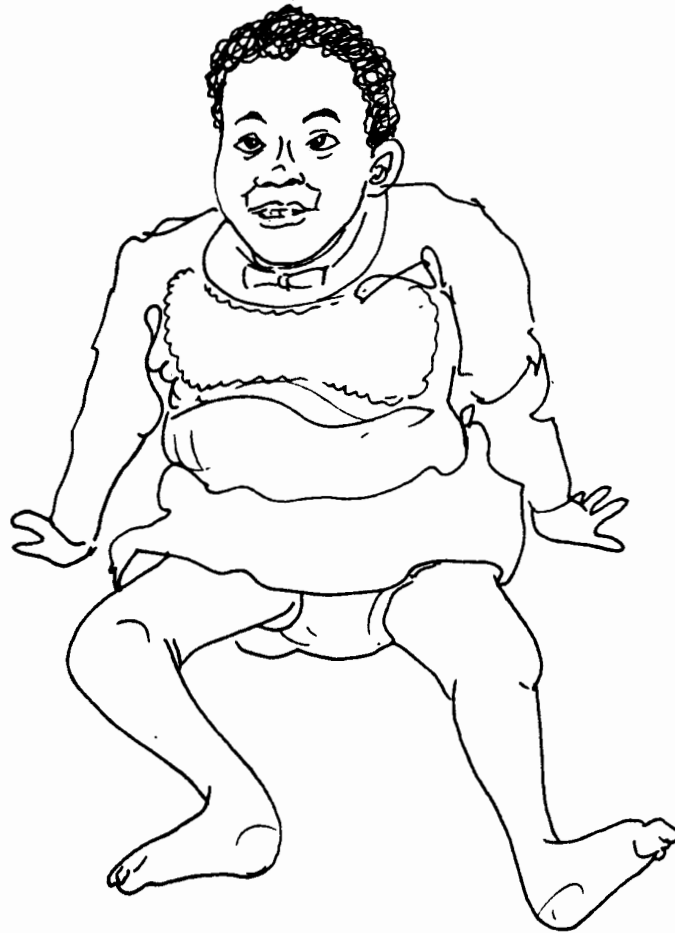
Because the legs are paralysed and are not moving and also the child is not standing up and stretching these joints.

In what position do these children spend most of the day?

They usually sit, so they get stiff at the knees, hips and feet.

Hip flexion contractures develop for 2 reasons:

- the muscles for bending the hips often work when those that straighten the hips are paralysed.
- the child sits a lot of the time, so the hips are in a bent position.



Knee flexion contractures develop as the child usually sits with the knees slightly bent, and seldom unless she has calipers, is able to stand up.

Dropped feet contractures develop as the feet usually flop down, with the toes pointing downwards when the child sits or lies. Also the child is unable to stand.

Is it possible to prevent joints from getting stiff and becoming contracted?

Yes, to prevent contractures from developing, joints must be moved and stretching exercises must be done. If contractures have developed, surgery will be needed to correct them. Stretching and movement can only prevent contractures from developing and not correct already fixed joints.

In the case of club feet and dislocated hips, surgery may be needed to correct the problem, before the child can stand up.

III.6. POLIOMYELITIS

Alms of this session:

1. To understand the complications of poliomyelitis.
2. To learn how it can be prevented, cared for, and what advice can be given to the mother.
3. To learn about calipers and crutches and understand their uses.
4. To recognise the importance of checking calipers and crutches to ensure their effectiveness.

Note:

This session was done in close relationship to the session on Immunization (II.3)

1. Understanding polio.

A. Examination of a young boy who has had polio.

This is Simphiwe Ngebase. Simphiwe is 4 years old. What should a 4 year old be doing?

Walking and running around.

What do you think about Simphiwe as you look at him?

- *He is crawling but in an unusual way, his legs don't seem to move much, he pulls himself around with his arms.*
- *He seems very bright and cheerful.*
- *He is talking away and shouting at everyone.*
- *He is feeding himself and throwing toys around.*
- *He isn't getting up, walking or running around.*

Is he moving his legs?

No.



Should he be up and running around?

Yes, at 4 he should be up and running around.

What do his legs feel like?

They are floppy, loose and heavy.

Let's ask Simphiwe to move his legs. Can he do it?

His legs are unable to move; in other words they are paralysed.

What about the rest of Simphiwe? His arms?

They are just fine and work quite normally.

Do you think Simphiwe has brain damage and why?

No, because he is playing using his arms and hands, and communicating with the other children.

He is talking a lot and appears to understand everything that is said to him.

So should he go to an ordinary school when he is old enough?

Yes, he is fine, it is just his legs which are a problem.

Have you seen other children with this kind of problem?

Yes, often walking around the community on crutches and going to school and the shops.

What is wrong with Simphiwe, Mama ka Simphiwe?

He has had polio.

Have you heard of polio before?

Yes, it is written on the immunization card.

Polio is caused by a very small germ. It can only be prevented by having the child immunized. It cannot be cured by taking medicines after the child has the disease. This is why it is so important to have children immunized.

How many times does a child have to be immunized against polio?

3 times.

At what ages?

Three months, four and a half months and again at six months.

Is a booster necessary?

Yes, at 5 years old.

B. How does the polio virus cause a lack of movement?

Where do the nerves that come down the spinal cord from the brain go?

Out to the body.

What do they do?

They tell the muscles to move.

Let's look at Simphiwe's legs again.

Does he feel if we touch him?

Yes, he is able to feel, so it is only movement which is lost and not feeling.

Is he wearing a nappy?

No, which usually means that the child knows when he wants to go to the toilet and is toilet trained.

Is Simphiwe toilet trained Mama ka Simphiwe?

Yes, he is.

The germ which causes polio, is known as a virus. It attacks nerves, but only the nerves that carry messages about movement. So as a result of polio, a child's arms, legs or trunk may no longer move. Nerves that carry messages about feeling are not affected and nor are the nerves that control the bladder and bowel.

The virus attacks the nerve just where the nerves leave the spinal cord to go out to the body. It sets up home in the nerve itself and gradually destroys it. When the nerve is destroyed, there is no message getting through to the muscle to tell it to move. The muscle is unable to move or do any work because it is not getting any message from the nerve. There is nothing wrong with the muscle itself.

While the polio virus is busy destroying one nerve cell, swelling occurs around that cell. This swelling can affect other nerves in the area for a time until the swelling goes down. The nerves are not destroyed so the muscles supplied by these nerves will be paralysed for some time, but will recover when the swelling goes down.

C. The course of the disease.

Let's ask Simphiwe's mother what happened to him.

He was well . One day he suddenly got flu. He became more ill and could not move. This was when I took him to hospital.

When he was there he couldn't even sit up and his arms and legs wouldn't move. For a couple of weeks he was unable to breathe so he had to be on a breathing machine.

How old was he when this happened?

He was one year old.

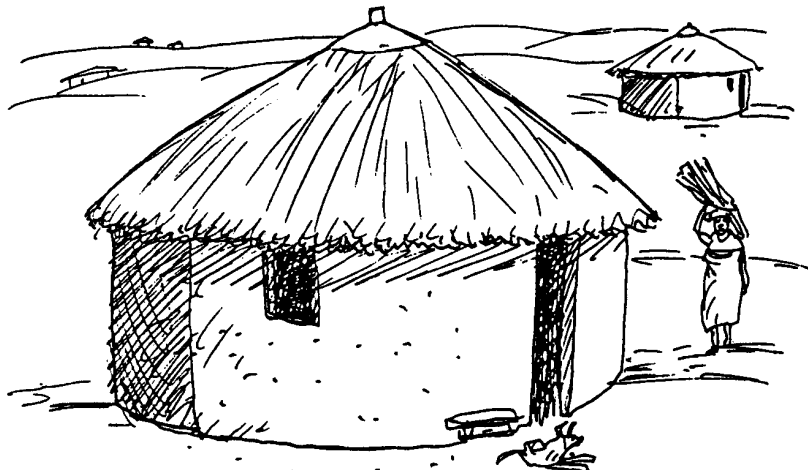
Boys tend to get polio more often than girls. They are usually between 8 months and 2 years old.

Had he been vaccinated?

No, the village that we come from in the Transkei is very small. It has no clinic and a mobile clinic comes very seldom.

How long was Simphiwe in hospital?

He was there for a long time until he got better. It took a long time before his arms were strong again. His legs are still not strong so he cannot stand up and walk.



Soon after a child has contracted polio, he will usually have to be admitted to hospital as his whole body is unable to move and he is unable to breathe. The whole body is paralysed because of the swelling around the nerves in the spinal cord.

As the child starts to recover, the swelling goes down, and the body will start to move again. It will only be the nerves that the virus has actually destroyed that will no longer work, and the muscles supplied by these nerves will be paralysed.

When children get polio, some recover completely, some may have just one foot paralysed, others may be like Simphiwe and have both legs paralysed and need walking aids. In some cases the child's arms may be paralysed. If the breathing muscles are affected, the child may die if he is not taken to a hospital quickly enough.

D. The complications caused by paralysis.

What do we mean when we say that a leg is paralysed?

It cannot move.

What tends to happen if a limb is not moved?

The joints get stiff.

Simphiwe is paralysed from the waist downwards, so both his legs are paralysed.

Which joints are not able to move?

His hips, knees, ankles and toes.

Let us feel each of these in turn.

Are any of them getting stiff?

Yes, his ankle is starting to get stiff. In fact both his ankles are stiff.

Stiff joints can stop children from walking and using their calipers and crutches.

2. Preventing complications.

Who spends the most time with Simphiwe?

His mother.

Who must be taught how to position, stretch and move the child so as to prevent contractures?

His mother.

There are three things we can do, and can teach his mother, to stop his joints from getting stiff.

1. Position correctly.
2. Stretch the stiff muscles.
3. Move the joints.

A. Position correctly.

What position is Simphiwe in for most of the day?

- *Simphiwe sits cross-legged on the floor.*
- *His hips are bent, his knees are bent and his feet are pointing down.*

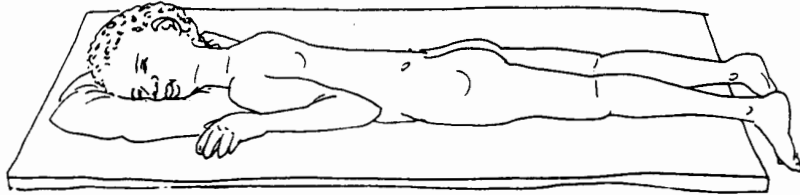
When we think of positioning Simphiwe, we must position him in such a way as to stretch the muscles which will get tight if he sits like this all day.

If Simphiwe's *hips* and *knees* are bent all day, how do they need to be stretched?

They need to be straightened.

What is the best position to stretch bent hips and knees?

He must lie on his tummy, with his hips and stomach flat on the bed and his knees straight.

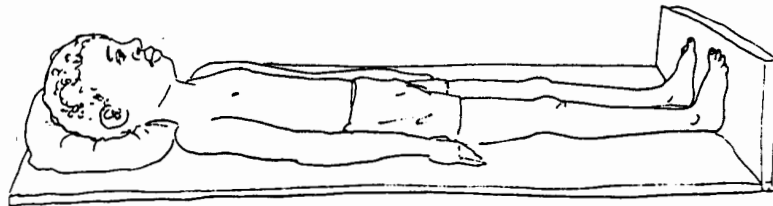


Simphiwe's *feet* usually point downwards. How must they be positioned for stretching?

The toes and the front of the foot must be moved up towards the head.

To position the feet for stretching:-

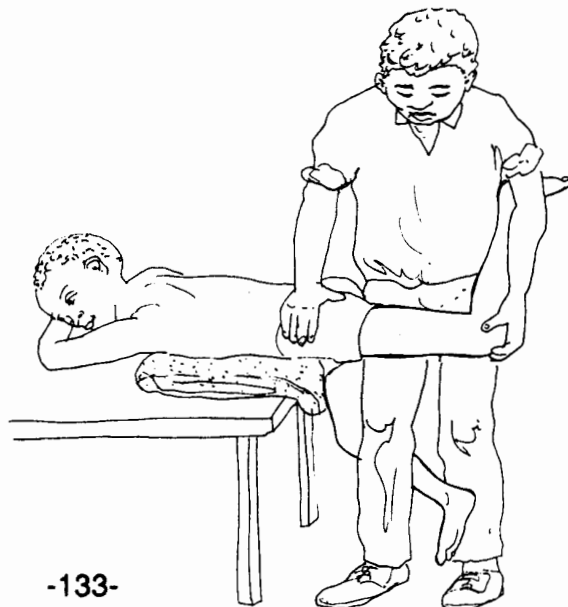
Simphiwe must lie on his tummy and have his feet over the edge of the bed. Lying on his back, Simphiwe's feet should be held by a board so that his toes point to the ceiling.



B. Stretch the stiff muscles.

• 1. Hips and knees.

The easiest way to stretch the *hips*, is with the child lying on his stomach. The hips can be stretched first by gently rocking them from side to side, increasing the pressure until the hips are flat on the bed.



A further stretch can be done by keeping the hips flat on the floor lifting the legs backwards one at a time with the knee straight.

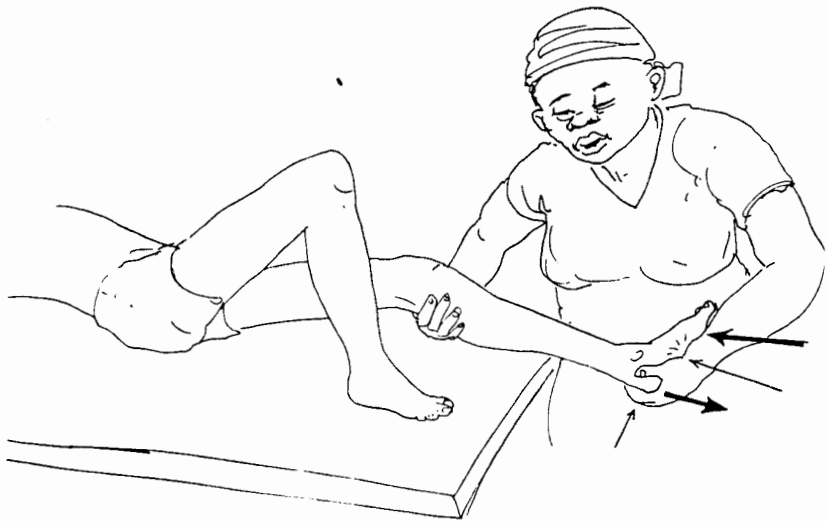
It is easiest to stretch the *knees* with the child lying on his stomach. With one hand above the knee and the other holding the ankle, the knee can slowly be straightened.

The child can also try to straighten his knees when he is sitting, by trying to push his knees down to the ground with his legs straight.

• 2. Feet.

When the calf muscle gets tight it pulls the foot down, so that the toes point down. Therefore the mother must be taught how to stretch the calf muscle. The child can be sitting or lying on his back. With her one hand the mother holds the knee straight, with the other she holds the heel so that the child's foot lies on her forearm.

She then stretches the back of the ankle, where the calf muscle attaches to the bone, by moving the child's foot towards his head with her whole forearm.



Another way of stretching the joints of the legs, is to stand him up in his walking aids so that the hips, knees and ankles are all stretched.

C. Move the joints.

If the joints are moved fully through each of their movements, this will also stop them from getting stiff.

The movements which need to be done with Simphiwe involve his hips, knees and his feet. His hips, knees and feet need to be moved up and down as much as possible (flexion and extension). His hips must also be opened and closed (abduction and adduction). See the session on Contractures (IV.3) for more detail.

In summary.

The biggest problem with polio children is to stop them from getting contractures in the paralysed legs or arms. To prevent contractures there are three things which are very important.

What are the three crucial things to do to prevent contractures?

- * position correctly
- * stretch the stiff muscles
- * move the joints

4. Walking aids.

We have mentioned Simphiwe's walking aids and have had a chance to look at them. They are called calipers and crutches.

The *crutches* are metal rods, with a ring of metal at the top. They are to help Simphiwe balance when he stands up in his calipers. The ring at the top is for his arm to go through.

The *calipers* are two pieces of metal joined by leather that fit on each side of Simphiwe's legs. There are 2 calipers, one for each leg. What are the calipers and crutches for?

They are to help Simphiwe stand up because his legs are floppy and cannot keep straight by themselves.

In Cape Town these are made at Red Cross Hospital at the orthopaedic workshop. They are difficult to make and are different for each child. As a child grows the calipers become too small, so it is important to check them and if necessary to send the child back to the orthopaedic workshop for bigger ones.

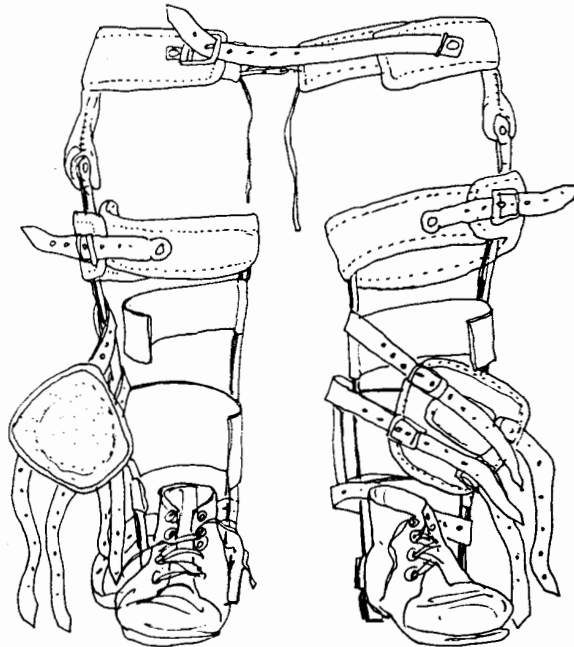
They can also break and then someone in the family might be able to fix them or they must be taken back to the orthopaedic workshop to be fixed. This takes time and is a bother so the mother must be encouraged to look after the calipers, and teach the child to do the same.

Let's ask Simphiwe's mother to put on his calipers so we can see if they still fit.

A. The shoes.

Can you see the shoes are lined with wool. This is to stop the feet from getting sores where the shoes might press on them. This is especially important for children who have no feeling in their feet in other conditions) as they do not feel pain when a hard bit of the shoe is pressing into them. We need to check that the shoes still fit and are not too small and rubbing in one place.

We also need to check where the metal rods fit into the heel of the shoes, that they still fit in and that they stop the foot from falling down.



B. The calipers.

A metal rod goes on each side of each leg. At the ankle, knee and mid thigh, the rods are held together by pieces of leather. The metal rods are strong and keep the legs straight, when the child stands up.

The rods run close to the legs, but must not rub the legs too closely or they may rub the leg raw, causing a sore. This tends to happen where the bones stick out closest to the skin, at the knee or at the ankle. It is necessary to check carefully to make sure the calipers are not getting too small and rubbing the child's legs. Always check the knee and ankle.

The top of the caliper is attached to a leather strap. As you can see from what Simphiwe's mother has done, it goes around the child's waist.

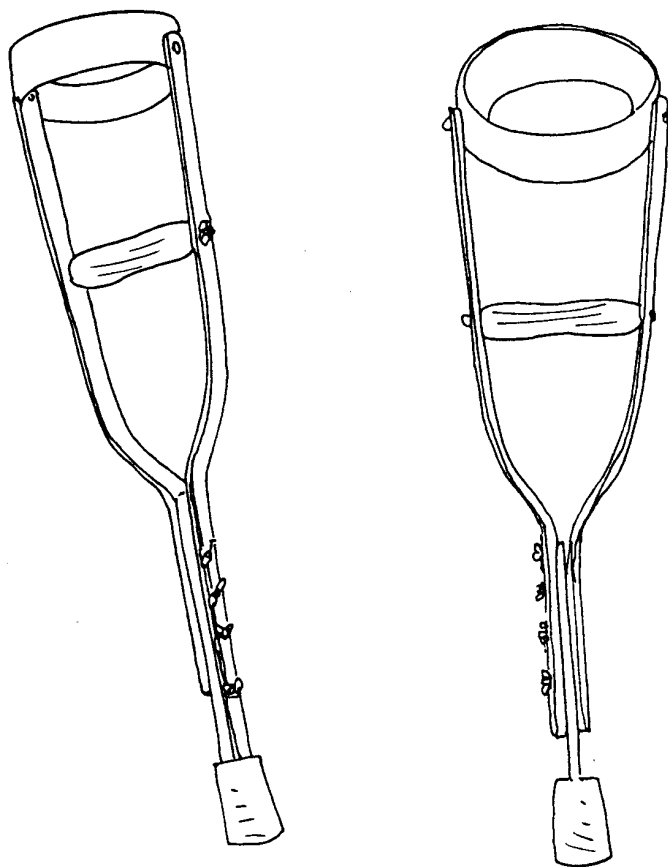
A hip band is necessary if the child has no working muscles around the hip. It gives the child some control over the leg. It must also be checked to make sure that it still fits and also that the leather has not broken.

C. The crutches.

The crutches are to help the child balance as he stands up in his calipers. They are a metal or wood rod, with a handle, and a ring for the arm. At the end of the metal rod is a piece of rubber which is to prevent the crutch from slipping. It is important for safety.

Unfortunately the ring at the top of the crutch tends to break, and the rubbers tend to wear out very quickly. These must be fixed or replaced as soon as possible.

Calipers and crutches must be fixed as soon as possible or the child will lose confidence and will be reluctant to use them when they are fixed.



If the child does not stand up for some time he will get stiff, the calipers will no longer fit properly and he will be unable to stand up. He will get stiffer and stiffer until walking is no longer an option and he can only crawl around.

He will then be unable to go to school and develop normally like other children.

Do you think it would be more difficult for a fat child to walk on crutches than a thin child?

Yes, much more difficult.

A fat child needs much more energy to walk around on crutches than a thin child.

The child with polio and the mother must be encouraged not to let the child get fat.

5. Caring for a child with polio.

A. Prevention.

All children must be immunized against polio. See the session on immunization (II.3).

B. Immediate care.

A child that gets the polio germ, initially seems to have a flu-like illness. He will soon be unable to move his arms or legs or even sit up. Children should be taken to hospital in case the breathing muscles are affected, as the child may then die.

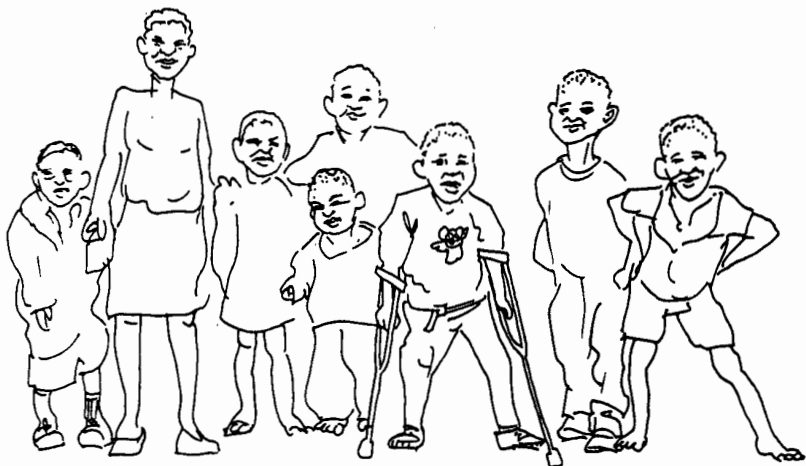
Usually children get polio in the Transkei, as it is not that easy for a mother to get her child immunized and she does not realize how important it is. However we are also starting to see children who are getting polio in Cape Town.

In the early stages of the disease, no medicines help. The child must rest a lot in a good position so as not to get stiff and contractures.

Vigorous exercises must not be done as they can increase the paralysis.

C. Care after the child has recovered, but has one or more limbs paralysed.

- Care must be taken to ensure that the child's joints do not get stiff through:
 - * good positioning
 - * moving the joints through their full movements
 - * braces and walking aids to keep joints in a good position.
- If possible the child must be given good food to build up his strength.
- Encourage the child to develop normally by treating him like a normal child and providing games and activities to stimulate him.
- Surgery may be needed to correct joints if they are not looked after correctly.



III.7. BLINDNESS

Aims of this session:

1. To understand blindness and limited vision.
2. To learn how you would test the eyesight of a child and an adult.
3. To learn how you would discuss stimulating a blind child with her parents.
4. To understand how a blind person should organise the place in which they do their work.

Location:

This session was done at League of Friends of the Blind (L.O.F.O.B) in Grassy Park. This is an institution for the rehabilitation of blind people. The session was run by the occupational therapist who works there, together with one of the mobility instructors who assisted with demonstrations and translation.

Teaching aids:

1. A pamphlet showing how to lead a blind person and to help him sit on a chair.
2. Aids from the L.O.F.O.B.

1. Blindness and different types of limited vision.

What does it mean if we say someone is blind?

They have no sight at all.

What does it mean if we say someone has limited vision?

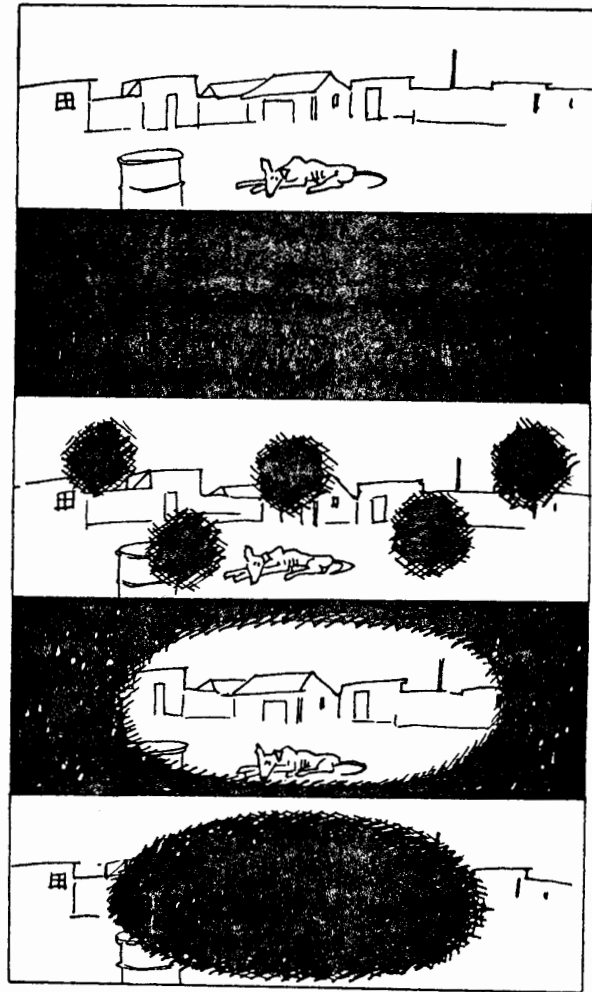
Their sight is limited in one way or another, they may not see clearly, may not see things far away, may not see well at night.

Have any of you come across blind people in the community?

- * *I have seen some blind children.*
- * *There are some blind adults in the community.*

Each of us in turn tried on different pairs of glasses which were made at L.O.F.O.B. to simulate different problems with sight:

- with one pair of glasses we could see nothing at all - we were in pitch darkness.
- one pair of glasses made vision patchy or spotted.
- one pair of glasses made vision misty or cloudy.
- with one pair of glasses we could see straight ahead but nothing on the sides.
- with one pair of glasses we could see things on the sides, but not straight ahead.
- one pair of glasses made it difficult to see in bright light.



People who have problems with sight may be blind and not see anything at all, or they may have limited vision.

- 9 out of 10 people who are said to be blind can see a little bit. The most common problems are similar to those we have just experienced:
- a person can only see things which are close to him clearly.
- a person may have difficulty seeing things in the bright sunshine.
- a person may have difficulty seeing things at night.
- a person may only be able to see from part of the eye, so they may only be able to see exactly what they are looking at, or they may only be able to see on the sides.
- a person's sight may be patchy, spotted or hazy.

Many problems which lead to blindness or limited vision can be avoided if the eyes are kept clean and the person has a good balanced diet. If a person has problems with sight they must see a doctor as soon as possible.

Any blind person, or person who develops problems with their eyes should be referred to the eye outpatients' department at Groote Schuur Hospital.

2. Blindness in children.

A. Different causes of blindness or limited vision in children.

What are the different causes of blindness in children?

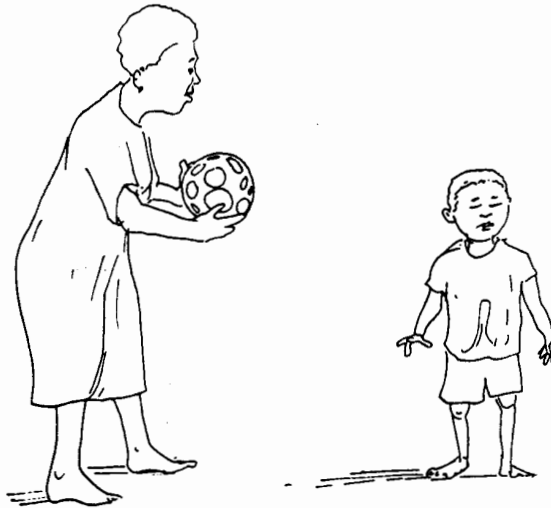
A child may be blind if:-

- the mother had German measles while she was pregnant.
- the hospital gave the baby too much oxygen at the time she was born.
- she inherits some eye condition from her parents.

B. How to test children's eyesight.

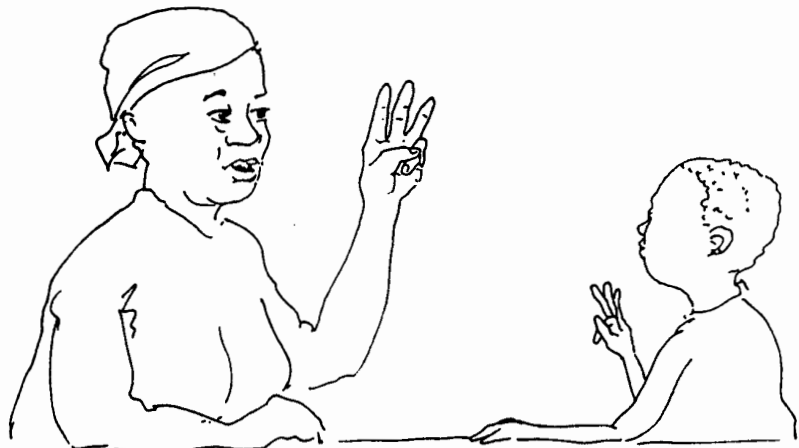
To test the sight of a child aged 3 months to 4 years.

- Hold a bright object such as a red ball, lighted candle or torch about 30 to 50 cm in front of the child while the child is sitting.
- Move the object from side to side. Repeat two or three times.
- If the child can see, her eyes will follow the bright object as you move it.
- If you are sure that the child's eyes do not follow the object, you will know that the child has difficulty in seeing.



To test the sight of a child aged 4 years and above.

- Stand at a distance of 3m in front of a child, hold up 3 fingers of one of your hands and ask the child to count them.
- If the child cannot count, ask the child to hold up as many fingers as you are holding up.
- If the child cannot do either of these two things, then she may have difficulty with seeing.
- The child may have difficulty seeing in the dark. This may be the case if after dark she falls over things on the ground or has difficulty in walking to different places.



C. Effects of blindness on a child and their family.

When a visually impaired child is born, the parents may be shocked and very upset. In some cases the parents do not realise that the child cannot see, until she is some months old, as she does not respond to smiles, but instead lies still and quiet all day.

If the parents are shocked and upset they will need a lot of support and advice on how to help their child grow up and develop as normally as possible.

The child must begin to learn from a very young age to do what every other sighted child learns. How to eat, walk, dress himself, play with other children, go to school and enjoy life as other children do.

A child's development will be affected if she is born blind or has limited vision. The earlier this problem is noted and the parents are taught how to stimulate the child, the greater chance the child will have of developing normally.

The most important thing that a child needs to know is that he is loved and wanted. Even though the child may not see well, she needs to know that she is also an important part of the family.

In the first months of a child's life she needs love, food, sleep and warmth. The parents must understand that a child with limited vision needs to be held close and played with even more than a sighted child.



It is common for parents with a child with limited vision to overprotect the child and so limit their experiences. However, the child needs to have every opportunity possible to learn about what is happening around her. The most important thing for the parents to remember, is that their child who is blind or can only see a bit, should have as many experiences and receive as much stimulation as any other child.

Our aim is that a child with limited vision becomes so curious, that they go and find out about things around them. Unless a child is actively stimulated she will not explore her world fully. She will remain passive and only know her own body.

Whilst encouraging the child to be as active and as curious as possible, it is very important to ensure that the child will be safe and will not hurt herself. Primus stoves should not be left burning on the floor as the child is very likely to burn herself. The child also needs to learn what is dangerous and how dangerous objects should be handled.

D. How to stimulate blind children or those with limited vision.

• Awareness of herself.

The child has to create in her own mind, a picture of the world, her position and movements in it and how to relate to it. So she needs to be:

- encouraged to touch and be aware of all the different parts of her own body.
- encouraged to move, to jump, skip, run, roll, hop, climb, stretch, slide, so that she knows just what her body can do.
- stimulated to be aware of different feelings, sounds and smells, and how these can be used to help her get around and compensate for her lack of sight.

• Hearing

Teach a visually impaired child to use her hearing:-

- Describe to the child what every sound means, even if it seems unimportant, eg. the sound of the floor being swept. This could be described as, "It is the broom's bristles being swept over the floor which makes the scraping sound".



- Sit outside with the child, listening to sounds and discuss them, wood being chopped, birds singing, water running, people walking past.
- Have the child walk towards you as you clap your hands. Have her follow you as you walk in different directions clapping your hands.

◦ Touch

- A child with limited vision, needs to learn to feel everything around her. She needs to learn the difference between rough and smooth, soft and hard, hot and cold.
- She will need toys to play with, so that she learns to use her hands together and what different things feel like.
- She also needs to play with different small objects, wood, a button, a piece of fruit, a bottle top.
- Like any other child, she needs to play in mud and on the grass.
- She must be encouraged to explore what ever is in her hands.



◦ Smell and taste

The child must learn different smells, odours, fragrances and tastes. She must also learn the direction the smell is coming from.

◦ Remaining vision

She must be encouraged to use any vision that she has.

◦ Social integration

She must be told how the rest of us:-

- sit - upright and straight, even when eating.
- listen - with the head straight, facing the person and not tilted
- she must be told that rocking, bouncing, thumb sucking and eye-poking are unacceptable and draw attention to the fact that she is different.

There is a school for blind children in Cape Town, Athlone School for the Blind. All children should be referred here, even if they are too young for school. They will be assessed here and should be able to attend school here at school going age.

3. Blindness in adults.

A. Different causes of blindness or limited vision in adults.

A person may be blind from birth (see the causes of blindness in children). How else may they become blind later on in life?

- * *diabetes*
- * *cataract*
- * *an accident which harms the eye*
- * *old age*

B. How to check an adult's vision.

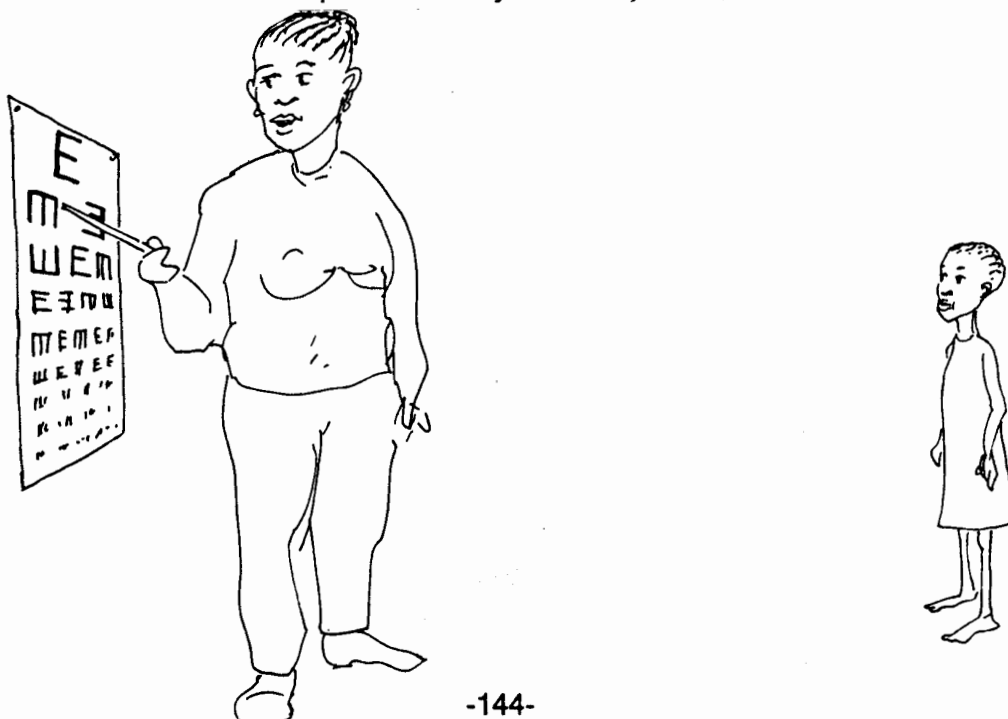
Do the following exercise:

- If a person says that they cannot see, ask them if they can tell light and dark.
- If they can tell light and dark, ask them if they can see your hand moving.
- If they can see your hand moving, ask them to count your fingers, do this a couple of times to make sure they are not just guessing.

We then divided into pairs to test each others eyes. We tested them without glasses and then used the different glasses that L.O.F.O.B. had made.

To test our eyes we looked at an eye or *Snellen* chart. The Rehabilitation Workers said at once that so few people in the community can read letters. So we used an E chart.

- The person must stand 6m (or 6 big steps) away from the E chart which is pasted on a wall. The person covers one eye and then reads from the top of the chart downwards. The person must look at the Es on the chart and point in the direction in which the E is pointing. (If the large top E cannot be seen, the person must walk towards the chart until the top E can easily be read.)



- This will give you an idea of how much the person can see. A person whose eyes are normal, can read the Es as far as the third line from the bottom. If the person cannot read the Es as far as this line, their eyesight is poor and they should be referred to a doctor so that their eyes can be more thoroughly checked.

If you don't have an E chart, the front page of a newspaper can also be used. To start with, see if the person can read the biggest headlines when holding the paper in their hands. If they can read these, try the smaller headlines and then the small print. If they can not read the small print, their eyes should be checked by a doctor.

C. Effects of blindness.

How do you think a person is affected by being blind?

- * *She can lose independence and have to rely on other people to do things*
 - * *to go out and buy things*
 - * *to visit friends and family*
 - * *to prepare food and wash clothes*
- * *She is no longer able to enjoy nice looking things in life eg. a beautiful flower, a happy child's face.*

What kind of feelings do you think a blind person has?

- * *She may lose a lot of self-confidence and feel inferior to her friends.*
- * *She may no longer feel attractive, and feel that she is just a burden on her family and friends.*
- * *She may be worried that she will now be unemployed.*
- * *The loss of money now that she no longer works will also be a great worry.*
- * *The person is afraid to move as they did before, as they might fall and hurt themselves or walk into things.*
- * *They may feel humiliated as they can no longer look after themselves and need help washing, dressing, cooking and cleaning the house.*
- * *They may become very frustrated as they have to do things when it suits other people and they have to be so reliant on them.*

D. Every day activities.

Although they cannot see, people who have difficulty with seeing can train to be very independent. They can eat, drink, dress and go to the toilet themselves. But besides these there are numerous daily tasks that a person does.

What are the common tasks that women in the townships do?

Cooking, fetching water, fetching firewood, taking care of the children, sewing, washing clothes, cleaning the home.

With most of these tasks, it is best to look at the way the person was doing the task before they became blind and only if this is no longer possible should another way be chosen. To assist in any task which is done every day, there are a few basic principles:

- the person must be familiar with their work area and house.
- the work place must be organised and utensils arranged and replaced in the same places.



- work should be done in the same pattern.
- more time is needed.
- check that the work place is safe.

If there are tasks which the person cannot be trained to do, someone in the family, or a friend or neighbour may have to be called in to help.

4. Practical session.

We then met 5 of the blind people staying at L.O.F.O.B. They each showed us a particular activity that they have learnt at L.O.F.O.B.

° Station 1.

A blind woman showed us that she has learnt clerical skills. She showed how she can dial on the telephone, file and use a tape recorder.

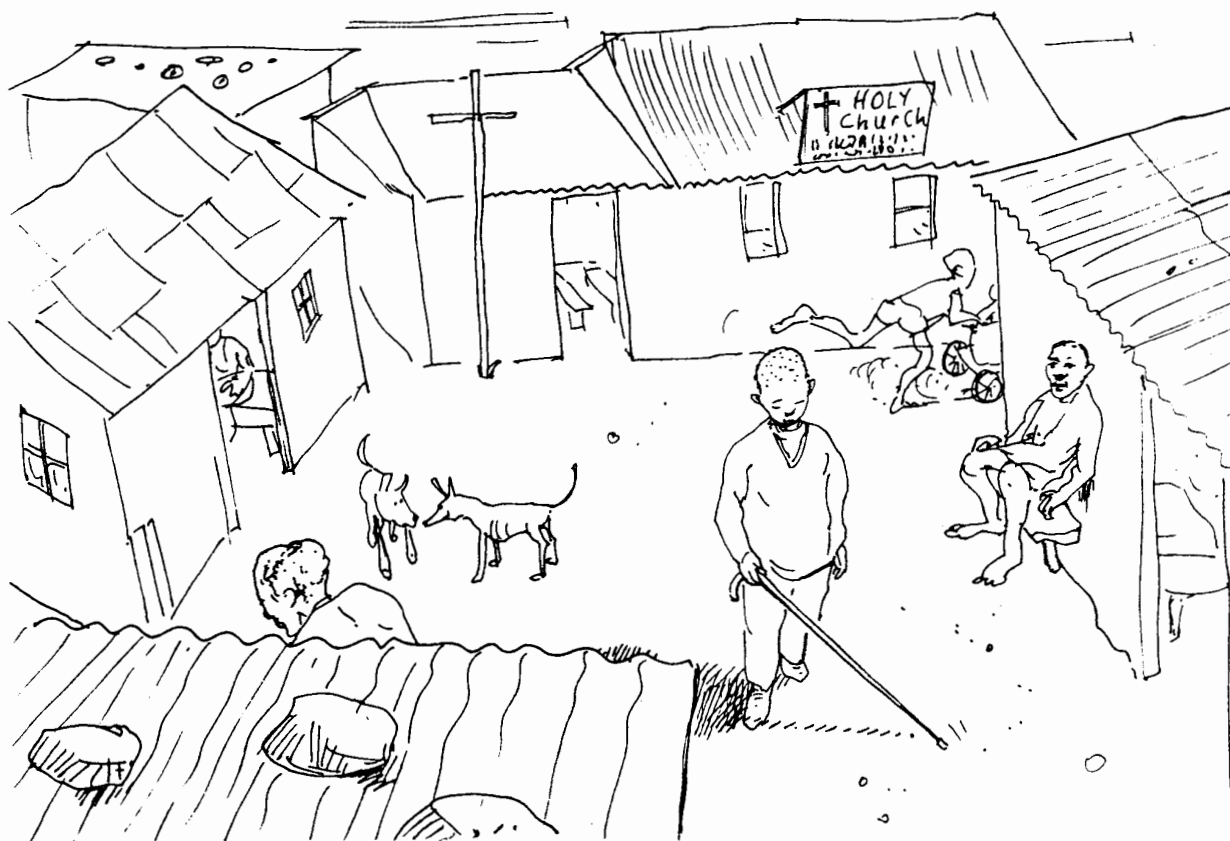
She also explained to us that braille is the writing that blind people read with their fingers. It is comprised of lots of little bumps arranged in different patterns for different letters. We had a chance to feel what the alphabet in braille feels like.

° Station 2.

A partially sighted man showed us how he uses a magnifying glass to read. He is able to write in big letters and he has also learnt how to type at L.O.F.O.B.

° Station 3.

A man showed us how he has been taught to use a long cane. Holding this cane in front of him, he walked with around the building without any further assistance. To learn how to use a long cane, the person needs training either at L.O.F.O.B. or Civilian Society for the Blind.



We were also shown how to lead a blind person around:

- walking with the leaders arm loosely at their side
- sitting down
- going up and down stairs.
- (see pamphlet for more detail of these)

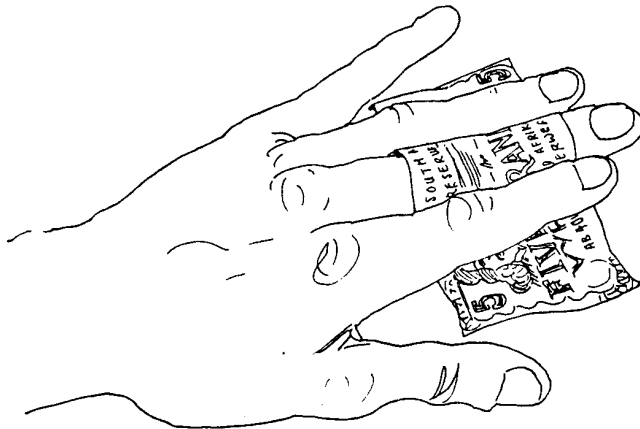
As a young active adult he has been assessed at a work assessment unit and will be placed in a suitable job. This can only be done by L.O.F.O.B. and Civilian Society for the Blind. We must refer young active adults from the community for work assessment and placement (through L.O.F.O.B and Civilian Society).

• Station 4

A blind man showed us the different handicrafts he has learnt at L.O.F.O.B., since he became blind. These included macrame, making a scarf and weaving.

He also demonstrated to us how it is possible for him to use money and how he differentiates between the different monies:

- coins, depending on the size and whether the edge is grated or not
- Paper, measured on how much of the middle finger is covered.



• Station 5.

A blind woman showed us how to make a cup of coffee, using her finger to feel when the water reaches boiling point, and also listening to the sound of the water and the milk as they go into the cup.

She emphasised how it is necessary for her to always have the kitchen very tidy and everything put away in the same place otherwise she cannot find things.

We discussed how important safety was, in the use of the stove. No newspaper should be near a primus stove.

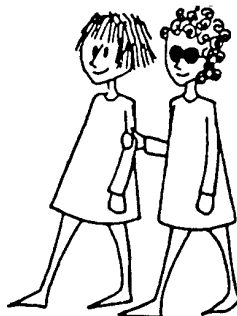
Gas must be checked before to ensure that there are no leaks which could cause a burst of flame.

She also showed us her method of buttering bread and making sandwiches.

First page of a pamphlet available from the League Of Friends Of The Blind.

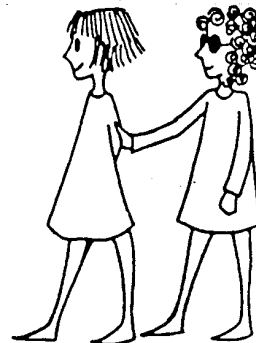
GUIDING A BLIND PERSON.

Stand by the side of the blind person with your arms straight, fingers pointing to the ground. Now ask him to take your arm. His hand should grip your arm just above your elbow, so that his fingers are on the inside of your arm and thumb on the outside. His elbow is bent. The grip allows the blind person to be half a pace behind you and he can detect when you're turning, by the movement of your body. There is no need to move your arm. Check that the blind person's toes are pointing in the same direction as yours - if not, you could be parting company!



WALKING IN SINGLE FILE.

You often need to do this in shops, church, and busy areas.. Your partner walks behind you. Indicate the need to step in behind you by moving your grip to the middle of your back, keeping your arm straight. Maintaining his grip above your elbow, the blind person should step behind you, checking that his arm is straight - if it isn't he will step into your shoes!



KERBS.

There is no need for you to say each time you come to a kerb. Just pause slightly before stepping up or down the kerb - the blind person will feel the change in arm movement.

III.8. DEAFNESS

Aims of this session:

1. To understand the causes of deafness.
2. To learn how deafness can be prevented.
3. To learn different ways of helping a deaf child.

1. The importance of hearing.

A. Meeting a deaf person.

When do you think a mother will first notice that her child is deaf?

When he does not answer or turn his head to a noise or someone calling.

Often then the parents will say "Our child is stupid," but the problem is that the child cannot hear what we are saying. He is not stupid at all.

Some children hear absolutely nothing , but others may be able to hear a little.

Moets is the SACLA handyman who you all know by now.

Can Moets hear?

No.

How do you know that
Moets cannot hear?

*Because he shows us with
his hands that he is unable
to hear. Also he cannot talk
and does not hear loud
bangs or crashes.*

But lets ask Moets to bark
for us like a dog.

Did that sound like a dog?

Yes, just like a dog.

Moets is showing us with his
hands that he can hear a
dog bark.

Do you think Moets hears anything?

Yes, there are a few things that Moets does hear, although he is unable to hear people talking. He is not completely deaf.



What would you miss most if you were deaf?

Hearing other people talk, their news and their advice.

B. How deafness affects a child.

For a growing child, hearing and speaking are very important for getting to know, understand and relate to people and the things around them. By talking to our families and the people around us they know what we want and how we feel and then they can meet our needs and we in turn can meet theirs.

Deaf children cannot talk and communicate with those around them. They can get very frustrated as nobody understands what they want or need. They can also get very lonely as they are unable to hear other peoples needs and problems.

Here are some important things about deafness:

- If a child is born deaf, it is more difficult for him to learn to speak.
- The more a child hears, the better chance he has of learning to speak and understanding what is said.
- If other disabilities are also present, learning to communicate becomes more difficult.
- The earlier the problem is recognised the better.
- The child is accepted and helped to learn to communicate in other ways.

2. The causes and prevention of deafness.

A. The causes of deafness.

According to the traditional beliefs, what causes deafness?

Traditionally, there are three causes of deafness:

- *A person may become deaf because a witch has urinated in her ear.*
- *They have heard spirits or they have heard the ancestors, neither of which they should have done.*
- *A tick has bitten them in the ear.*

Do you think these reasons are helpful for us?

No.

There are two types of causes of deafness:

1. Causes before the baby is born.

- hereditary (it runs in the family)
- infection during early pregnancy
- premature (early) birth
- poor diet, a lack of iodine
- certain medicines taken during pregnancy
- difficult birth , baby slow to breathe

• 2. Causes after birth.

- ear infection, especially long lasting ones with pus
- meningitis
- certain medicines
- frequent loud noises.

How can you tell if your child has an ear infection?

He will be hot and feverish, miserable and crying a lot. He may keep rubbing his ear and there will be pus coming out of his ear.

Do ear infections tend to get better by themselves?

No, you must take your child to see a doctor.

Ongoing ear infections cause a child to become deaf.

**Deafness is not because the child has done something wrong
or because someone in the family is being punished.**

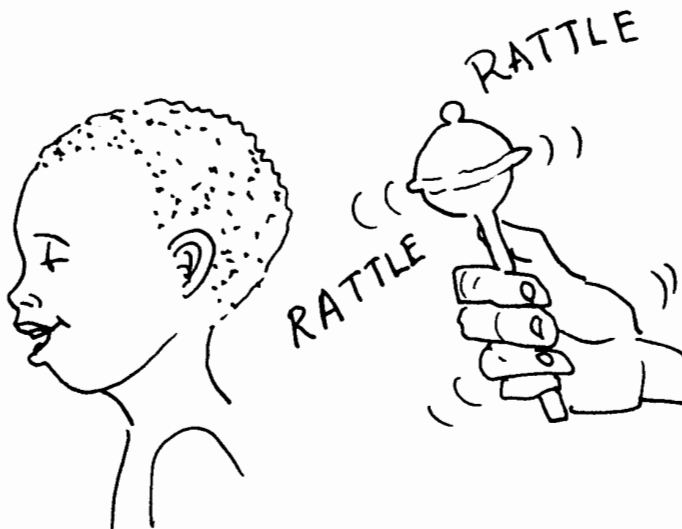
B. How to test to see if a child hears.

Early diagnosis is important because the earlier special training begins, the more a child can learn to communicate.

Look for signs to show if a baby hears or not:

- Does he blink or show surprise when you make a sudden loud noise?
- As he grows does he turn his head or smile when he hears familiar voices?
- By 18 months, has he begun to say a few words?
- By 3 or 4 years old, does he use a lot of words?

If not he may have a hearing problem.



C. Where to go for help?

There is a school for the deaf which has just opened in Khayelitsha. If you find a deaf child in your community, that child must first be seen by a doctor and then with a letter written by the doctor must go to the school. It is called Noluthando school. There is also a school for deaf children in Umtata in the Transkei. It is called Efata.

Also remember that in the community, local deaf adults, like Moets, can be teachers for deaf children.

D. Prevention of deafness.

We must educate people about these things:

- Prevent ear infection and if a child gets an ear infection, treat it at once.
- No medicines should be given to a mother during pregnancy.
- Woman must be vaccinated against German measles.
- Women must have regular check-ups during pregnancy.
- A woman should eat well during pregnancy, she should eat iodised salt and food rich in iron, vitamins and minerals.
- Never put pointed objects in the ears.
- Avoid being near very loud noises.

3. Helping a deaf person communicate.

A. General guidelines.

Here are a few general guidelines which can be helpful:

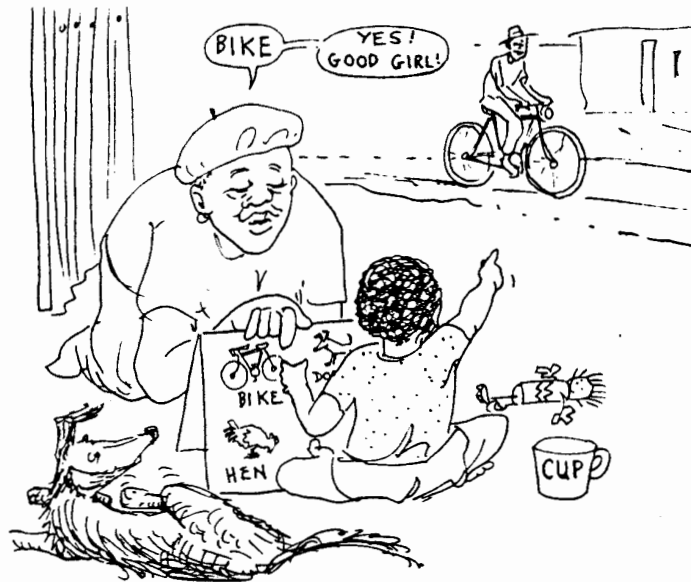
- if a person is slightly deaf, speak more clearly and slowly.
- if a person is slightly deaf, suggest they cup their hand or use a hearing aid.
- if a person became deaf after he learnt to speak, he can learn to lip read.
- if a person is born deaf, it is very difficult for him to learn to lip read, so he can learn sign language.
- the person could be taught national sign language.



B. Helping a child communicate:

Let's summarize the ways to help a child communicate:

- by demonstrating
- by helping with hearing and speaking
- by teaching lip reading
- by teaching communication using pictures and pointing
- by teaching finger spelling
- by teaching reading and writing
- by teaching sign language



Try all methods and use whatever helps the child most.

It is also very important to help the child learn to make sounds and speak.

- If the child hears at all encourage him to notice and listen to different sounds.
- Play games and exercises to help him learn to use his mouth, tongue and lips. (eg. lips together, ooo, teee).
- Encourage him to blow and suck. For example, use a whistle.
- Tongue exercises are also important.
- Encourage the child to make different sounds.
- If the child uses his mouth and lips, but not voice, have him feel the "buzz" or vibration in your throat when you make different sounds and try to copy this.
- Get the child to feel and compare the movement of air in front of yours and his mouth with sounds like "ha", "he", "ho", "m", "p", "b", "f".



- Stress the separate sounds for words: for example,
 - * nose: n - o - se;
 - * ma: mmmm - aaaah.
- Little by little add a word each day.

Some children, like cerebral palsied children, can hear, but do not develop the ability to speak because they cannot control their mouth or tongue movement well enough to speak.

Others are mentally retarded and may be very late in learning to speak. Some are intelligent, but for other reasons cannot speak. These children need help to look for ways to communicate as best as they can.

C. Lip reading.

Here are some tips about lip reading:

- Do not start lip reading until the child is 3.
- Hold an object in front of the child and slowly, repeating often, say the name of the object. Also do this in front of a mirror.
- Some signs will be needed as so many letters look the same in lip reading:
k = g = h; t = d = s; ch = j.



III.9. STROKES

Alms of this session:

1. To learn to recognise a person who has had a stroke.
2. To understand the usual cause of strokes.
3. To learn how to demonstrate to the family of a person affected by a stroke how to position and care for the person so as to avoid likely complications.
4. To learn some ways of helping a person who has had a stroke to be as independent as possible.

Teaching aid:

A pamphlet on strokes outlining: the causes of strokes; the positioning of a stroke patient in bed and in a chair; how daily movements should be done; and how a stroke patient should clasp their hands.

Location:

Part of this session was done at Groote Schuur Hospital.

1. The causes of strokes.

A. Movement.

When we discussed the skeleton, we also discussed movement. Which parts of the body are involved in movement?

Bones, nerves, muscles, joints, brain.

The brain is involved in controlling movement so that it is smooth, uses the right amount of strength, and is the right size. It is also involved in co-ordinating messages from the outside world.

I want to move a box sitting on the stove. My eyes see that it is a big box. My brain receives that information and tells my arms to open wide to pick up the box. As I try to pick it up, my arms feel that it is heavy. That information is taken to my brain which tells the muscles in my arms to work hard as it is a big, heavy box. So my muscles clench tight to lift up the box.

What will happen if a person's brain is damaged?

The co-ordination of movement will be affected and so will the co-ordination of messages from the outside world.

Speech, swallowing and the control of a person's urine and bowels may also be affected.

B. What happens to a person who has a stroke?

Why is it called a stroke?

It is called a stroke as it happens so suddenly without warning. The person suddenly falls down unconscious.

The person will collapse unconscious onto the floor and may remain unconscious for some time. After a time of unconsciousness, the person becomes conscious, but will be paralysed or unable to move one side of their body, the side affected by the stroke.

This side of the body will feel floppy and heavy. Feeling, on this side may also be affected. The person may not be able to feel if their arm or leg is painful, hot or cold, or up or down.

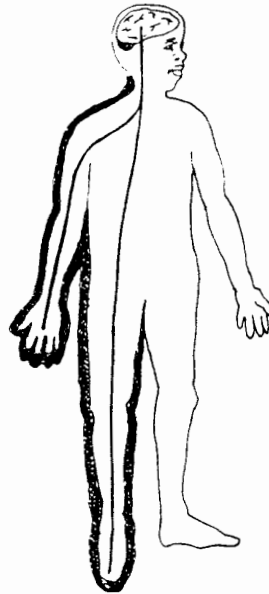
The person may also be unable to speak or swallow.

This stage of paralysis may be a few hours, a few weeks or even a few months.

Usually the stage of paralysis is followed, by a slow return of some movement and feeling. At the same time the muscles on the side affected by the stroke become increasingly tight.

This tightness keeps the arm bent and close to the body, and the leg straight and turned in. This tightness can make it impossible for the person to move the side affected by the stroke and also causes a lot of pain.

A person can suffer from a further stroke. This could affect the same or the other side. Sometimes a person recovers completely from a stroke. Strokes are a fairly common cause of death in elderly people. However some people carry on living after one or even two strokes.



C. What causes a stroke?

High blood pressure is the most common cause of strokes. A person may have high blood pressure for some time and one day suddenly collapses with a stroke. This happens when a small artery carrying blood to the brain closes down.

A section of the brain no longer gets blood and the oxygen it needs from the blood to keep living. Just like a garden without water, it withers and dies.

Because the brain is damaged movement and feeling on one side of the body will be affected. Speech and swallowing can also be affected.

How old are people who suffer from high blood pressure?

They are usually over 40.

If high blood pressure is the most common cause of strokes, how old do you think most people who have strokes will be?

They will be over 40.

What is usually done for people who have high blood pressure?

They are given pills which they have to take every day.

These pills will never cure high blood pressure, but they will control it so that the person will not have a stroke or suffer serious other damage as a result of the high blood pressure.

A person who has had a stroke as a result of high blood pressure will also be given pills. She must take her pills regularly as otherwise she might have another stroke. It is important to explain to the person with a stroke and her family, that a stroke is as a result of high blood pressure and that to avoid another stroke, she must take her pills regularly. More pills must be obtained from the day hospital before the others run out.

2. Looking after the person in a hospital.

A. The unconscious patient.

For part of this session, we spent time in Groote Schuur Hospital with a person who had recently had a stroke.

(To aid identification, the patient is dressed in a track suit in our illustrations).

We have already discussed that strokes occur suddenly. A severe stroke will cause the person to collapse unconscious. Any unconscious person must be taken to hospital as soon as possible, as they need special care and close observation.

Looking at Mrs. Adams, do you think she is conscious or unconscious?

She is unconscious, as she is just lying in her bed. She is not able to move and she did not greet us when we greeted her. In fact, even when we spoke to her she did not respond in any way.

As Mrs. Adams is lying there is there anything slightly unusual about her?

She has a tube going into her nose and a bag full of urine hanging on the side of the bed.

An unconscious person is unable to swallow, but still needs food and liquids. The tube that you see in Mrs. Adam's nose goes into her stomach. Through this tube she is given liquid and liquid food. Sometimes a stroke patient will be sent home with one of these tubes in their nose and you will have to help the family manage this.

What is the bag on the side of the bed full of urine for?

It is for urine.

Mrs. Adams does not know when she needs to urinate or in fact when she does urinate. The catheter pipe, takes urine from the bladder into a catheter bag. This has

She also does not know when she wants to have a bowel action, so underneath her she has a waterproof sheet, so that the whole bed does not get wet and dirty.

Sometimes people do not regain control of their urine and bowels and so have to rely on a catheters and waterproof sheets. At home people use old newspapers and big pieces of plastic to act as waterproof sheets.

Have you seen Mrs. Adams move since we've been here?

No not at all and we've been here 20 minutes.

What can happen to a person who is lying in bed and not moving at all?

They can get pressure sores.

What should be done for Mrs. Adams?

She must be turned every 3 hours. This will ensure that the blood flows well and pressure sores do not develop.

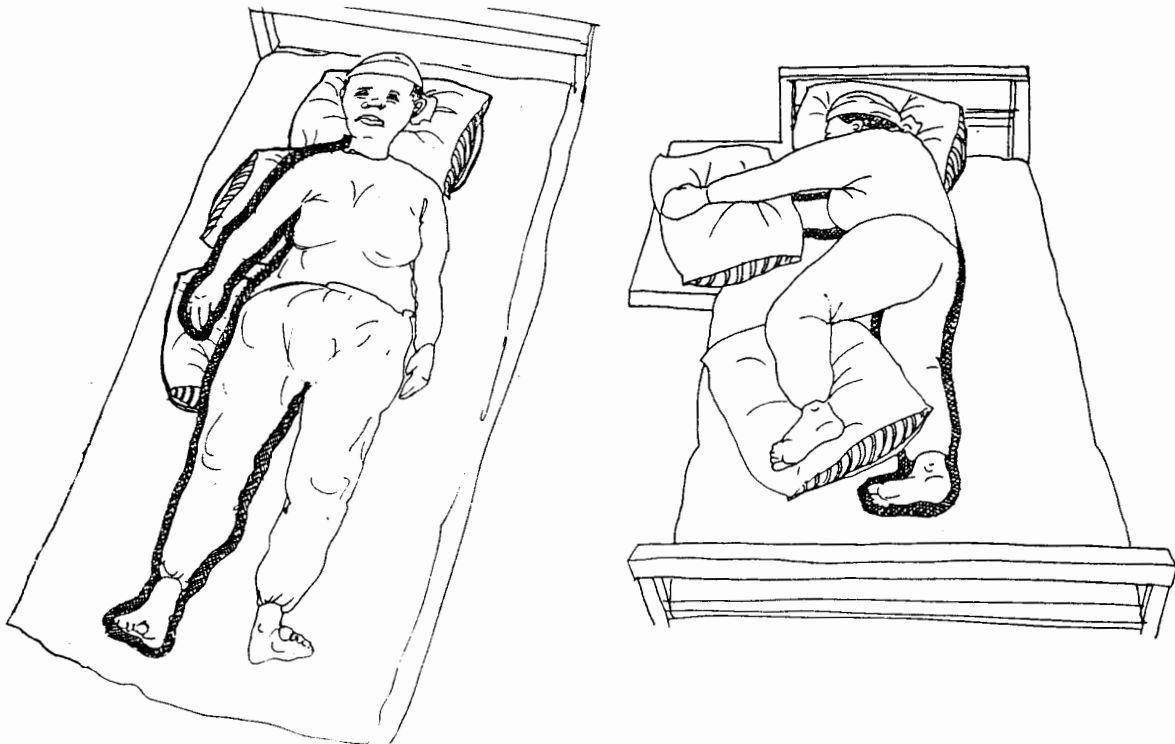
B. The positioning of the patient.

The positioning of a person who has had a stroke is very important. The family has to be taught how to do this. The person can lie either on their side or on their back. This will prevent the person from getting stiff and limit the typical tightness that develops in people who have strokes.

We divided into two groups of three and then each group positioned Mrs. Adams on her side, but on a different side.

Care of the shoulder affected by the stroke was emphasised at all times.

Together we all positioned Mrs. Adams on her back, keeping the shoulder of the stroke arm forward the whole time.



Here comes a physiotherapist, let's watch and see what she does for Mrs. Adams.

What is she doing?

She is shaking Mrs. Adams chest and then putting a pipe into her throat to make her cough.

An unconscious person is often unable to breathe deeply or cough. They tend to get secretions in their chests. The physiotherapists have to suction out the phlegm by putting a small pipe into the lungs. The patient then coughs and the secretions come out of the chest.

After a few days the person may regain consciousness and be allowed to go home.

3. In the early stages at home.

This was done in the community.

(To aid identification, the patient is dressed in a track suit in our illustrations).

A stroke is a terrifying experience for both the stroke victim and their family. The person's life is suddenly destroyed. They have lost all independence and become totally dependent on their family. The most basic and ordinary activities they used to do by themselves each day, can no longer be done without help.

This is Mrs. Mbangata. She had a stroke three weeks ago, and is now at home. Do you think that she feels good about having to be looked after, washed and fed by her family?

No, not at all.

It must be explained to the family what a stroke is and what caused it. If it is as a result of high blood pressure, the family must be told that the person's pills must be taken regularly and that more pills must be obtained from the day hospital before the others run out.

At this stage it is difficult to say whether the person will walk and work again, but they need to be told what a serious problem a stroke is, and that the person may never be independent again.

What are some of the problems that Mrs. Mbangata may develop?

- *pressure sores*
- *chest infections*
- *urine infections*
- *pain, especially in the shoulder affected by the stroke*
- *tightness in the side affected by the stroke*
- *contractures on the side affected by the stroke*

The family must be told about these and how they can be avoided or minimized.

In the early stages most stroke patients look similar to Mrs. Mbangata. However a stroke affects every person in a different way, so that no two people who have had a stroke are exactly the same.

A. The face.

What is the first thing you notice as you look at Mrs. Mbangata lying in the bed?

- *Her face, the one side looks as if it is hanging and loose.*
- *Her mouth is falling open on the same side and she is dribbling.*

What do you think will happen if Mrs. Mbangata tries to eat anything?

Food will fall out of her mouth.

Where is she looking?

Her head is turned towards the normal side. Her eyes are constantly looking towards the normal side, and her head is turned in this direction.

Let's see if we call her from the side where she has had the stroke if she will turn her head in this direction.

"Mrs. Mbangata, Mrs. Mbangata, can you look at me?"

Did she turn her head?

No.

Did her eyes move over to the side that has had the stroke?

No.

• Management

- The person must be encouraged to look towards the side that has had the stroke.
- The person must be encouraged to move their mouth and try to talk.
- The person must eat food like apples and meat that needs chewing. The family must not give them sloppy food only.

B. The body.

Is Mrs. Mbangata lying straight?

No, not at all.

She is not lying straight as she cannot feel the side of her body that has had the stroke. Her head will be turned towards the normal side and any movement that is done will be done with the normal side. The side that has had the stroke tends to get left behind, ignored and forgotten.

• Management

- The family must turn the person every 3 hours to prevent pressure sores.
- The family must be taught the correct positions for the person who has had a stroke, both in lying on their sides or on their back. Special care must be taken of the shoulder, it must be protected and supported at all times.
- The person must be positioned in bed with the side with the stroke closest to the edge where they get into and out of bed.
- The person must be encouraged to do as much as possible for themselves. They must not "forget" about the stroke side but include it in the movement.

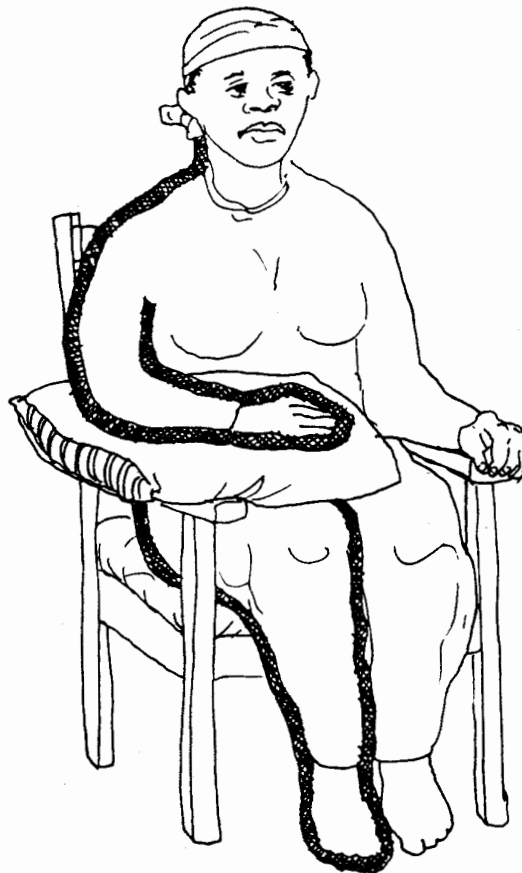
We then got Mrs. Mbangata out of bed and sat her in a chair. Does Mrs. Mbangata look comfortable in this chair?

No, not at all, she seems to be really frightened and is clutching onto the chair with her good arm.

She is frightened as she has no balance or feeling on the side that is affected by the stroke, so she just seems to keep falling over.

• Management.

- To learn how to balance, the person must sit out of bed in a chair each day. The chair should have arms so that the person is not frightened of falling out of it.
- Always approach the person from the stroke side.
- Encourage the person to do as much as possible for themselves.



C. The arm affected by the stroke.

When we sat Mrs. Mbangata in the chair was she aware of the hand that was affected by the stroke?

No, not at all. She seemed to ignore the arm that was affected by the stroke and even after we put it on a cushion, it slid off and she didn't notice it hanging at her side.

The affected arm will be floppy and lie turned in. Often the person will roll onto their hand without knowing it, or let it fall over the side of the bed or chair as they cannot feel it.

The shoulder can easily be damaged and become very painful. A painful shoulder can make a whole arm painful and stop the person from moving it.

• Management

- The shoulder must be protected and kept forwards at all times. Show the family how to position the shoulder and arm when she is lying, both when the person is on their back or on one side or the other.
- The arm must be supported at all times and treated carefully. Use a pillow under the arm, when the person is sitting up.
- Show the person how to clasp their hands together.
- Encourage the person to touch their stroke hand often.



D. The leg affected by the stroke.

As Mrs. Mbangata sits here in the chair, what does her leg feel like.

It feels floppy and very heavy.

When she was lying in the bed, what position was her leg in?

It was straight and lying turned in. The foot was pointing downwards. The foot tends to get very swollen.

• Management

- The leg must be correctly positioned and a cushion must support the whole leg, including the foot, when she is lying down.
- When sitting, the foot must be flat on the floor, so that weight goes through the foot and leg.
- If the foot gets swollen, the person must not sit all day long.

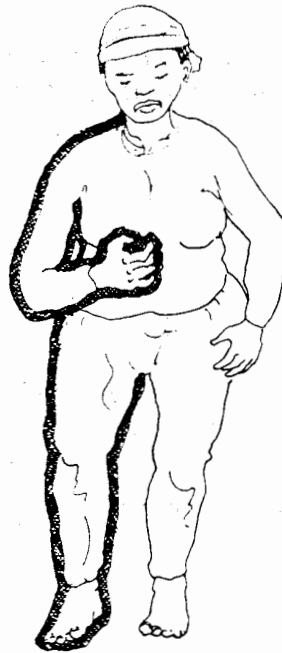
4. Tightness of limbs.

A. The limiting of movement.

As time passes, some movement may return, but the side affected by the stroke also starts to get more and more tight. This tightness can limit any movement that is coming back.

This tightness usually causes the arm and the leg to adopt certain patterns.

- the arm:
 - * the arm bends
 - * the shoulder pulls up and back
 - * the arm is held close to the chest and turns in
 - * the elbow is bent
 - * the hand is held clasped
- the leg
 - * the leg straightens
 - * the hip pulls up and back
 - * the hip is straight and turned in
 - * the knee locks straight
 - * the foot points down and in



B. Reducing tightness on the side affected by the stroke.

If the person with a stroke has tight muscles on the side affected by the stroke, movement cannot be done on this side before the tightness is made less.

If you are trying to reduce the tightness or do movements with the side affected by the stroke, at no stage must the person feel any pain. Pain will only increase the tightness.

There are 4 methods of reducing the tightness:

- **Movement** - Encourage the person to use their affected side as much as possible. Encourage them to move as much as they can.
- **Rotation** - Encourage the person to roll and turn. By lengthening the tight muscles, their tightness will be reduced.
- **Weight bearing** - Get the person to weight bear through their affected arm and leg.
- **Lengthen the tight muscles** - Teach the person to gently stretch the muscles which are most tight.



5. Recovery and chronic stage.

At all times the person must be encouraged to do as much for themselves as possible. When doing things, the side that has had the stroke must not be ignored and left out, but included in the movements and activities.

A. Transfers.

In getting from the bed into a chair or wheelchair, or getting back into the bed:

- the person must transfer over the side that is affected by the stroke.
- the feet must be flat on the floor.
- block the knee that is affected by the stroke with your knees, to prevent it from collapsing and to get the person to take weight through this leg.
- the person's hands must be clasped together.
- you may have to support the arm affected by the stroke.



B. Standing up and walking.

Someone who has had a stroke usually stands up using the normal side only. They must be encouraged to use the affected side to stand up and take weight through that side.

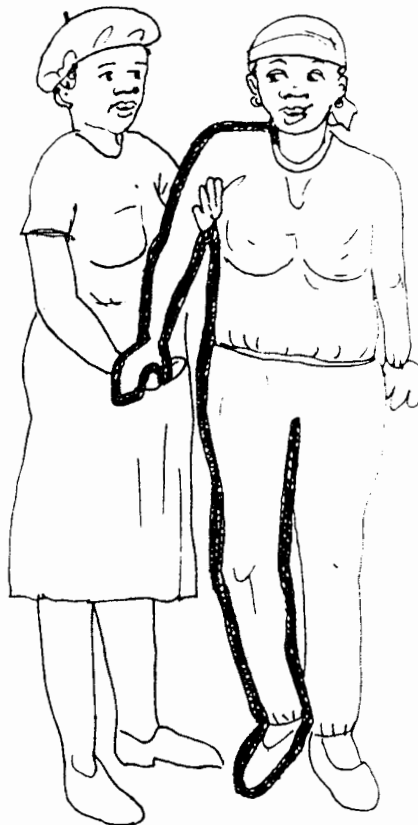
- they must clasp their hands,
- reach forwards with both hands, and then
- stand up taking weight through both legs.

They will usually need help and this is best given if their hands are clasped and put around your neck. You will also need to block the knee affected by the stroke as you did in the transfer.

This is to keep it straight and prevent it from collapsing, and also to get the person to take weight through this leg.

The person may need support in walking:

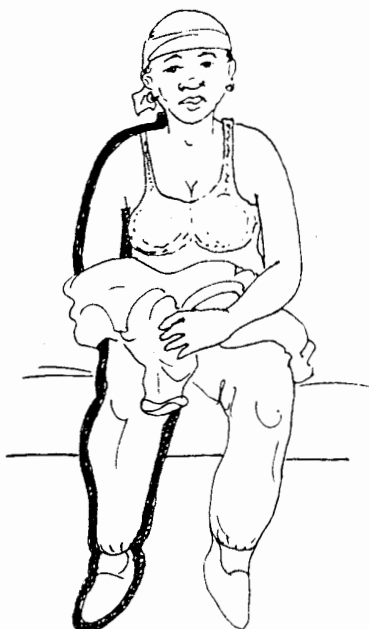
- stand and support the side that is affected by the stroke; hold the arm affected by the stroke in your hand, so that the person can put weight through the affected arm.
- with your other hand you can give support under the shoulder of the affected arm.
- you might have to help the person by helping them move the foot affected by the stroke.
- if they use a stick it should be used in the hand affected by the stroke or in both hands together, to encourage the person to take weight through their affected side.
- a stick should not be used in the normal hand.



C. Washing and dressing.

The person must be encouraged to do as much for themselves as possible. When washing they must try to include the hand that is affected by the stroke.

In dressing, the person must be encouraged to do as much for themselves as possible. Jerseys and shirts with buttons down the front are much easier for the person to put on and take off. It is much easier to dress the side affected by the stroke first. When putting on a jersey or shirt, hang the arm affected by the stroke down either next to the chair or between the legs, it is then much easier to put the jersey on.

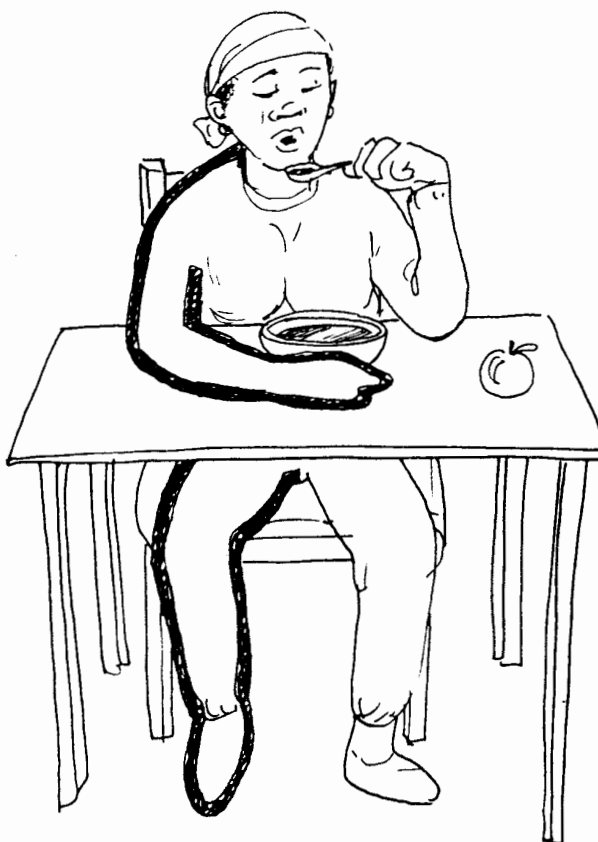


Trousers can be put on in bed or while sitting or standing. Again it is much easier to dress the side affected by the stroke first. Shoes and socks can be put on by crossing the legs. The affected arm must not be left behind, but brought forward. Help will be needed with the laces.

D. Eating and drinking.

Here as well, the person must be encouraged to do as much for themselves as possible. They must also try to involve the arm affected by the stroke in as much of the movements as possible.

- When *eating*, the arm affected by the stroke should be on the table with the hand lying flat, not ignored under the table.
- When *drinking*, the person must clasp their hands around the cup and then drink using both hands.



III.10. SPINAL CORD INJURIES

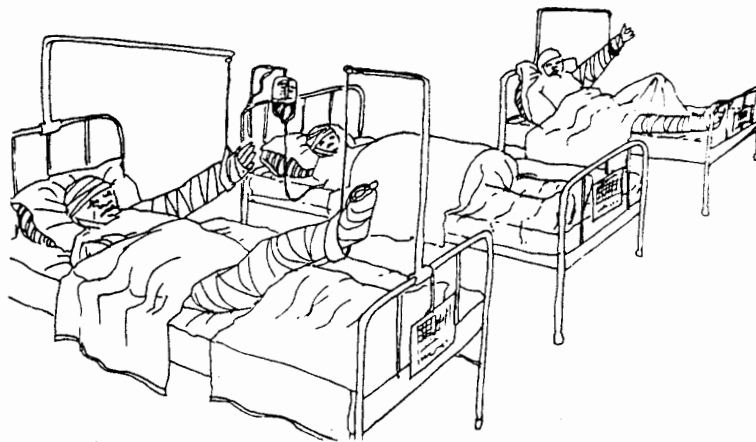
Aims of this session.

1. To know the problems that are likely to develop with people who have spinal cord injuries and how to avoid these.
2. To demonstrate how a person with a spinal cord injury and their family should work together to achieve maximal functional independence.

1. Visit to Conradie hospital.

We visited the spinal unit at Conradie hospital. Here we saw:

- the intensive care unit with a number of patients recently admitted.
- the wards in which people with spinal cord injuries are being rehabilitated.
- the physiotherapy ward. Here we saw the patients on the mats exercising their arms and doing passive movements to their legs, and in the parallel bars learning to stand up.
- the ward where people with pressure sores are confined to bed. We saw pressure sores exposing the sacrum, the head of the femur and the knee.



2. The spinal cord.

We'll start by revising a small section of what we did when we first learnt about the spinal cord.

What is the spinal cord made up of?

Nerves.

What protects the spinal cord?

The backbone.

Is the backbone easily broken?

No. The injury needs to be associated with a lot of force.

What do the nerves do?

Carry messages to and from the brain:

- There are nerves that come down from the brain and run down the spinal cord, telling the body to move in a controlled and appropriate way.
- There are nerves from the body that pass into the spinal cord and take messages to the brain about what all the parts of the body are feeling, and what position they are in.

What happens if the nerves coming down from the brain are cut?

The different parts of the body will not get messages to move in a controlled and appropriate way.

They will stop moving. If an arm or leg no longer moves, it is said to be paralysed.

What happens if the nerves running up to the brain are cut?

The messages about feeling and position sense will no longer be taken to the brain where they are interpreted and understood.

The part of the body supplied by the cut nerve will lose all feeling.

For example: If the nerve running up to the brain from the foot is cut, the foot cannot feel:

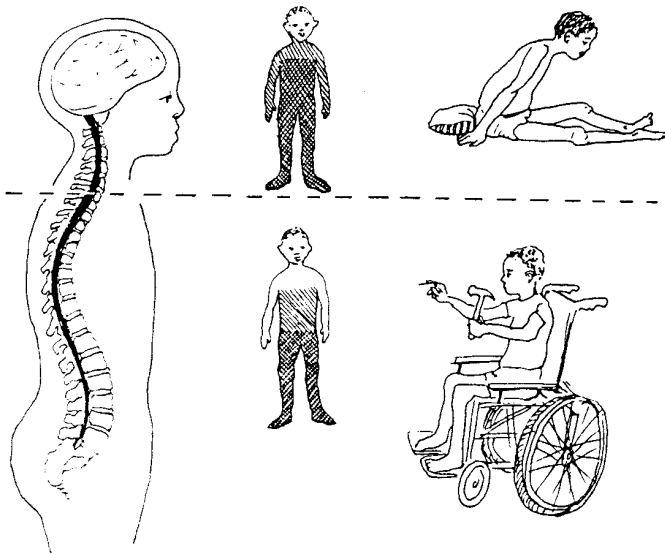
- If you stand on the foot it will feel no pain.
- If boiling water is spilt on the foot, the foot will not feel that the water was hot.
- The foot will not be able to feel if it is on the ground or lifted up. Walking is very difficult.

If the cord is cut what happens?
Feeling and movement below the level of the injury are lost.

A. Injury at the neck

If the cord is damaged at the level of the neck what will happen?

- *The person will lose controlled movement and feeling from the neck down.*
- *The arms and hands will be paralysed to some extent.*
- *The chest, trunk and leg muscles will all be paralysed.*



What is the problem if the chest muscles are paralysed?

Breathing may be affected and the person will not be able to breathe deeply.

This is why we saw that one person at Conradie on a breathing machine. If the stomach muscles are not working the person will be unable to breathe deeply and cough.

If a person has lost movement and feeling in his arms and legs he is said to be a *Quadriplegic*. You all know the young man, Siyabulela Tshibika, who lives opposite the road from our clinic. He was shot in the neck (C4) and is now a quadriplegic.

B. Injury at the back.

If the spinal cord is damaged in the lower part of the back, the person will lose movement and feeling in their legs. The hips and trunk may be affected depending on how high up the back the injury is. The higher up the back the injury is, the more movement and feeling will be lost.

A person with this type of injury is called a paraplegic. This young man, Milton Ntswayi, is a paraplegic (with a T8 lesion).

Quadriplegics and paraplegics will also have other problems:

- Bladder and bowel control will be affected.
- Temperature regulation will be affected.
- Blood pressure regulation will be affected so that the person may get dizzy when they stand up.
- The legs which are usually heavy and floppy, may have periods of sudden tension and tightening of the muscles. This can cause the legs to "jump" or suddenly straighten. These movements are often painful and are referred to as "spasms".

C. Complete and incomplete injuries.

Here we have some wool wound round 2 nails.

If we take these strands of wool, we could think of them as the nerves running down the spinal cord. If we cut all of the strands, it's as if the spinal cord has been completely broken. There is no link at all, between the 2 halves.

Can any message at all get between the top and the bottom?

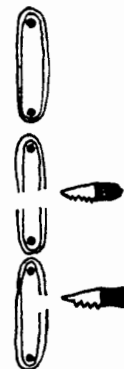
No. There is a complete break and no messages can get through.

This is known as a COMPLETE INJURY. If a person has a complete injury, they will have no controlled movement and no feeling at all below the level of the injury.

Strands of wool wound round 2 nails representing the nerves of the spinal cord.

COMPLETE INJURY
All the nerves are cut, no messages can get through.

INCOMPLETE INJURY
Some nerves are cut, others are not cut. Some messages get through, but not others.



But sometimes the cord does not get broken completely. Looking at these strands of wool, some may be cut, but some may remain intact. Some messages can still get through. The injury is then known as an INCOMPLETE INJURY. So the person may have some controlled movement and feeling below the level of the injury. One side may have lost more feeling and movement than the other side.

3. Causes of spinal cord injuries and immediate treatment.

A. Causes.

What kind of accidents did we hear people at Conradie say had caused their injury?

Accidents with which a lot of force is associated, motor vehicle accidents, stabbings, bullet wounds, falling off a train.

The people that we saw at Conradie hospital in wheelchairs, were they mostly men or women?

Mostly men.

Why?

Men are more often involved in fights and accidents where a lot of force is experienced. In Joburg in the mines, there are often rock falls which break the miners backs, either causing paraplegia or quadriplegia.

How will you know if a person has damaged his spinal cord?

- *loss of feeling and movement in their legs.*
- *unconscious.*

B. Immediate treatment.

If someone in the community is severely injured in the back and is unconscious or cannot move or feel their legs, they may have damaged the spinal cord. They have to be treated very carefully to prevent further damage.

If a person has damaged their spinal cord but it is an incomplete injury some nerves are not broken.

What could cause them to break too?

Movement.

It is important not to move the person's head, neck or back. The person will have to be lifted when the ambulance arrives. During the lift and while the person is being taken to hospital, their head, neck and back must be kept straight and moved as little as possible.

C. Learning to lift a person with a spinal injury.

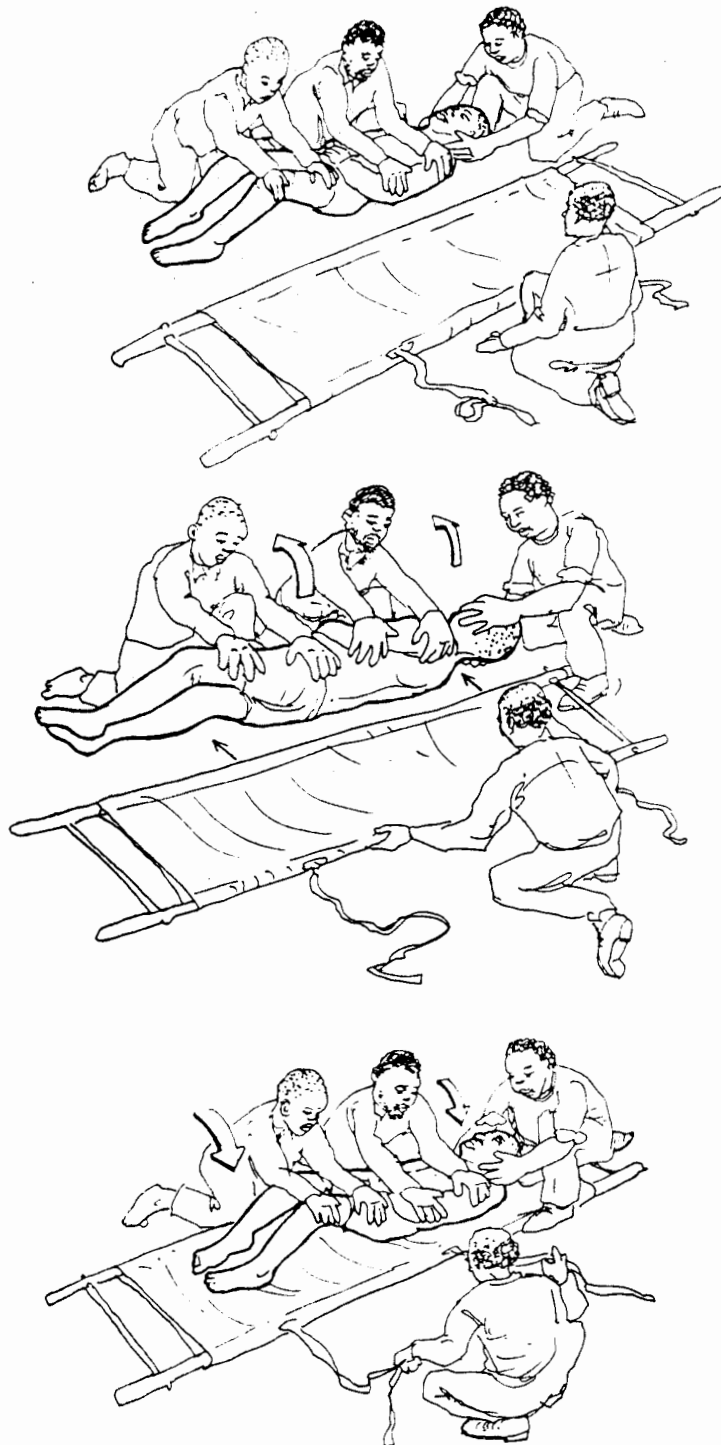
We had 4 people to do the lift:

- Injured person rolled like a log to one side, with their back or neck kept straight. 3 people standing on the side to which the person is being rolled:
 - * 1 keeping the neck straight and in the middle
 - * 1 turning the shoulders and keeping the back straight
 - * 1 bending up the knees before the roll is started, and then rolling the pelvis and legs so that the back does not turn.

This involves working together as a team with one person counting "1,2,3, turn," so that everyone rolls the injured person at the same time.

- The person on the other side then slipped a stretcher under the injured person.
- The injured person was rolled back onto the stretcher. The same method was used as that to roll the person in the first place, without turning their neck or back.
- The person was then tied onto the stretcher, not too tight, but tight enough to limit any movement from occurring. Their neck was secured using a pillow.

- The stretcher was then carefully lifted up. One person counted, so that they all lifted at the same time, and the person's back and neck were not moved in any way. They put the person down in a similar way, as if putting the person in a van or ambulance that would transport them to the hospital.



4. Management of a person with a spinal cord injury.

A. Hospital care.

People with spinal cord injuries are taken to special hospitals where they are given special care. Conradie is the hospital in Cape Town where these people are managed.

To start with, they may have to be in a brace for 6 weeks, so that their back cannot move. This ensures that no further damage can occur because of movement. If there is a danger of a lot of movement occurring because the bones are broken, the person will be operated on and steel rods inserted next to the backbone to stop any movement from happening.

The goal for a spinal cord injured person is to become as independent as possible. It usually takes 6-9 months for the person to learn how to live in a wheelchair. When the hospital staff feel that the person will manage at home in a wheelchair, they will be discharged.

B. Home management.

As R.W.s we will see people with spinal cord injuries in their homes in the community. At Conradie certain things were done for these patients. What were these?

Turning, preventing pressure sores, positioning, assisted breathing and coughing, exercises, self-care.

These things are all done in hospital, but must also be done at home.

At home there are two important aims to focus on:

1. To enable the person to do as much for themselves as possible.
2. To ensure the person with the spinal cord injury and their family are aware of the complications that are likely to develop and how these can be prevented.

5. Aim 1: To enable the person to do as much for themselves as possible.

At Conradie the person will have learnt to do most activities that he has to do each day by himself, or with minimal assistance. However, at home things are not so easy to do, for example:

- The ground is sandy so that it is difficult to walk with crutches or drive a wheelchair.
- Sometimes a wheelchair doesn't fit into a shack.
- The bed is very soft so that the person can no longer move themselves off the bed into a chair.
- Once they come home these people often become very depressed. I read an article in the paper a while ago about people who had had spinal cord injuries in the mines. In a study of these men, it showed that many of them got so depressed, that to get back into hospital, they opened up old pressure sores with a knife so that

they had to be re-admitted to the hospital where they had already spent 6-9 months. Although this is no doubt depressing for them, it is less depressing than being at home where they can no longer do the things they used to do and are so dependent on other people.

A. Our aim as R.W.s.

As R.Ws we need to visit these people in their homes and encourage them to use the things that they learnt at the hospitals, adjusting these where necessary and showing family members how to assist them.

The person needs to be as independent as possible in meeting their own basic needs: moving about, eating, bathing, dressing, toileting and other skills needed each day. It is frustrating and depressing for a person to have to rely on other people for their needs.

Paraplegics can become almost completely independent, needing limited help only. Quadriplegics will never be completely independent.

The person must keep active, fit and strong, so that they can do as much as possible. The muscles that the person does have must be as strong as possible to make up for the paralysed muscles. Paraplegics need very strong arms to move the rest of their body. It is very important that people do not get fat as this makes all activities more difficult.

The person must be encouraged to do as much for themselves as possible and get out of bed each day. Paraplegics and quadriplegics should:

- Get out of bed and sit in a wheelchair each day.
- Stand up each day for at least 20 minutes. This is to prevent contractures and bone weakening and encourage blood flow and urine drainage.

B. Rolling and moving from one place to another.

1. Rolling.

Some quadriplegics can, with the aid of a rope fixed to the bottom of a bed, roll themselves over needing minimal assistance only. We asked Siyabulela (C4 lesion) to roll himself over. He could not. We watched his mother turn him over to the left:

1. She moved him to the right side of the bed, first his shoulders and then his hips. She was careful not to drag him over the sheets.
2. He turned his head to the left.
3. She crossed his right leg over his left leg.
4. She turned his shoulders and then his hips to the left.
5. She positioned him with pillows to keep him on his side.

Siyabulela's mother said she is constantly tired as it is such a lot of work to look after Siyabulela, feeding, turning and cleaning him.

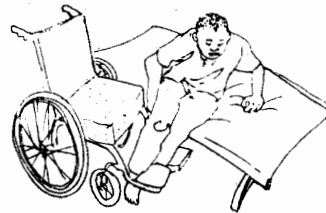
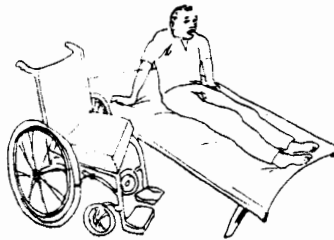
We then watched Milton turn himself, noticing how he had to do everything with his arms and what strong arms he has and has to have.

• 2. Moving from one place to another.

(From the bed to a wheelchair)

Quadriplegic: We had to help Siyabulela sit up. 2 people lifted him into a chair, one person holding him under the arms and the other person holding his legs.

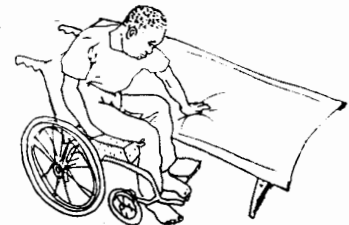
Paraplegic: Milton sat himself up, moved his legs over the side of the bed and then lifted himself into the chair. If the bed is the same height as the chair it makes it much easier for him.



• 3. Getting around in the wheelchair.

Siyabulela cannot move his wheelchair himself. As he has so few muscles that work he needs a chair with a high back, the sides and arm rests so that he can balance.

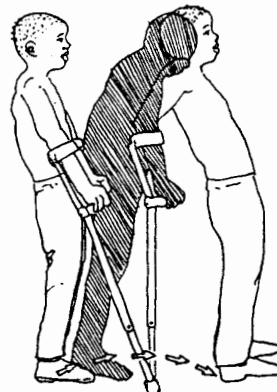
Milton can get himself around in his wheelchair. He does not have the sides of his wheelchair in, as then he can move more. He pushes on the wheels to get himself around.



• 4. Standing up and walking around.

We put Siyabulela's calipers on for him. We stood him up, one person pulling his hips forward, and one person lifting up his shoulders. He got dizzy very soon, so we had to sit him down.

Milton put his own calipers on. He then stood up using his crutches.

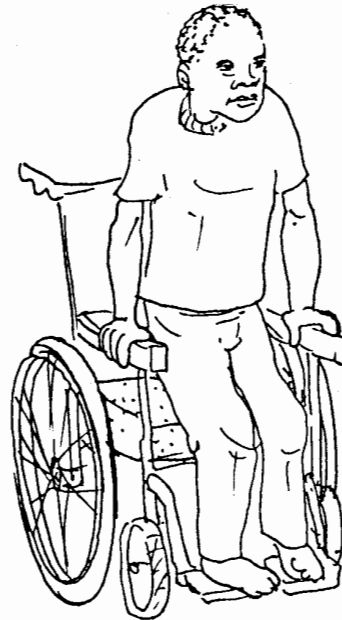


C. Exercises.

For a person with a spinal cord injury to move themselves they need to have strong arms, good balance and be aware of their legs and arms which have no feeling.

• 1. Arm exercises to maintain strong arms:

- sitting in a wheelchair:
 - * throwing and catching a heavy ball
 - * pushing down on the arms of the chair to lift up their bottom
- lying on their stomach:
 - * push ups.



• 2. Maintaining good balance

People with spinal cord injuries will be taught how to balance at Conradie, but we need to encourage them to remain confident of their balance.

Why does the person need to learn how to balance?

The nerves carrying feelings from the legs to the spinal cord are cut, so the person does not feel their bottom or legs anymore. They feel as if they are sitting on nothing.

This is frightening. They must be encouraged to move in this position although it is frightening.

With the person sitting, either in a wheelchair or on the floor:

- throw a heavy ball to the person, not only straight to them, but also high up in the air and to the sides.
- the person must lift both arms out to the sides and above their head.
- Encourage the person to move as much as possible and to do as much for themselves as possible, picking up things from the floor, opening the door so they can go through.



3. Care for legs.

A person with a spinal cord injury must look after their legs as they move from one place to another.

Be aware that they have no feeling in their legs and protect them so that they do not bump against the hard edges of the bed, chair or wheelchair.

In lifting up their bottom, they must ensure it is high enough, so that they do not scrape their bottom and get pressure sores.

6. Aim 2: To ensure that the person with the spinal cord injury and his family are aware of the complications that are likely to develop and how these can be prevented.

A. Blood pressure.

Patients will experience a loss of adjustment of their blood pressure to changes in body position.

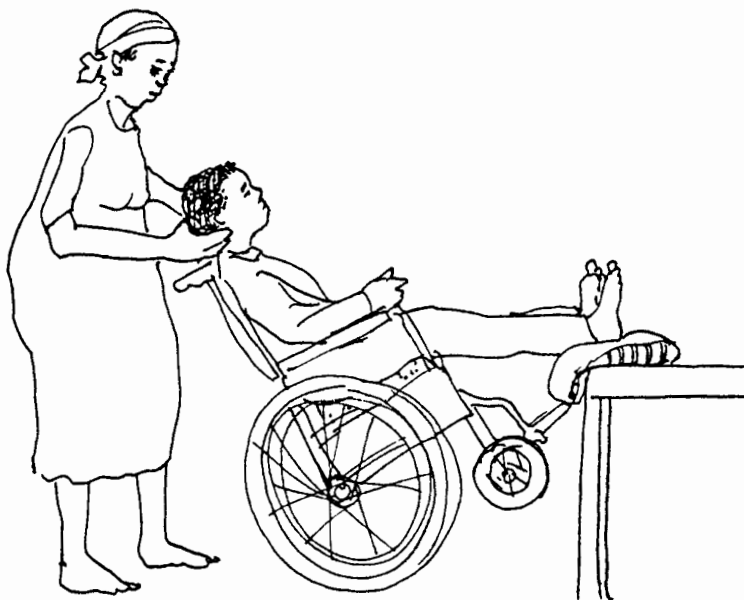
What happens to you if you stand up very quickly after you have been lying down?

Get dizzy.

This happens to a far greater extent to paraplegics and quadriplegics. The person gets dizzy as all the blood flows into their legs when they stand up. As no muscles in the legs work there is nothing to pump the blood back to the heart. Not much blood gets pumped to the brain so the person gets dizzy and faints, unless they sit down.

At Conradie the person will have been taught how to sit and stand up without getting dizzy and fainting. They must get out of bed every day otherwise it will become a problem again.

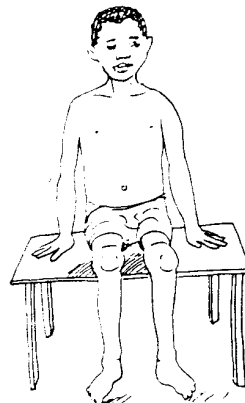
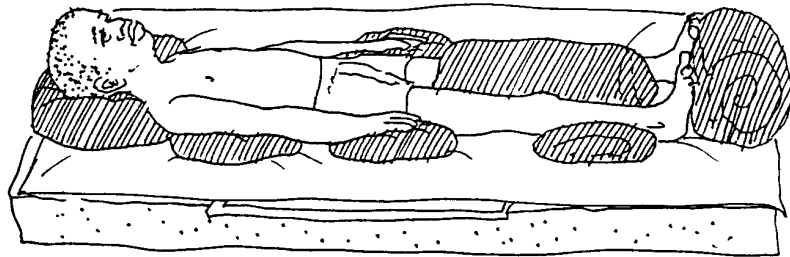
If a person does get dizzy sit them down and tilt them backwards in their wheelchair, lifting up their legs and feet. This encourages the blood to flow back to the heart and head.



B. Pressure sores.

Loss of feeling can lead to pressure sores and other injuries. The following must therefore be kept in mind.

- What kind of mattresses were people lying on in the hospital?
Thick, firm mattresses.
At home, it is important that paraplegics and quadriplegics lie on thick, soft mattresses, but these must also be firm, and not sag too much in the middle.
- Where were the pillows and the cushions?
In positions to keep the pressure off the bony areas and to keep the body in a good position. These must also be used at home.
(Practical session on how to use cushions to keep the pressure off the areas which are likely to get pressure sores.)
- How often were the patients turned?
Every 4 hours.
- Keep the skin (especially round the bottom and genitals) and the bedclothes clean and dry.
- The person must use a wheelchair cushion whenever they sit in wheelchair.
- When sitting, the person must push down on his arms to lift up his bottom every 15 minutes.
- Eat a balanced diet and do not get too fat.
- Move and exercise to encourage good blood flow.
- Check the skin daily for pressure areas.



C. Avoiding contractures.

Every day exercises should be done to prevent muscles from shortening and joints from stiffening. See the session on Contractures (V.3). These exercises must be done for the rest of life. They must not be done too vigorously or the joints will be damaged. Hold the paralysed parts of the body carefully and gently. Paraplegics should be able to do these for themselves.

D. Assisted breathing and coughing.

If a person has a neck injury what movement will they lose?

They will lose the movement of their arms and legs.

Yes but what else as well?

Their trunk and chest muscles will also be paralysed.

What do we use our chest muscles for?

For breathing and coughing.

The person will be unable to breathe deeply or cough. They will tend to get pneumonia. They will need to be assisted to cough, to prevent this. The family will need to be taught how to do this.

(Practical session on assisted coughing.)

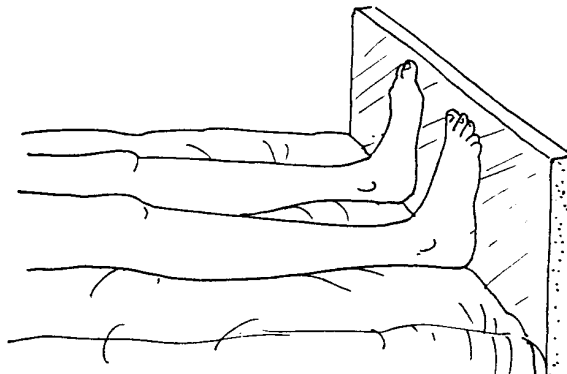


E. Maintaining good positions.

Did you notice that the patients feet were all kept straight at the bottom of the bed by a board. Why was this?

This is to stop the feet from pointing downwards and becoming stiff in this position.

The feet must also be carefully positioned when the patient is sitting.



In people who have spasms, the legs often pull together and pull up. To stop this a pillow should always be between the legs. In side lying the bottom leg should be straight. In sitting the legs may also pull together and a pillow will be needed between them.

In a chair with a straight back, the person will tend to slump forwards. The wheelchair or any other chair that the person sits in must be made to tilt backwards. This will stop the person from slumping forwards.



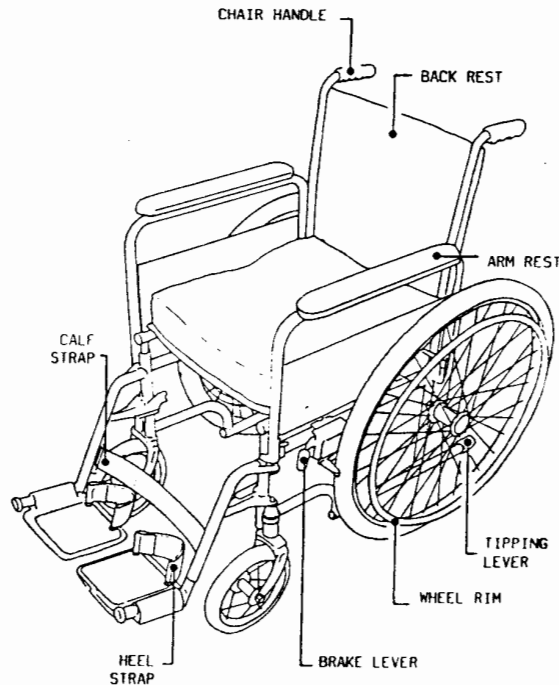
The person has to learn how to balance while sitting although they cannot feel their bottom on the bed. They also have to learn how to move, although the prospect is terrifying as the person feels that they will fall.

F. Temperature control

Temperature is often affected and the person tends to get very hot or very cold. They must be taught that they must not allow themselves to get too hot or too cold. On a very hot day they cannot sit out in the sun, but must be in the shade. On a very cold day, they mustn't sit next to an open flame or fire to warm themselves up. They have no feeling in their legs and will not feel when they are too hot and are burning themselves.

7. Wheelchairs and other appliances.

Each person is discharged from Conradie hospital with a wheelchair and a wheelchair cushion. The wheelchair can quite easily break. As R.W.s we must fix these or take them to Conradie to get fixed. We must also check that the cushion is still in good condition and that the person uses it whenever they sit in the wheelchair.



The person may have a number of other appliances. These may vary from calipers and crutches to a twisted spoon with a loop of leather which enables a quadriplegic who cannot move his fingers to feed himself using his wrist muscles.

These other appliances that the person was given must also be checked:

- Does the person use them?
- Ask him to show you how he uses them. Does he use them correctly?
- Do they work or are they broken?

III.11. AMPUTATIONS

Aims of this session:

1. To understand what an amputation is.
2. To know the different causes of amputations.
3. To recognize the problems that are likely to develop and learn how these can be avoided.

Teaching aids used:

1. Bandages.

1. The causes of amputations.

A. Examination of a woman with an amputated leg.

This is Mrs. Nxazisa. She lives with her married daughter and her family.

When you look at Mrs. Nxazisa what do you see?

Her left leg looks a bit different from her right leg.

If you look more closely at her left leg what do you see?

It is actually a plastic leg, whereas her right leg is a normal leg.

In English we say that the leg has been amputated. Let's find out why the leg was amputated. Mrs Nxazisa what was the problem with your leg before it was amputated?

For a year my left foot was constantly swollen. Towards the end of the year, my toes got sores on them and then went black. When they went black, they were really sore so I went to the day hospital. At the day hospital, they sent me straight to Groote Schuur Hospital where my leg was cut off, just below the knee.



Mrs. Nxazisa's story of her swollen foot and rotten toes, suggests she had problems with the way in which the blood flows round her body (blood circulation).

In a healthy person, fresh blood is pumped out to the legs and arms by the heart and then is usually pumped from the legs and arms back to the heart.

Mrs. Nxazisa's foot was swollen because the blood was not being pumped back to the heart. As not enough fresh blood was getting to the foot, it went rotten.

B. The causes of amputations.

The most common cause of amputations is poor circulation. Usually legs are amputated and sometimes arms.

How old are most people who suffer from problems with blood circulation?

They are usually over 40.

Are there any diseases you know of that tend to cause problems with blood circulation?

Diabetes and heart conditions.

What is diabetes?

It is blood sugar sickness.

Do you know of anyone else who has ever had to have an arm or leg amputated, and why it was cut off?

In the Transkei I knew an old man whose toes all went rotten, one at a time. One by one they had to be cut off. Some time later his whole foot had to be cut off and after a year his leg was cut off below the knee.

This old man's problem was also one of poor blood circulation, like Mrs. Nxazisa. Not enough blood was getting to his toes so they went rotten and had to be cut off.

Blood circulation was still a problem and his feet were not getting enough blood so then his foot had to be cut off. Below the knee his leg was not getting enough blood so finally his leg was cut off.

Does anybody know of a younger person who has an arm or leg cut off?

- * *I knew a man who was involved in a car accident, his leg had to be cut off as it was completely crushed.*
- * *I knew a young girl who had to have her arm cut off as she had a growth and it was growing very fast making the whole arm swollen and painful.*

After poor circulation, the most common reasons for limbs to be cut off are major accidents and growths which are growing and spreading to other parts of the body.

C. Examination of the stump and plastic leg.

Let's look at Mrs. Nxazisa again. Mrs. Nxazisa could you take off your plastic leg?

Look at what is left of Mrs. Nxazisa's leg. It is known as the stump. Can you see the scar?

Yes, its quite big, running along the whole front of the stump.



Could you put your leg back on Mrs. Nxazisa.

Before Mrs. Nxazisa puts on the leg she puts a sock over the stump. This sock is known as a stump sock.

This sock is very important because it prevents the stump from getting pressure sores from too much rubbing. It is just like the sock we put on before we put on a shoe.

When they cut off your leg, did you have a big scar?

Yes, from one side to the other.

Mrs. Nxazisa, did you have a lot of pain in your leg before it was cut off?

Yes.

Mrs. Nxazisa do you put your plastic leg on every day?

Yes, and I go for a walk each day.

Afterwards, although it was cut off, could you still feel pain?

Yes, it was very strange. I could still feel my leg throbbing and causing a tremendous amount of pain although it was no longer there.

This ghost-like pain is common in people who have had an arm or leg amputated. If the leg was painful for a long time before it was amputated, the person can still feel the pain after the leg was amputated.

Where is Mrs. Nxazisa's leg cut off?

Above the knee.

This is one of the more common amputations. The other common amputation is just below the knee. More rarely just the toes or foot are cut off. Occasionally the whole leg is taken off from the hip.

2. The prevention and handling of complications that are likely to develop.

A. Swelling.

Mrs. Nxazisa does your stump swell at all?

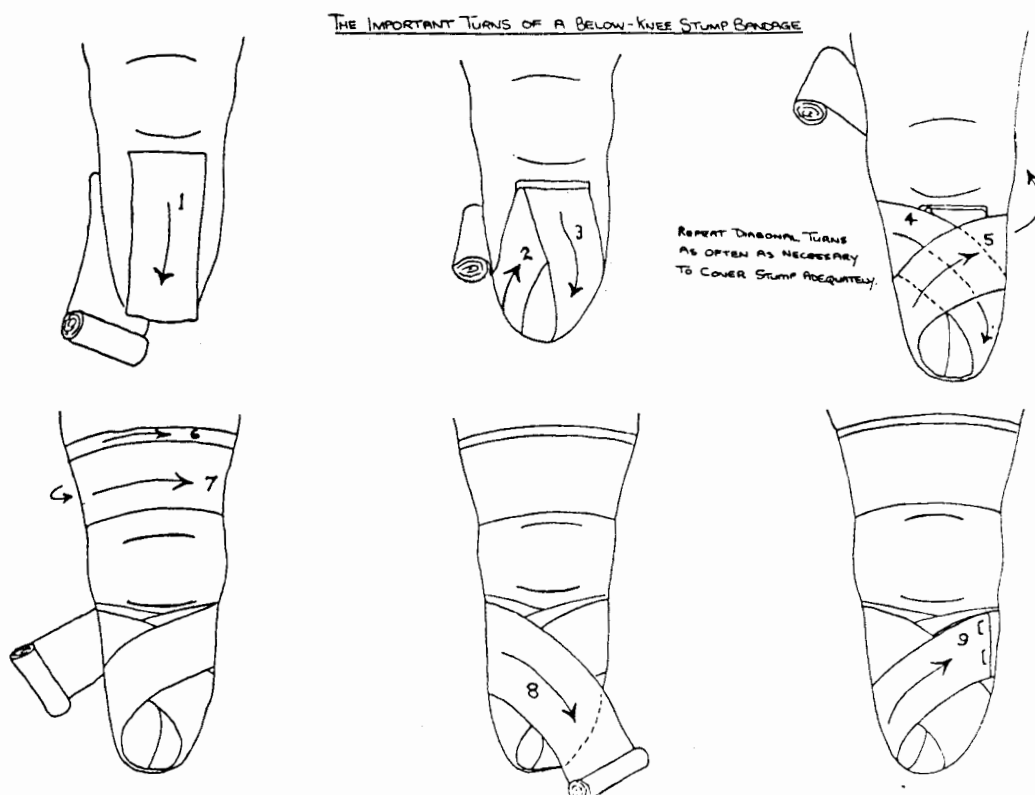
Towards the end of the day, if I have been up all day, my stump is slightly swollen. It is far worse though if I do not wear my plastic leg, then my stump becomes very swollen.

Swelling of the stump is a problem for all people who have had an arm or a leg amputated. There are two simple practical tips that can help this problem:-

° 1. Bandaging.

Whenever the person is not wearing their plastic leg or prosthesis they must wear a stump bandage.

The pictures on the next page illustrate how to bandage a stump. Practise this.



Just after the leg has been cut off, the stump is bandaged carefully in the way we have just been practising.

This gives the stump a good shape, smooth and conically shaped so that it can fit easily into a prosthesis.

By wearing their plastic leg the person keeps the stump in a good shape and regular bandaging is not necessary.

When the person is not wearing their plastic leg because of a pressure sore or some other complication, bandaging is necessary for *two reasons*:

- It stops the stump from swelling.
- It keeps the shape of the stump so that when the person starts to wear their plastic leg again, it still fits.

Although Mrs. Nxazisa has had her stump for a long time it is still necessary that she bandages it if she does not wear her plastic leg for a day.

° 2. Do not let the stump hang down.

Do not let the stump hang down. Support it on a chair or pillow at all times to reduce the chance of swelling.

B. Contractures.

Mrs. Nxazise is an amazing person, who stands up and walks around on her plastic leg. Many amputees never stand up and walk around.

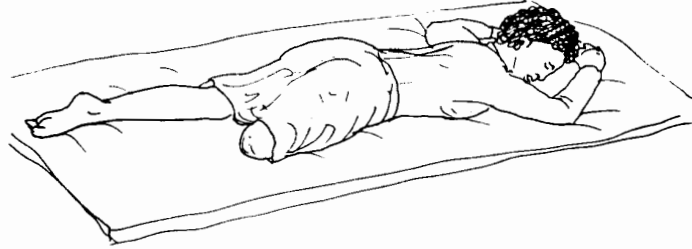
What is likely to happen if a person just sits all day in a chair or wheelchair?

They get stiff at the front of the hips particularly, and behind the knees so that they can not straighten their hips or knees.

To stop this problem, the person should stand up for half an hour each day. If this is not possible, the person must lie on their stomach for half an hour a day.

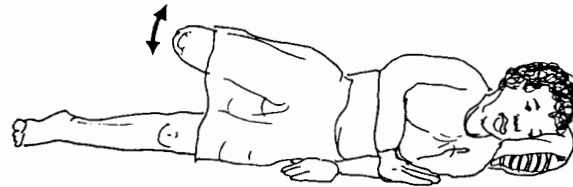
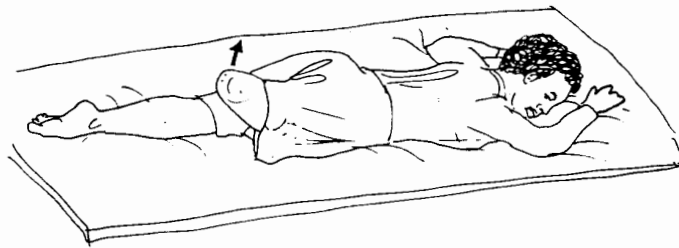
If the person had their leg cut off below the knee, they must lie with their knee straight so that the whole leg is flat on the bed.

If the hip becomes stiff the plastic leg will stick out straight in front of the person when they stand up.



◦ Exercises to prevent contractures.

- Lying on your stomach lift the stump up towards the roof. If the amputation is below the knee remember to keep the leg straight.
- Lying on each side, lift each leg sideways.
- Lying on your back, grip a pillow tightly between your legs while someone tries to pull it out.



C. Pressure sores.

What happens if a person who is unable to move a lot, stays in one position for a long time?

They will get pressure sores on the areas that take the most pressure.

An amputee who is sitting a lot, will tend to get pressure sores on their bottom, as this is the area that is taking the most pressure.

Where will most of the pressure be experienced in an amputee who is walking around a lot?

On the end of the stump, where it comes into contact with the plastic leg.

This is where pressure sores are most likely to develop.

To reduce the chances of getting a pressure sore at the end of the stump:-

- Always wear a stump sock.
- If a stump sock gets a hole in it, get a new one as a darned hole can also cause a pressure sore.
- Wash the stump daily with soap and water, and dry it thoroughly afterwards.
- Put the stump in the sun daily.
- Wear a clean stump sock every second day.
- If the reason for the leg being amputated was poor circulation, look after the other leg. Try not to injure or cut the leg in any way and do not burn it or let it get too cold.
- Do not get too fat, as this increases the pressure that the stump must cope with. Putting on weight also makes a person reluctant to move, further increasing the chances of a pressure sore developing.
- Take medicines regularly if a doctor has prescribed these.

3. Other concerns for amputees.

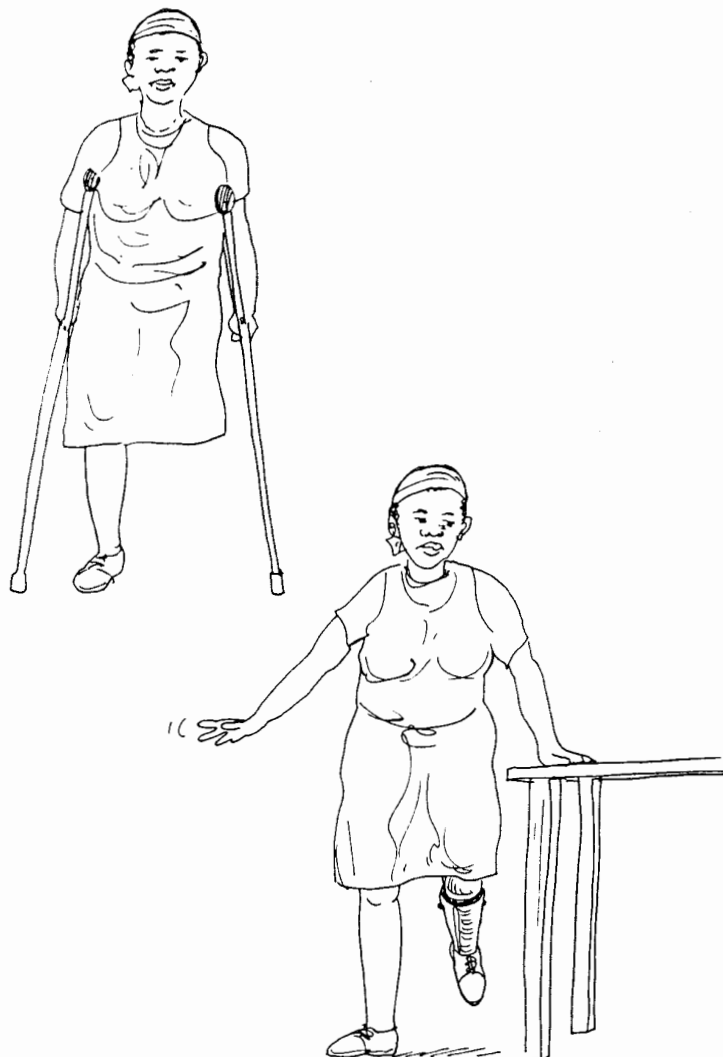
A. Walking.

Walking with a plastic leg is difficult to get used to and uses a lot more energy than walking around with two ordinary legs. The person must not get fat, as then even more energy is needed.

These exercises to get the person more confident about balancing can be helpful:

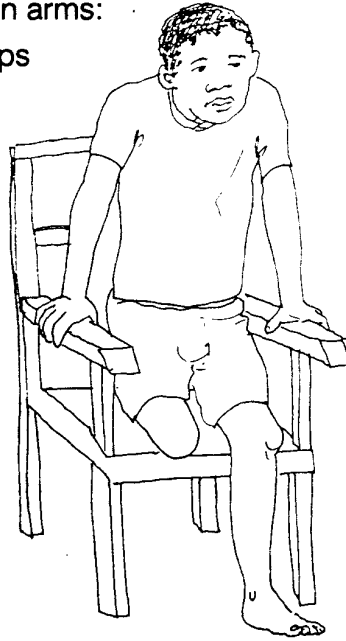
- Standing next to a table:
 - * Balance on the good leg only.
 - * Balance on the plastic leg only.

If the person gets a pressure sore on their stump, or their plastic leg has to be sent in for repairs, they will have to walk with crutches. To walk with crutches, the person must have strong arms:



These exercises will help to strengthen arms:

- Lying on your stomach do push ups
- Sitting in a chair, do push ups.



B. Looking after the plastic leg.

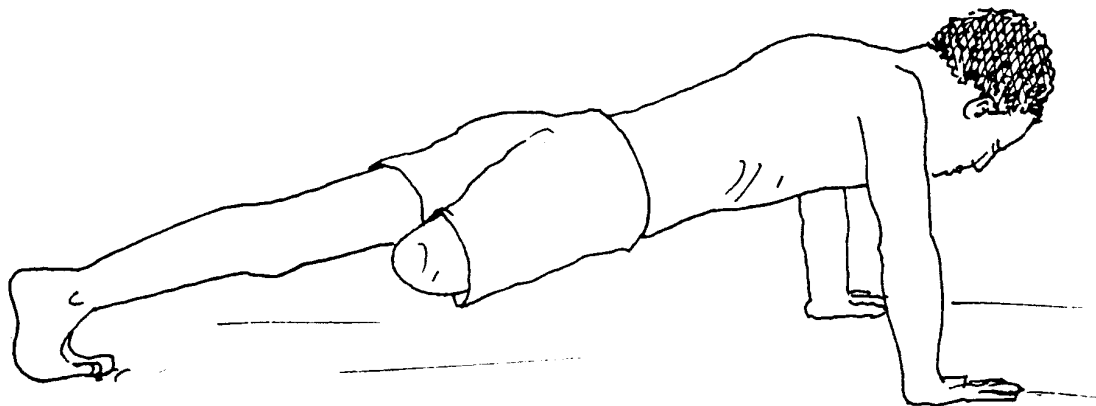
A plastic leg is very expensive to make, and made specifically for the person using it. It must be treated carefully and no-one else must be allowed to wear or use it.

- A plastic leg must always be worn with a sock.
- New shoes must have the same size heel as the plastic heel.
- Wash the plastic leg with a moist soapy cloth.

C. Looking after the other leg.

If the leg was amputated because of poor circulation, the other leg must be looked after.

- Do not bruise, bump or cut the leg.
- Take medication regularly.



IV. MANAGEMENT OF PATIENTS



A severely handicapped child with his family.

IV.1. ASSESSMENT AND RECORDING

Aims of this session:

1. To learn to assess and examine a handicapped child and adult.
2. To recognise the difference between doing a good home visit and doing a bad home visit.
3. To learn to record the aims, exercises and action to be undertaken for each patient.
4. To become familiar with the process of record keeping, assessment and examination.

Teaching aids:

1. An A4 note book for record keeping.
2. An assessment sheet (see next page).
3. A monthly recording sheet.

1. Initial assessment and examination.

A. The record book.

Each R.W. was given an A4 note book in which all the relevant data about a patient would be recorded. As the rest of this session makes clear, this includes:

- the initial assessment and examination
- tracings of joint or other relevant measurements
- aims of treatment
- activities and exercises discussed and taught
- action taken
- further visits

B. The assessment sheet.

Each R.W. was given the assessment sheet which follows on the next page. This assessment sheet is the guideline for the assessment questions that should initially be asked of the mother, handicapped person or available relative. The questions assume the patient to be a child, and must be adapted by the R.W. for adults. Hopefully the R.W. will get to know it off by heart and no longer need to follow the paper.

The assessment falls into five main areas:

1. Basic details of the patient.
2. Questions about the handicapped person's history and condition and problem.
3. Looking, feeling and examining the handicapped person more closely.
4. Identifying the specific problems that the person has.
5. Treatment programme that is suggested for the person.

ASSESSMENT SHEET.

1. Basic details:

- * Name:
- * Date of birth:
- * House Number:

2. History and condition of the patient

- * Did you notice anything wrong with your child when he was born?
- * Did you have problems during your pregnancy?
- * Did you have problems during labour?
- * Was your child born in a hospital or in your house?
- * Was your child born in Cape Town or in the Transkei?
- * When did your child get ill?
- * When did you first notice a problem?
- * What are the problems with your child?
- * Are these problems getting worse, better or staying the same?
- * What do you understand is wrong with your child?

- * Does your child fit?
- * Does your child take pills for the fits?
- * Has your child been seen at Red Cross Hospital?
- * What is the folder number?
- * Does the mother get a single care grant?

3. Looking at and examining the child more closely, what do you see?

- * Is the child stiff or floppy?
- * Which parts of his body are affected?
- * Is his head the right size?
- * Is there any part of his body which can only move a bit?
- * Measure how much these joints can move?

- * Is the child's development normal?

4. Identify specific problems

- * What are the specific problems that the child (and her mother) have?

5. Treatment programme.

- * Record the exercises and the reasons for these exercises.
- * How many times must the child be seen each week by the R.W.?

C. Examining and measuring patients.

The examination involves looking, feeling and examining the handicapped person more closely, and focussing on the problems that the person has. This is broadly outlined in the third part of the assessment sheet.

Measurements of joints and other relevant measurements need to be recorded at this stage as well. All measurements must have the date next to them. The method of measuring joints is described in the session on contractures (IV.3). The method of measuring head circumference is described in the session on hydrocephalus (III.4).

D. Doing the assessment correctly.

As can be seen, some of the questions are difficult to ask because they are personal and delicate. The manner in which the assessment is done is therefore very important. To make this clear we did role plays showing a bad home visit and then a good home visit.

Role play: Good and bad home visits.

° 1. Bad home visit

Two of the R.W.s did a role play showing a bad home visit. After they had finished, we discussed why we all thought it was a bad home visit. Some of the points mentioned were:

- the R.W. was very high up
- she had no patience and was too forceful
- she acted like a nursing sister
- no clear explanation was given
- she was insulting about the person's dirty house and child

° 2. Good home visit

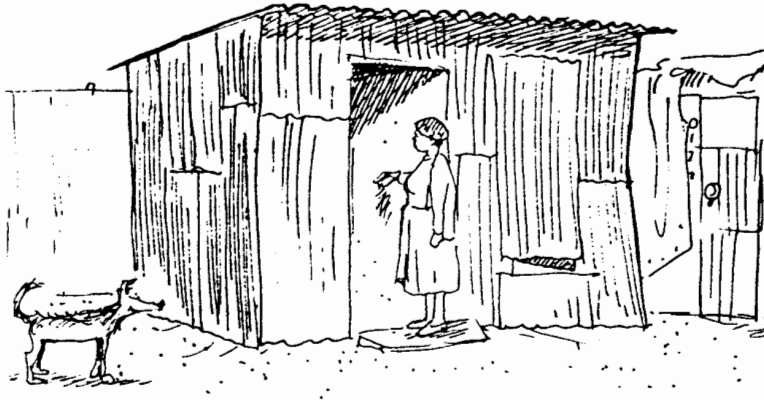
Two R.W.s then did a role play showing a good home visit. After they had finished, we discussed why it was a good home visit. Some of the points mentioned were:

- the R.W. did not behave as if she was high up
- she explained who she was and why she was there
- she was understanding and empathetic about the amount of work the mother had to do and the fact that the house had not been cleaned yet
- she was patient, warm and friendly.

The R.W.s then broke up into pairs and each pair acted out a good home visit and a bad home visit.

E. Practical session: home visits.

In the afternoon each person did three home visits in their area, and the next morning reported back on how they had gone. Although they had felt very apprehensive going out, they had no problems. In fact they found that people in the community were very positive when they explained what they were doing and what they would be doing in the future.



Although none of the R.W.s set out to visit handicapped people, all of them met one handicapped person on their visits. Two of the children that the R.W.s met had been seen by us at Vukani clinic. They were thrilled to hear that there will be a person working in their area, as neither of them manages to get to the centre any longer.

2. Recording and assessing treatment.**A. Aims of treatment.**

After the R.W. has made the initial assessment and examination of a handicapped person, this person will be seen by the R.W. and the physiotherapist. Together with the handicapped person or their mother they will decide on the child's aims and problems.

At times there will be definite goals to work towards achieving. At other times the aim may be to prevent the handicapped person's condition from deteriorating. These aims need to be clearly written down underneath the assessment. When they are achieved there needs to be recognition of this and the date of the achievement clearly marked.

A follow up assessment of these aims and the person's condition must be made when the aims have been achieved, or after two or three months.

B. Exercises taught and activities discussed.

After the aims of treatment have been discussed and noted, certain exercises and activities need to be discussed. As with the aims, these need to be discussed and agreed on by the mother or handicapped person, the R.W and the physiotherapist.

No more than three or four exercises will be discussed at one time. These will each be demonstrated by the physiotherapist and then performed by both the mother and R.W. The number of times the R.W. will come to the house will also be negotiated.

The exercises or activities, and the number of times a week that the R.W. will come to the house will also be recorded in the record book.

IV.2. FITS

Aims of this session:

1. To understand fits and epilepsy and their causes.
2. To understand how to look after a person who is fitting.
3. To be able to discuss with a mother how the pills work and how they should be taken.

1. Understanding fitting.

A. Our experience of fits.

We say a person has fits when he suddenly loses consciousness or has a change in his mental state and makes strange jerking movements.

Have any of you ever seen anybody fit? What happens to a person when they fit?

- * *My son Vuyo once fitted. He fell down on the floor and for a minute or so, his eyes blinked and he wasn't able to talk or hear. When he had finished fitting he was very tired and fell asleep for a long time.*
- * *A man who lived next to me in the Transkei used to fit. He was a bit of a mad person, and just used to wander around all day mumbling to himself. About once a day he would suddenly be thrown onto the ground by the "amafufunyana" (spirits). He would often really injure himself as the spirits would throw him into a fire or into a hole in the ground so that he fell a long way. His whole body would start jerking and his arms and legs would go up and down. He would have froth coming out of his mouth and he would often bleed as well, as he bit his tongue. When the spirits left him, he would sleep for a couple of hours. Then he would get up and carry on wandering around and mumbling to himself.*

Have you all seen someone fitting?

Yes, more than one person.

Fitting is common. 1 out of every 10 or 20 children fits by the age of 15. 1 in 50 of these children will go on to fit again and again.



Nowitness, one of the R.W.s has brought her child Nkosinathi with her today. Nkosinathi has cerebral palsy and fits regularly.

Nowitness could you tell us what happens to Nkosinathi when he fits?

When he fits his eyes start to blink and the one side of his body starts to jerk, mostly his arm, but also his leg. After a while it gets less and less and then it stops. Then he falls asleep.

When did Nkosinathi first fit?

Just after he was born.

B. What causes fits?

According to Xhosa tradition, what causes fitting?

There are many different causes of fits.

- *The amafufunyana, a particular spirit that has entered a person, can cause that person to fit.*
- *If a person has a vision and in that vision sees a snake or a mermaid, this may cause them to fit.*
- *A "bad wind" (omoya omdaka), can cause a person to fit.*

Using special equipment, doctors have shown that fits are caused by damage to, or an abnormal condition of the brain. We have discussed the brain in other sessions.

Is the brain tough and strong?

No not at all, so it can easily be damaged.

One of the first reactions of the brain to damage is to fit. Children or adults who have brain damage, from many different conditions, may fit.

Let's make a list of the different causes of brain damage which may cause fitting:

- In hydrocephalus increased fluid in the brain causes pressure on the brain which can damage it, causing the child to fit.
- If labour takes too long and the brain does not get enough oxygen, it will be damaged, resulting in fitting.
- Children or adults who have cerebral palsy, which is as a result of brain damage at birth, often have fits.
- Children who have had meningitis, an infection of the lining of the brain, which can damage the brain, often fit.
- In adults a brain tumour, as the tumour damages certain parts of the brain, can cause fits.
- In small children fits are usually caused by a high fever. The brain does not like high temperatures and in response fitting may occur.
- In small children diarrhoea and vomiting will lead to dehydration. The brain does not like water loss and in response fitting may occur.
- Worms, usually tape worms, can cause fits by forming cysts in the brain, which damage the brain.

- * In 1/3 of people who fit it is caused by injury to the brain; before, during or after birth.
- * In 1/3 of people who fit there is a family history of fits.
- * In 1/3 of people who fit the cause is unknown.

C. What is epilepsy?

A child or adult has epilepsy if she fits often even though she may in all other ways be very healthy.

The fits that we described earlier in this session were very different.

BIG FITS: In some people epilepsy causes a loss of consciousness and violent movements and the eyes roll back. Big fits seldom last longer than 10 or 15 minutes.

SMALL FITS: In milder forms the person may "blank out" for a moment and will just stop and stare, or may suddenly behave strangely and suck their lip or blink their eyes. Small fits last a few seconds. The person then carries on as if nothing has even happened.

- Fits usually last a short time.
- Sometimes a person can have a long fit which may last several hours. This is a medical emergency and the person should be rushed to hospital.
- Fits also vary in their frequency. They may come hours, days, weeks or months apart.
- People who fit, whether it is a big or small fit, do not remember that they have fitted.

Do you think Nkosinathi has epilepsy?

Yes, because he fits often.

Does he have big fits or small fits?

Big fits.

Did the man in the Transkei who was sometimes thrown into the fire, and Vuyo, who fell down with his eyes blinking have big or small fits?

Big ones.

Have any of you ever known someone to have small fits?

- *Yes, though I only realise it now. My neighbour has small fits. Sometimes when I talk to her I suddenly see her just staring at me and not listening at all. After a very short time, she carries on talking but she hasn't heard the things I said.*
- *My daughter had a friend, who would suddenly stop playing the game they were playing. My daughter said her eyes would blink a few times and then she would carry on the game as if nothing had happened. Sometimes if they were climbing a fence or tree, she would fall.*

2. Responding to a fit.

Nowitness, what do you do when Nkosinathi fits?

- *Nkosinathi usually fits when he is sick, if he has a chest infection or a cold. So when he's sick, I try not to go too far away from him.*
- *Once when he had a fit he rolled off the bed, so when I think he may fit I either put him on the floor, or I put him on the bed so that he cannot roll over.*
- *I always sit with him and hold him so that he doesn't hurt himself. I also try to stop him biting his tongue.*

Let's make a list of what to do when a child has a fit, as it may be necessary to check these different points with a person who fits and their family.

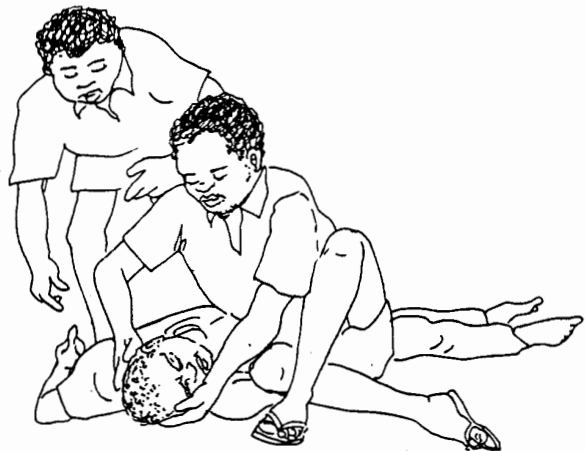
A. Protection.

- Sometimes the parents or the child may be able to recognise when the fit is about to begin, because of a "warning" sign. The warning may be a sudden fear or strange smell or sight. The child must be quickly laid down on a soft mat so that she cannot hurt herself.

Do you think it would be possible to hold all people who have fits?

No, adults are just too big, and some people have such strong fits that they may kick or hurt the person holding them.

The person should be lain on the ground, but in a place where he cannot hurt himself. Lie him on his side, or turn his head to the side.



- If the person has already started fitting, do not move them unless they are in a dangerous place. Remove any sharp or hard objects near him. Lie the person on their side.
- Protect the child from injuring himself, but do not forcibly control his movements. Do not try and hold him still and limit his movements.
- Undo any tight clothes, especially those around the neck and chest which may limit breathing.

B. Biting his tongue.

Nowitness, you said that you try to stop Nkosingathi from biting his tongue. How do you do this?

I try to put a cloth in his mouth.

I think every mother tries to stop her child biting his tongue when he fits, but it is very dangerous as it can stop the child from breathing through his mouth.

DO NOT PUT ANYTHING in the child's mouth: nothing to stop him biting his tongue and nothing to eat or drink.

C. Foam in the child's mouth.

Nowitness, does a lot of spit come out of Nkosingathi's mouth when he fits?

Yes, a lot of foam and spit, which I wipe up.

Always turn the head of a fitting person to the side so that the spit drains out and doesn't go down into the lungs.

D. After the fit.

Nowitness, what does Nkosingathi do after he has fitted?

He always sleeps for a long time.

When the fit is over the child may be sleepy and confused, **LET THEM SLEEP**. If they have a headache give them paracetamol.

3. Medicines to prevent fits.

How are fits cured in the Xhosa tradition?

It is a difficult process and takes a long time. There are only two ways of getting rid of fits. Either seeing the witchdoctor or by praying. The witchdoctors cure fitting, by driving out the spirits that cause the fits.

In your experience do these methods work?

No.

Is it always that easy to suggest to people who have fits that they should go and see a doctor about it?

No, not at all. The people will often only go to a witchdoctor. Other people who go to the Zionist churches, also refuse to go to the doctor.

There are no medicines that cure epilepsy. There are medicines that can prevent fits and prevent more brain damage if they are taken regularly.

As long as a child has epilepsy, (which may be all his life), he must take the pills daily.

If a person does not fit for a long time, epilepsy may be stopped permanently. Even if a child has stopped fitting, he must still take the pills for at least a year. He may then stop taking the pills if he still hasn't fitted, and the epilepsy may never return.

Nowitness, does Nkosinathi have pills?

Yes, he has always had one pill every night since he was born.

Do the pills run out?

Yes. Once I went back to the Transkei and we ran out of pills there and couldn't get anymore. Then Nkosinathi started to fit almost every day, so I came back to Cape Town, where I got some more pills. After a couple of days the fitting then got less. The doctor said I must never run out of pills and must get more pills before the others run out.

Let us write down the names of the drugs most commonly used to treat fits. Often people do not know what the pills they are taking are for, or they have forgotten. If you recognise the name on the packet as one of the names here you will know these pills are to stop fitting.

Nowitness, what kind of pills does Nkosinathi take?

They are small white ones, I do not know their name.

Have you got the packet here with you? Can someone read the name of the pills?

Yes, it says phenobarb.

The drugs most commonly used are

- phenobarbitone, and
- epineutin.
- Tegretal is also sometimes used.

If the child has fitted for a long time and been admitted to hospital, they will be given a valium injection, which will stop further fitting.

These drugs are strong drugs and must be taken correctly. As rehabilitation workers we must check that the correct dose is being taken, as is written on the packet.

- If the person is still fitting a lot they need to go back to the doctor as they need a larger dose or stronger pill.
- If the person is very drowsy and keeps falling asleep, they need to go back to the doctor as the dose is too much for them.

4. Helping the community understand epilepsy.

A. Beliefs.

What do you think that you as R.W.s can tell people in the community about epilepsy?

- *We have to do it in a gentle way, and listen to people's beliefs, and try to explain to them about how we now understand fits.*

- *We need to explain that epilepsy is not the result of witchcraft or evil spirits and it does not mean that the person is mad, or that the ancestors or parents of the child misbehaved.*
- *We also need to try and encourage the person and family to see a doctor and to take the pills regularly if they do go. Otherwise the person who fits will suffer from further brain damage as a result of the fitting.*
- *It is not infectious and cannot be passed to other people.*

Is it going to be an easy job?

- *No, not at all. We will have to be very patient and understanding of people believing in traditional beliefs. We will have to keep explaining again and again.*

Children or adults with epilepsy must be encouraged to lead as normal a life as possible. Certain precautions are necessary though:-

- the person may not be allowed to drive
- the person may not work at a great height in case they fall while fitting.
- the person should not work somewhere where the conditions may precipitate fitting, for example: a very hot place.

B. Prevention of epilepsy.

1. Avoid causes of brain damage, as this can cause fitting:

before birth:

- * the mother must attend ante-natal classes.
- * the mother must not drink, smoke or take strong medicines.
- * the mother should eat a balanced diet if she can afford it.

during labour:

- * it is safest to have your child in hospital or a maternity and obstetric unit (MOU).
- * if labour starts to go wrong get to a hospital as quickly as possible.

after birth:

- * If the child is very hot, cool him down, by taking off all his clothes and wiping him with a cool, damp rag.
- * If he has diarrhoea, he is losing a lot of liquid, try to replace this liquid by giving him water (use the salt sugar solution that we discussed in the session on oral rehydration (1.5)).
- * If the child does not improve, take him to a doctor. The brain of a child is very sensitive and if it gets too hot or dry, may be damaged.

2. Avoid marriage between close relatives. This is because the combination of the same family history and characteristics can put a child at greater risk of brain damage.

3. People with epilepsy must take their medication regularly, even if they haven't fitted for a year.

IV.3. CONTRACTURES

Aims of this session:

1. To learn to recognise when a child or adult has contractures.
2. To understand the causes of contractures and deformities.
3. To understand how contractures can be prevented.
4. To learn the positions, stretching exercises and movement used to prevent contractures at the joints of the leg and arm.
5. To learn how to measure contractures.

Teaching aids:

1. A jointed stick made from two spatulas rivited together at one end.

1. Contractures and deformities.

A. Examination of a child with contractures.

This is Thandile, and this is his mother. They live in Site B just down the road from our centre. Thandile is 6 years old.

What do you notice as you look at Thandile?

- *He is lying on the bed with his arms held tight against his chest and his legs sticking out straight.*
- *Although he is 6 years old, he can only lie.*
- *He is unable to speak, drools continually and his mother has to feed him.*

What do you feel if you try and bend Thandile's legs?

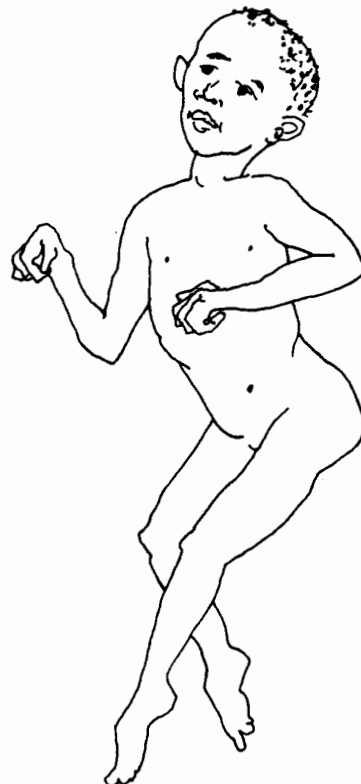
They are stiff and do not want to bend at all.

Why is it that Thandile's legs will not move?

The muscles and the joints are stiff.

What is wrong with Thandile?

Thandile has cerebral palsy.



He has not developed normally because of the cerebral palsy.

How does this affect his muscles?

They are very tight and tense.

In Thandile's case the tight muscles and stiff joints are because of brain damage from cerebral palsy.

B. The causes of contractures and deformities.

What is a contracture?

A contracture is a joint that is stuck and unable to move.

- *Does Thandile have contractures or joints that cannot move?*
- *His hips, knees, and feet cannot move.*
- *His shoulders, elbows, wrists and fingers cannot move.*

What is a deformity?

A deformity is a joint that no longer moves, it hasn't moved for some time and has become abnormally shaped.

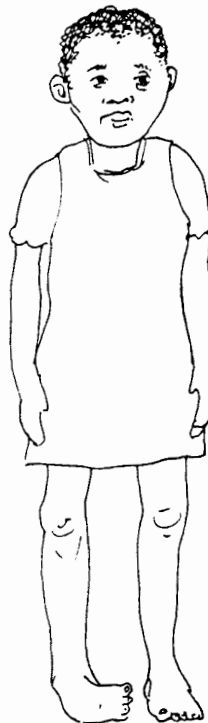
Look at Nokutula's foot. She was born with her foot like this. Does her foot look like an ordinary foot?

No, not at all.

Can you move it into a more normal position?

No.

Her foot is said to be deformed.



Why have Thandile's joints become stiff or contracted?

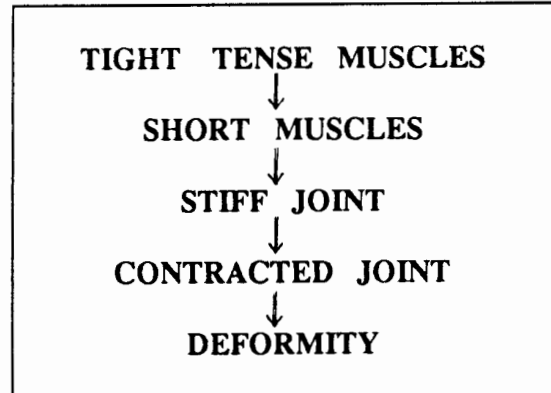
Let us focus on Thandile's knees. The muscles that move his knee are not in balance with one another, the muscles that straighten his knee, are much stronger than those that bend his knee.

The muscles that bend the knee cannot do so, so the knee joint is stuck or contracted in the straight position.

Why are Thandile's muscles unbalanced so that some pull stronger than others?

The brain damage Thandile suffered as a result of his cerebral palsy, causes certain muscles to work harder than other muscles.

- Tight, tense muscles eventually shorten if they are not stretched.
- Short muscles pull the joint into one position so that it becomes stiff.
- A stiff joint eventually becomes stuck in one position or contracted.
- The bone and other structures around a stuck joint eventually change their shape and position causing a deformity.

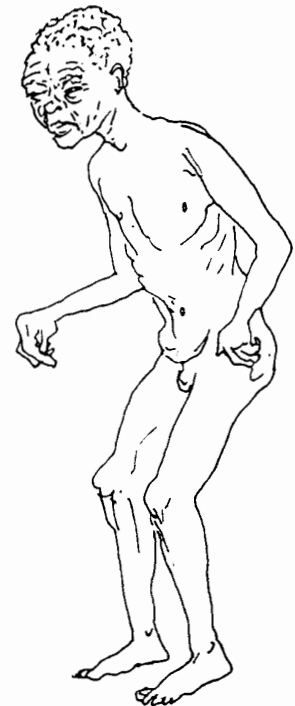
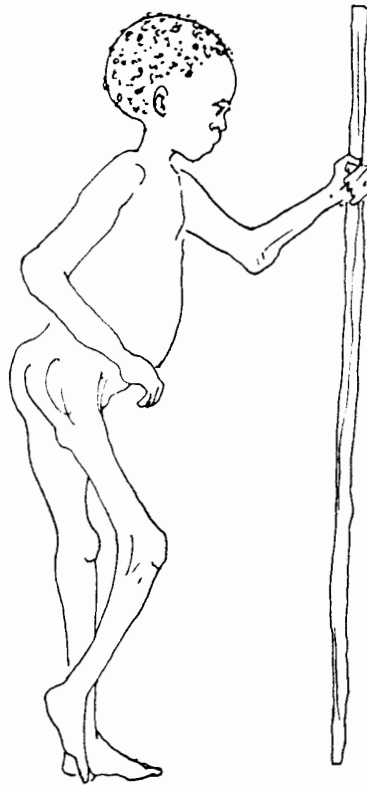


C. People who get contractures.

Who is likely to get contractures?

People who are unable to move, either because they are old and they just lie in bed, or because they are paralysed.

- Children with polio get hip, knee and ankle contractures.
- Spinal cord injuries
 - * the shoulders move closer to the head, so that the neck seems to shorten.
 - * hip, knee and ankle contractures from sitting too much.
- People with 1 or 2 legs amputated often get hip and knee contractures as they sit in a chair all day.
- Old people with arthritis usually walk bent over so they get contractures in the neck, shoulders, back, hips, knees, and ankles. They also get contractures of the arms, wrists, fingers, feet and toes.
- People who are sick and too weak to get out of bed.
- Adults who have had strokes.



- Cerebral palsied children.
- Children born with club feet, spina bifida or other deformities.
- Children or adults who have been burnt.



2. Prevention of contractures.

Why is it important to know about contractures?

Contractures can be prevented if the person and their family understand and know how to prevent them. Once a contracture has developed a lot of stretching is needed to lengthen the muscles and joint capsule which have become tight. This is usually very painful.

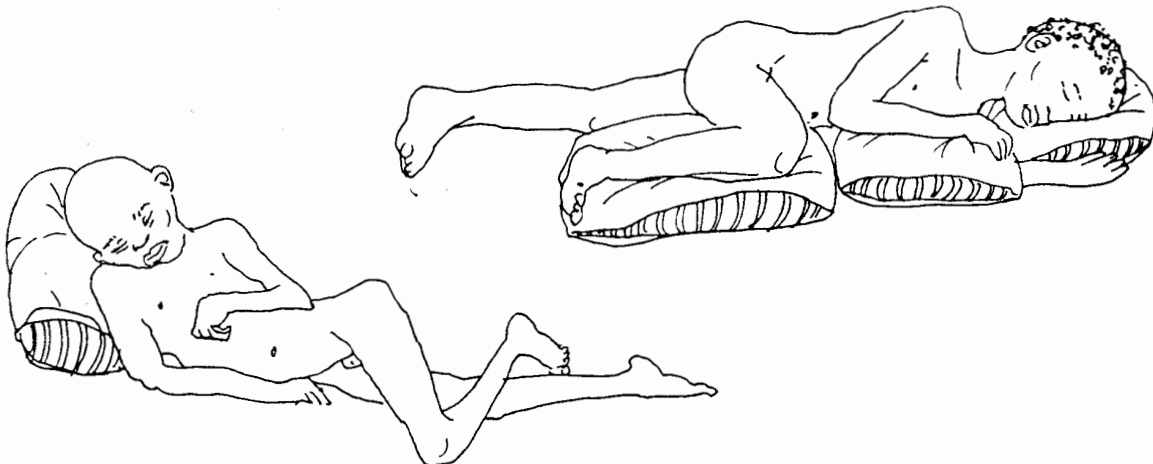
PREVENT CONTRACTURES, DON'T LET THEM HAPPEN, ONCE THEY OCCUR IT IS VERY PAINFUL FOR THE PERSON TO CURE THEM.

There are three ways of preventing contractures:-

- * Correct positioning.
- * Stretching the tight muscles.
- * Moving the joint fully each day.

A. Correct positioning.

This involves putting the person in a position so that their tight muscles and joints are stretched. The person needs to remain in a such a position for no less than 20 minutes each day.



B. Stretching the stiff muscles.

Stretching exercises are done where there are stiff muscles. The stiff muscles are stretched.

Stretching exercises are done slowly and the joint is held with firm steady pressure in one position so that the muscle and other tight structures are slowly stretched. Ideally the person should do these himself, but he may need help.

C. Moving the joint fully each day.

These are exercises in which the joint is moved as much as is possible in all the directions that it normally moves. They are done smoothly, regularly and repetitively to any joints that are getting stiff.

These are different to stretching exercises. They must begin as soon as possible to prevent contractures and deformities from developing.

The person must try and help as much as possible and they should be done daily.

They also help get the blood flow to that area to keep it healthy.

Paralysed people will have to do these exercises for the rest of their lives. Games (which include exercises) are much more fun than just exercises.

To illustrate the difference between moving a joint and stretching a stiff muscle let's look at Thandile's knees. His knees are tight and straight.

To *move the knee*, we will gently and rhythmically bend and straighten the knee as much as possible, 20 or even 30 times. This is not painful.

To *stretch the knee*, we will try to bend the knee using more energy and pressure. We will bend the knee until it is bending more than it usually does. We will hold the knee in this position and count to 25. After a short rest we will do this again and then a 3rd time, hoping to bend the knee a little more each time.

Be careful:

- * Protect the joint.
- * Be gentle and slow.
- * Never force the joint.
- * Do not do exercises on joints that are floppy or move more than they should.
- * Don't force a person to bend their neck.
- * In a quadriplegic, a person whose arms and legs are paralysed, don't stretch the fingers with the wrist bent down.
- * If a person is spastic only do these if a specific joint is getting tight.

3. Contractures in the leg.

If a person is either lying in bed all day or is sitting in a chair and does not stand up, the ankles, knees and hips of this person become contracted. Lets look at the contractures that are most likely to develop in the leg and how these can be avoided.

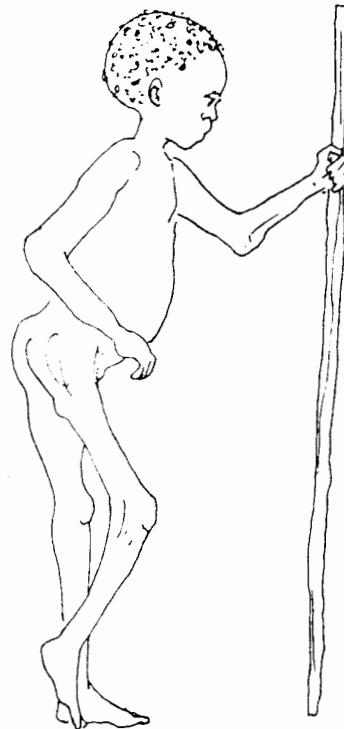
(This was essentially a practical session. All positions used, movements and stretches done were demonstrated. The R.W.s then practised these in pairs.)

A. Ankle.

Usually the calf muscles are stretched as we walk around as the foot is flat on the floor. If a person spends a long time lying in bed, the calf muscles are always in one position and are not stretched. They become short and tight.

Contracture most likely to develop:

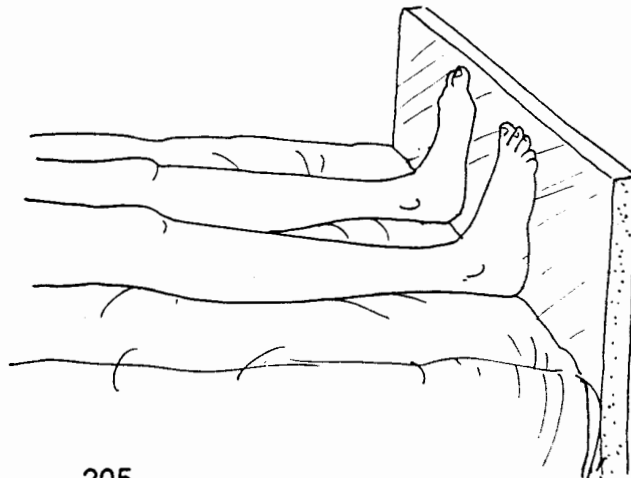
The muscles that pull the foot down have shortened so that the foot is pointing downwards. The foot cannot be pulled up so that the heel can be put down. Feel the tight heel cord that keeps the foot pointing down.



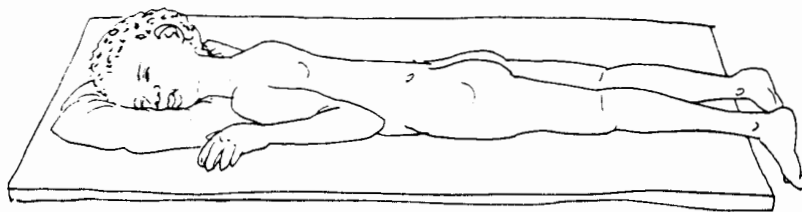
1. Correct positioning.

How should the ankle be positioned when a person has to spend a long time in bed, so that the ankle does not get stiff?

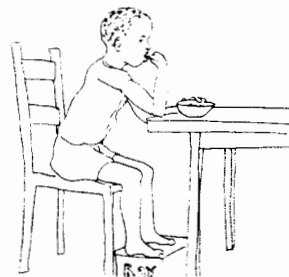
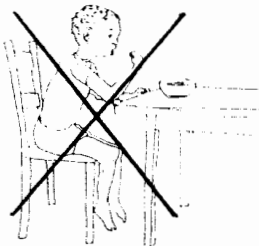
- Lying on their back. A board should be placed so that it keeps the toes pointing up towards the ceiling. (This cannot be done for a child who is tight because of brain damage. If something is put under his feet, it will encourage him to push down even harder).



- Lying on their stomach.
The feet should stick over the edge of the bed so that the toes point towards the floor and not towards the bottom of the bed.

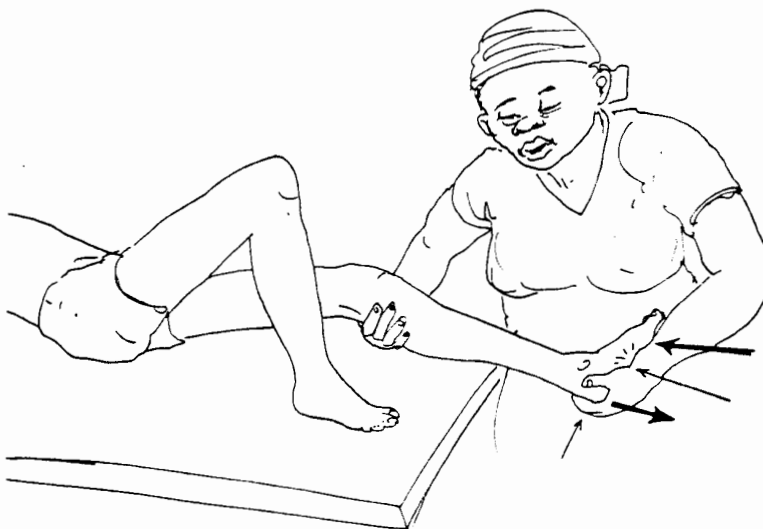


- Sitting. The feet must always be flat on the floor. Check that the heel is flat on the floor. In a wheel-chair the feet must be flat on the foot plates.



• 2. Stretching the stiff muscles.

- Hold the heel in your hand so that the foot lies on your forearm. Your other hand is needed to stop the knee from bending. Stretch the muscle by holding tight to the heel and pushing the foot with your forearm towards the knee. Count to 25.
- Have a rest.
- Stretch again in the same way, counting to 25.
- Increase the length of the stretch up to 5-10 minutes.



• 3. Moving the joint fully.

Hold the ankle in the same way as you did to stretch it. Move it rhythmically up and down as far as it will go in each direction quite fast, 20 or 30 times. The medical term for moving the ankle up is *dorsiflexion*, and to move it down is *plantarflexion*.

B. Knee and hip.

The knee and the hip are done together as there is a lot of overlap.

Most commonly, knees and hips tend to get contracted in people who are sitting all day either in wheelchairs or ordinary chairs.

What position are the hip and knee in if the person is sitting all day?

They are both bent. They get stiff and then can no longer straighten.

The other contracture that is common in people who are sitting in a chair all day, is for the legs to get stuck close together.

When we stand up what do our knees and hips do?

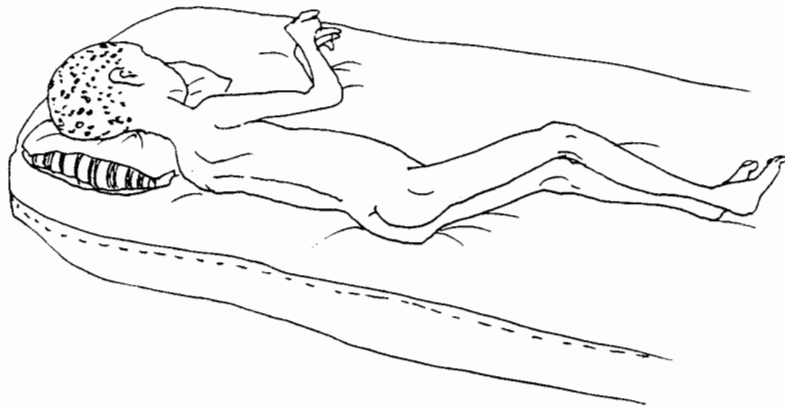
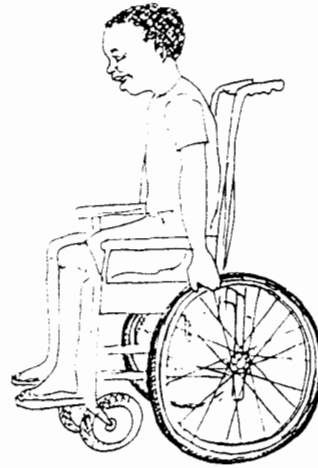
They straighten.

It is impossible to stand up straight if the hips or knees are stuck in a bent position.

Now how does Thandile compare with this?

He is different, his legs are stuck straight.

Yes. A further common contracture in children who have cerebral palsy, like Thandile, is for the leg to be stuck out straight and stiff.



• 1. Correct positioning.

What positions would prevent a person's hips and knees from getting tight?

There are two positions in which the hips and knees get stretched at the same time:

- The person must lie on their stomach with their knees and hips straight and their feet over the edge of the bed.
- The person must stand up each day with the knees and hips straight and their feet flat on the floor.



To prevent the hips from getting stuck close together, the person should always sit in their wheelchair with a cushion between their legs, to keep their legs open.

We have noticed that Thandile's legs stick out straight and stiff.

What position should he be put in to stop his hips and knees from becoming stiff?

His hips and knees must be bent.

Thandile's hips and knees are best stretched while he is sitting up straight, with his legs open, his knees bent over the edge of the bed, and his feet flat on the floor or a box.

• 2. Stretching the stiff muscles.

KNEE.

What stretch can be done to prevent the knee joint from getting stiff?

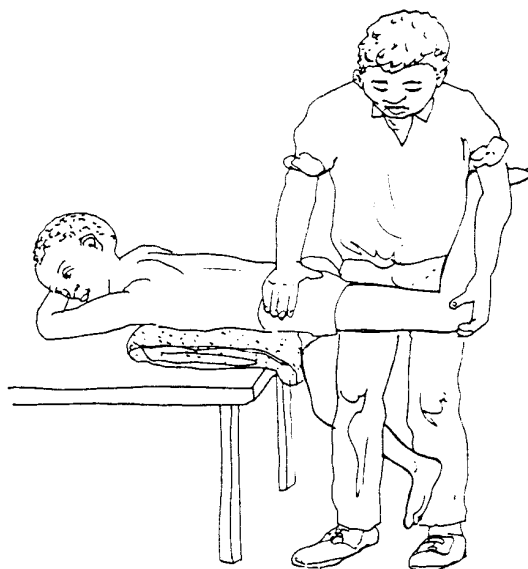
- If the person is able to, he can sit on the floor with his legs out straight in front of him. He can then hold his knees down flat onto the floor. This exercise is more effective if it is done on the floor, rather than on a soft bed.
- If the person is unable to do it himself, someone in the family can do it for him. This can be done while the person lies on their stomach or lies on their back.
- With Thandile it is easiest to bend and stretch his knees when he is lying on his stomach.



HIP.

What stretch can be done to prevent the hips from getting stiff?

- With the person lying on their stomach, someone else takes one leg at a time and pulls it up, keeping the bottom on the floor with the other hand. It is easier to do if the knee is bent.
- With Thandile it is easiest to bend his hips when he is sitting or lying on his back.



3. Moving the joint fully.

KNEE.

The person's knee must be bent and straightened in as large a movement as possible. This can be done with the person lying on their stomach or on their back. The medical term for bending is *flexion*, and for straightening it is *extension*.

HIP.

While the person is lying on their back, the hip can be bent up and straightened, as well as the legs being opened and closed. The other leg must be opened to avoid cheating. The medical term for opening the leg is *abduction*, and for closing the leg it is *adduction*.

If the person's knee and hip are constantly bent the emphasis in these movements would be on straightening the hip and knee. In the case of Thandile, the hip and the knee are constantly straight. The same exercise would be done but the emphasis would be on bending the hip and knee.

4. Contractures in the arms.

How can we avoid contractures of the arm.

Treat the arm just like the leg.

How then would we prevent joints in the arm from getting stiff?

- *Position the joint correctly,*
- *stretch the tight muscles and*
- *move the joint.*

Because Thandile has tight, stiff muscles, regular, repetitive movements of the joint are not as worthwhile as a longer stretch at the point where the muscles start to get tight and stiff.

A. Shoulders.

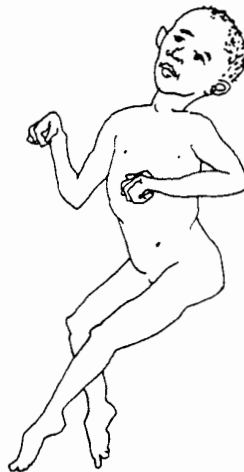
1. Correct positioning.

Look at Thandile's arms. Try and move them. Are they easy to move?

No, they are tight and do not want to move.

What position have they stayed in all the time that we have been here?

His arms have been held tight against his chest with the wrists bent down.



Are Thandile's shoulders in a normal, comfortable looking position?

- *No his shoulders are pulled up high so that his neck is short.*
- *His shoulder blades are pulled back.*
- *His arms are held tight next to his body.*

Sit with your shoulder blades pulled back. Is this a comfortable position?

No, its very tiring and then gets painful.

Imagine how tiring and painful this is for Thandile.

Can Thandile's shoulder easily be lifted up or moved to the side?

No, not at all and it is obviously painful when his shoulder moves as he cries.

The position of Thandile's shoulders must be improved before his arms are moved. The first and most important thing to do with the shoulders is to bring the shoulder blades forward.

If Thandile's arms are moved when the shoulder blades are back, this will damage the shoulder joints so that whenever the shoulders are moved, they will be painful. Pain makes Thandile even stiffer and will make him hold his shoulders even tighter.

What position should we put the shoulder in to prevent it from getting stiff, tight and stuck in this position?

To stop the shoulder from getting stiff, the shoulder blades must be brought forward and the arms turned out by holding them above the elbow. Then the arms can then move forward away from the chest.

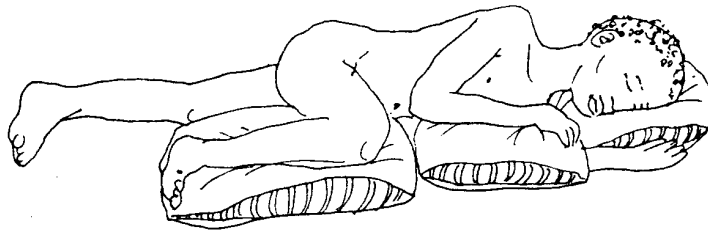
Sitting.

Put a pillow under his arm to keep the arm forwards and away from the body.

Put the arms forward on a table or a box.

Side lying.

Ensure the underneath shoulder is forwards. Move the shoulder that is uppermost forwards. Support it on a pillow to keep it in this position.



• 2. Moving the joint and stretching stiff, tight muscles.

Firstly, to attend to the shoulders pulling up and making the neck short, push the shoulders down to make the neck longer, hold this for the count of 10 and then repeat it.

It is most important to move the shoulder forwards and up. This can be done smoothly and slowly, but the shoulder blade must always be kept forwards. If the child experiences pain, the movement is too fast or too big.

The muscles are tight and stiff in the case of Thandile, so a longer stretch at the point where the muscles start to get tight and stiff is necessary.



B. Elbow.

• 1. Correct positioning.

In what position does Thandile like to hold his elbow?

Bent with the forearm turned in, so that his hands are clasped to his chest.

How can we prevent it from getting stiff?

Try to straighten it.

When the shoulder is positioned so that the arm is away from the chest, the elbow must be straightened and the forearm turned out. This is the case whether the person is sitting with his arms on a box or table or whether he is lying on his side.

• 2. Moving the joint and stretching stiff, tight muscles.

The elbow can be gently bent and straightened. As it is straightened, the forearm must be turned out and as it is bent, turned in.

The elbow is not usually stretched as stretching the elbow can cause the muscles to tear and bone to start forming in the muscle itself. This can be very painful.



C. Wrists and Hands.

• 1. Correct positioning.

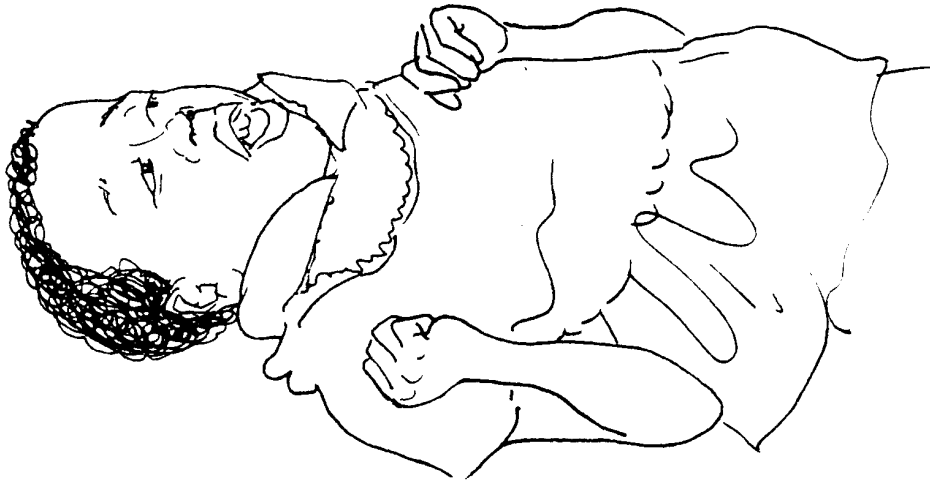
What position are Thandile's hands and wrists in?

- *The wrists are bent down.*
- *The fingers are bent at the hand, but are then straight.*
- *The wrists and fingers are tight and cannot be lifted up.*

Can you see the tight muscles on the forearm? Do they feel tight?

Yes.

These are the muscles that are bending the wrist and the fingers.



In some other children who have tight muscles, the wrist is bent up and the fingers held tightly closed.

How should we position the wrist to prevent it from getting tight?

The wrist must be positioned so that it is straight or bent up and the fingers are held open. The family should spend time stroking the fingers open.

• 2. Moving the joints and stretching stiff, tight muscles.

Regular, repetitive movements are not worthwhile if person has tight, stiff muscles. For tight stiff muscles a longer sustained stretch is more valuable at the point where the muscles start to get tight and stiff. For Thandile the wrist should be bent up with the fingers straight and this position held for a short time.

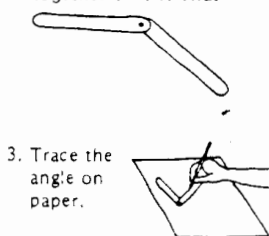
5. Measuring joint positions and contractures.

Each R.W. was given a jointed stick made from two spatulas riveted together at one end.

A. Measuring the knee.

- A R.W. lay on the bed with her knee bent up, as if she could bend it no further. Each R.W. in turn measured how much she could bend the knee:
- 1 arm going down the length of the upper leg.
- The rivet at the joint. (The exact position of the joint was located by moving the joint. The rivet was placed at the point of movement, where the joint is.)
- 1 arm going down the length of the lower leg.

1. Rivet the pieces together on one end.



2. Line them up exactly with the joint.



4. Do this again every 1 or 2 weeks to see if the joint is straightening with exercise.

March	✓
April	✓
May	✓
June	✓

The movement present was recorded by tracing around the sticks onto a piece of paper and then writing down the date.

B. Measuring the elbow.

A R.W. sat on a chair, with her elbow supported on a table so that it was bent. The other R.W. in turn then measured how much she was bending her elbow using the same methods and steps as above.

Why is it important that we make a recording of the movement that is present at a person's joint?

So that we can tell how much the joint is moving.

Do you think it is necessary to measure the joint again?

Yes, so that we know if the movement at that joint is increasing or decreasing.

It is important to put the date next to each measurement.

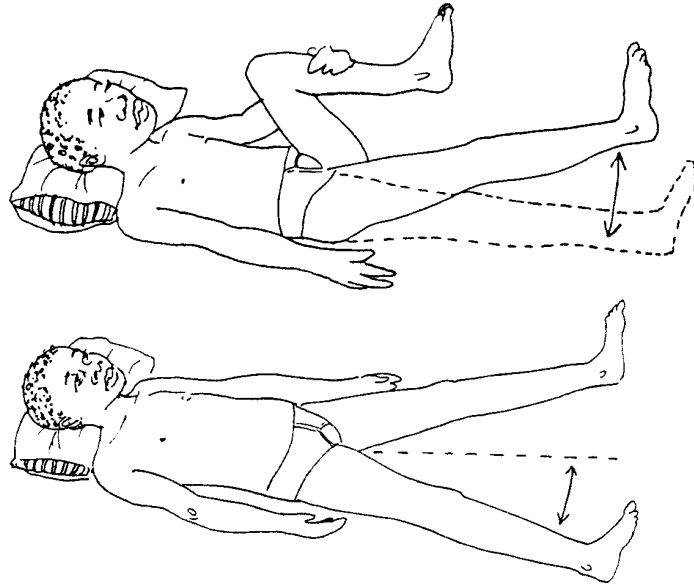
Where should we keep these records of a person's joint range?

With their assessment notes.

C. Cheating!

When testing certain muscles it is necessary to check that the person is not cheating and using other muscles to do the same work. Here are two ways to stop them from cheating.

- To lift the leg up straight, or to bend the hip, the person can cheat by bending their back more. To stop this from happening, the other knee must be bent up and held onto the chest.
- When the person opens the leg out to the side, the other leg must be opened to stop the pelvis from moving.



D. How to tell if a joint's movement is stuck or if it is limited by tightness.

To work out whether the tight joint can be stretched or not, the joint must be moved until it will go no further. At this point try to feel what is stopping the movement:

- *It feels hard at the end of the movement.* If the joint feels that it will move no further because of what feels like a bone blocking the movement, no amount of stretching or exercising will move the joint any further and can only hurt the person or cause further damage to their joint. This joint is stuck and contracted.
- *It feels springy at the end of the movement.* If the joint cannot move any further because of a springy elastic tightness, this is most probably caused by a tight joint capsule and tight muscles. These can be lengthened by stretching exercises, movement and positioning.

We cannot help a joint that is fixed or stuck. No amount of movement, stretching or positioning will improve the situation. But movement, stretching and positioning will stop the joint from getting more stiff.

E. Surgery.

Thinking back to Simphiwe who had polio and Thuleka who had spina bifida, how were their contractures fixed?

They had operations to lengthen their shortened muscles. This is the last resort and is not possible for every person. If a person does have an operation to lengthen their shortened muscles, these muscles tend to get tight again, so they must be positioned, stretched and moved to prevent shortening. If not, the operation is a waste of time.

IV.4. PRESSURE SORES

Aims of this session:

1. To understand the causes of pressure sores.
2. To learn who is likely to get pressure sores.
3. To learn how pressure sores can be avoided and treated.

1. People with pressure sores.

At Conradie we saw some patients with pressure sores.

Why did they have pressure sores?

They had legs and arms that they could not move or feel.

They spend the day either sitting in a wheelchair or lying in bed.

Where were most of these sores?

On the top of the thigh bone or on the tailbone at the base of the spine.

Have you seen pressure sores on people other than the spinal cord injuries that we saw at Conradie hospital?

I have seen an old person who just lay in bed all day, who got pressure sores.

I have seen a child, with brain damage who was very thin and curled up in a ball. His legs were pressed tightly together and he got pressure sores between his knees

How common are pressure sores?

Very, very common.

They can start in hospital, because of inadequate nursing care.

A. The causes of pressure sores.

Why does a pressure sore develop?

If a person lies for a long time in the same position without moving, the skin is pressed against the bed or chair.

The blood vessels are squeezed shut so that the blood cannot bring oxygen to the skin and the flesh which is necessary for it to remain alive.

If the person does not move or roll over for a long time the skin and flesh in that area will die.

First a dark patch will appear, (which is difficult to see if the skin is very dark). If the pressure continues, an open sore will develop.

The skin and flesh are very similar to a garden. If a garden is not watered, it will wither and die.

As we all sit here for a couple of hours, do we all sit dead still?

No, we sit still for a while, but then we start to feel uncomfortable and we shift our weight or move slightly without even realising that we are moving.

If we sit dead still for a long time, blood vessels are forced to close so that some parts of our skin and flesh are not getting blood.

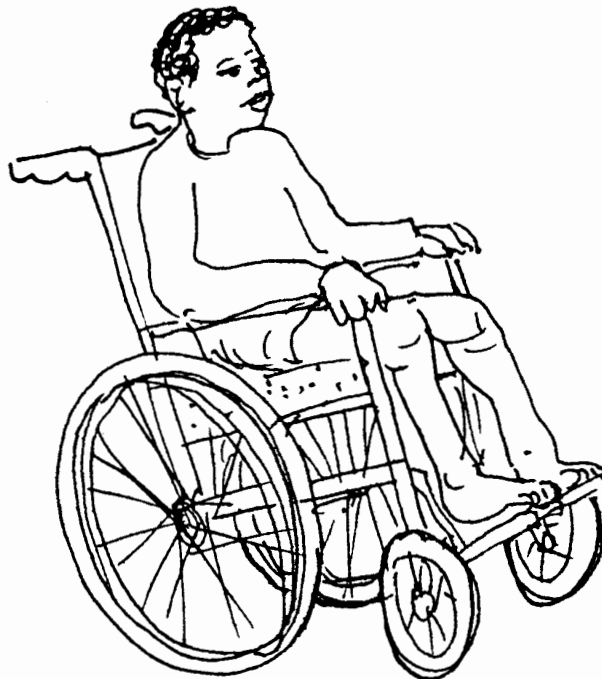
This causes us to feel uncomfortable. Just by moving the pressure is taken off the blood vessels so the blood can flow in them again and reach the skin and flesh that was not getting blood.

Would it be normal for one of us to get a pressure sore?

No, not at all, because we can feel when we are uncomfortable and move.

Are people with spinal cord injuries able to feel uncomfortable when they have been sitting in one position for too long and then change their position?

No, they cannot feel, so they do not feel uncomfortable. They are also unable to move and change their position.



B. Where are pressure sores most likely to develop?

How do most people lie at night?

On their backs or on their sides.

Let's all try lying down on our sides.

Where do you feel the most pressure between your body and the bed?

At the top of the thigh bone, where the bone is very close to the surface of the skin. It is possible to feel this on most people, unless they are very fat.

Let's try lying on our backs now.

Where do you feel the most pressure between your body and the bed?

At the very bottom of the spine over the tailbones, where they are close to the surface. It is also here at the tailbones that a lot of pressure is taken during sitting. It is here where the bones are closest to the skin, that pressure sores are likely to develop.

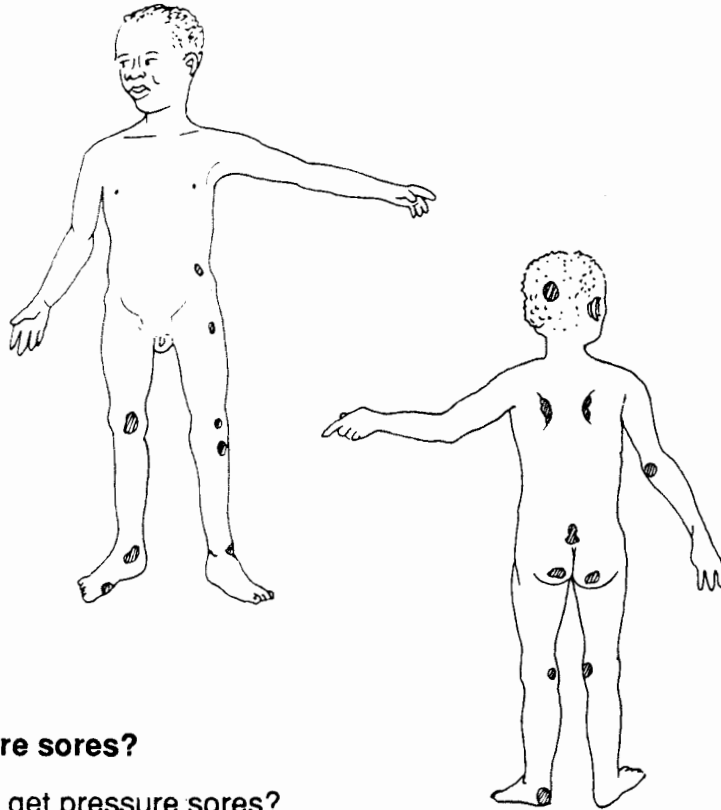
Someone mentioned that they had also seen a child with pressure sores between his knees. Can pressure sores develop in other areas?

They can develop over any bony area.

Another common area is at the ankle bones or the feet.

Practical.

Each R.W. was given 2 rough sketches of a front view and a back view of a person. They marked on both these views, the places where the bone is close to the surface where pressure sores are likely to develop. Most R.W.s felt on their own bodies to help them achieve this task.



C. Who is likely to get pressure sores?

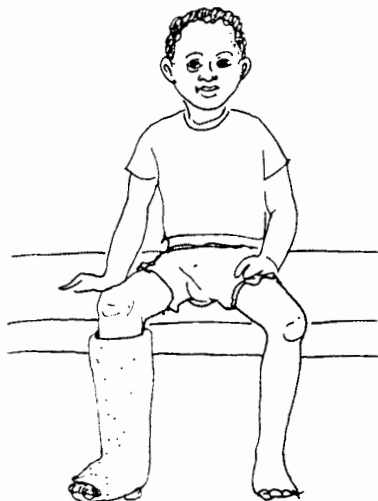
Which people are most likely to get pressure sores?

People who cannot move and people who cannot feel all the different parts of their body.

Let's make a list of these people.

- *Older people*, who may be reluctant to move and spend a lot of time sitting or in bed.
- *Ill, weak or disabled people* who cannot move themselves. This would include people who are disabled by polio, a stroke, brain damage or a severe motor car accident.
- *Spinal cord injuries* who are unable to feel and move parts of their body.
- *A person with a broken arm or leg* who has a plaster cast, may develop a pressure sore where the plaster presses on a bony point.

At first this will be very painful and the person will complain, but then the spot will go numb and the person will stop complaining, even though a pressure sore may be developing.



2. The prevention and treatment of pressure sores.

A. The seriousness of pressure sores.

Do you think pressure sores are dangerous?

No, they go away quickly.

Unfortunately, while many people think this, they do not go away, and are in fact very serious.

They tend to develop in people who are not well or strong enough to get better easily or quickly.

In spinal cord injury patients pressure sores are one of the major causes of death and can take 6 months to heal.

Pressure sores contain dead tissue so they can easily become infected. If a sore reaches the bone, the bone can become infected, and this is very difficult to heal. The person may have to spend months in bed in a hospital, which is very boring and expensive.



B. The prevention of pressure sores.

Pressure sores can cause death and are difficult to heal.

They must be prevented.

Who has to take major responsibility in preventing pressure sores?

The sick or injured person and their family.

Why do you think a pressure sore is called a pressure sore?

It is a sore caused by pressure.

How do you think they can most easily be prevented?

By removing the pressure.

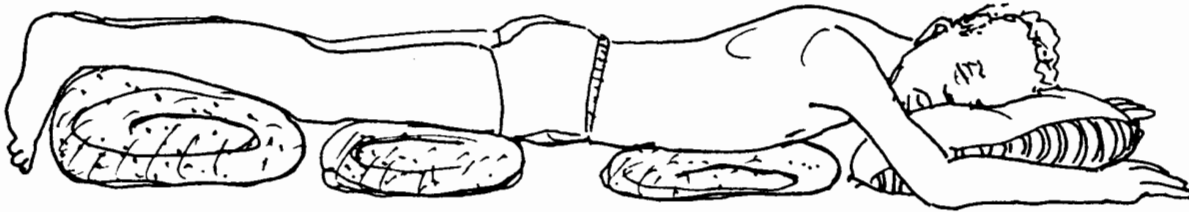
How is this done?

The person must be moved regularly.

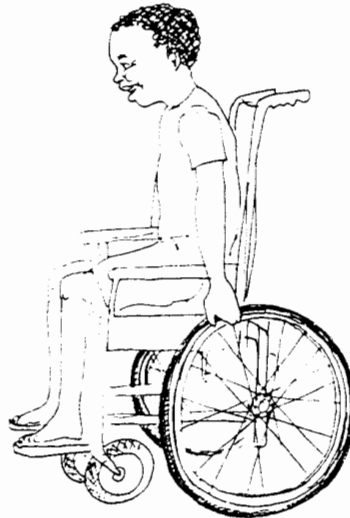
While a person is lying in one position, the skin is being pressed between the bones and the bed or chair. The blood vessels are squeezed shut so that they cannot carry oxygen to the skin and flesh. By moving, the pressure is taken off and the blood vessels open and blood can flow in them again.

To prevent pressure sores:

- Avoid staying in the same position for very long.
 - * Lying - turn every 2 hours, and once in the middle of the night.



- * Sitting - lift up the body every 10 or 15 minutes.



- Which areas of the body are most susceptible to pressure sores?
Where bone is closest to the surface of the skin.
Therefore, use thick padding and soft pillows to protect the bony areas of the body. The mattress must be thick enough, so that the bony parts do not rest on the bed itself.
- What happens to your fingers if you spend an hour washing?
The skin becomes wrinkled and soft and can easily tear.

- Therefore, use soft, clean, dry bed sheets. Change the bedding each time it gets wet. (A person who stays wet gets pressure sores, especially if it is from urine.) Avoid wrinkles in the sheets.
- Bathe the person daily. Dry the skin by patting it and not by rubbing it.
- Examine the whole body each day, especially checking the areas likely to get pressure sores. The person should do this themselves.
- Good nutrition is important for the pressure sores to heal. The person must not get fat, but should get fruit, vegetables and protein if there is enough money.
- A wheelchair cushion must always be in the wheelchair.
- One of the most effective ways to prevent pressure sores is to get the person to lie or sit on a clean sheep's skin.

C. Treatment of pressure sores.

A person with a pressure sore should be referred to hospital, if they remain at home the basis of the treatment is:

- Keep the pressure off completely and continuously:
 - * with a ring of padding, if the sore is just developing.
 - * through positioning the person correctly.
- Keep the area completely clean. Wash with boiled water twice a day.
- Eat well and drink lots of liquid.
- Do not rub the area, as this may break the skin and flesh.
- The person must not get out of bed.

IV.5. URINE AND BOWEL MANAGEMENT

Aims of this session:

1. To learn how a person can avoid getting urine infections.
2. To understand how a person will feel and what you will notice if they have a urine infection.
3. To understand how you would avoid constipation in a person who has a spinal cord injury.

1. Lack of control with the bladder and bowel.

A. Damaged nerves.

In the community you will sometimes come across people who have lost control of their urine and their bowels.

During this course we have mentioned in a couple of our sessions that some people can lose control of their bladders and bowels.

Which conditions can lead people to lose control of their urine and bowels?

Those with spinal cord injuries and children with spina bifida.

Why do these people not have control of their urine and their bowels?

The nerves are cut, or no longer working, so that the person does not feel that they need to urinate or have a bowel action and are not aware when they have done so.

If a person has no control of their urine they will have a pipe which drains urine from the bladder into a bag at their side.

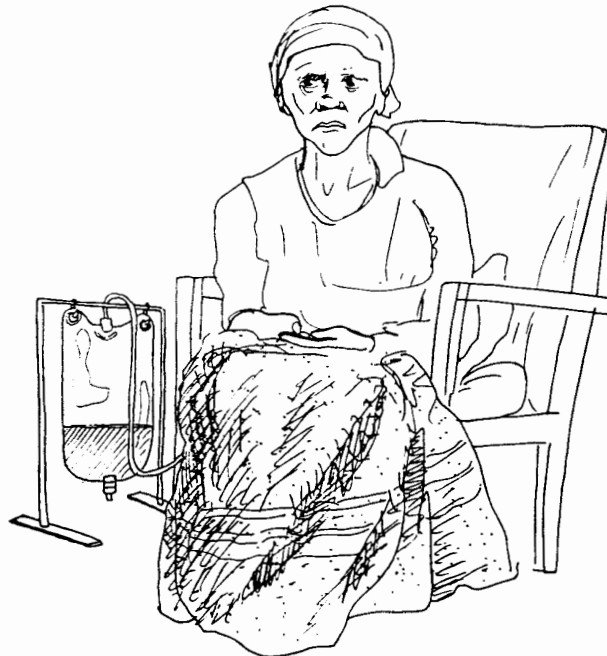
Have any of you ever seen anybody in the community with a pipe draining their urine into a bag?

Yes, I've seen an old woman with a stroke who had one.

Could she walk?

No.

Some times old people who have a stroke or who are unable to walk easily have a pipe put in so that the wee drains into a bag and the old woman does not get and stay wet.



So it is not only people who have had spinal cord injuries or those who have spina bifida who may have these problems.

Here is Siyabulela whom we met earlier. He was stabbed in the neck and now is unable to move or feel from the waist down.

Siyabulela, can you feel when you want to urinate or have a bowel action?

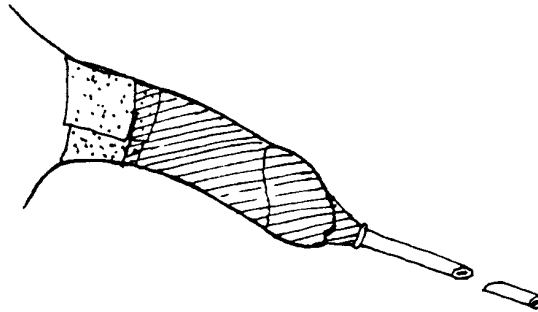
No, not at all.

B. The risk of infection.

Look at the catheter that Siyabulela has. It is like a condom that is attached over his penis and then the urine runs into a pipe which drains into a bag.

He is very lucky that he doesn't have a pipe that goes into his body. Some men and all women will have to have pipes that go into their bladders.

As soon as anything has to be put into the body there is a risk of infection. In fact even with a pipe like Siyabulela's, there is a risk of infection.



The bladder is like a bag which stores the urine.

What part of the body makes the urine?

The kidneys.

Urine infections are dangerous as they can travel up into the kidneys and damages the kidneys. Kidney damage is very serious and can kill a person.

With people who have pipes in their bladders the most important thing is to avoid infections.

2. Caring for people who have lost control of their bladder or bowel.

A. A person who has no bladder control, or is using a catheter.

The following are important things to be aware of:

- The person must drink two litres of water a day.
- The pipe must never be blocked as this will cause the urine to flow back into the bladder and if the bladder is full, to flow back into the kidneys.
- Empty the bag regularly so that the urine will not flow backwards into the kidneys.
- If the pipe or the bag leak, they must be changed at once.
- Everything must be kept clean, especially when changing the pipe.

- Anybody who has a pipe in their bladder and complains of feeling unwell, check the bag to ensure that they have not got an infection. Check the urine is the right colour and doesn't have solid bits floating around in it.
- Stand up daily to drain the bladder completely.

If a person has an infection of their urine, they must be seen by a doctor immediately.

When you have an infection of your urine what do you notice?

- *My urine is very strong and often smells.*
- *I usually feel burning as it comes out.*
- *I have pain in my back and at my sides.*
- *I seem to have to wee often.*

A person with a pipe in the bladder who has an infection may feel these things as well:

- aching body
- a fever
- increased spasms in their legs
- sweating or goosebumps

B. No bowel control.

If you are constipated how do you get your stomach to work?

I eat wholewheat bread so that I do not get constipated.

Roughage - fruit, vegetables and wholewheat bread can stop us all from getting constipated.

If that doesn't work what do you do?

I take pills to make my stomach work.

Constipation in people who have spinal cord injuries or who have spina bifida is a big problem as their bowels are unable to move or work. It is important to get them to have a bowel action regularly every second day.

It avoids a lot of embarrassment if the person can do so first thing in the morning while they are still in bed, so that they can be easily cleaned up and their clothes are not dirtied.

Ways to keep the bowels working:

- Eat a lot of roughage.
- Get the bowel to work every second day:
 - * take laxatives at night
 - * get the person to lie on their left side in the morning
 - put in a suppository, sometimes they can do this themselves.
 - give them something hot to drink
 - put plastic and old paper under the person and wait for the person to have a bowel action.

IV.6. CHEST INFECTIONS

Aim of this session:

1. To learn how to clear the secretions out of the chest of child and an adult.

Teaching aids:

1. Two milk bottles with water and green food colouring.

1. Treating chest infections.

A. Learning to clear the lungs.

Are your children often sick in the cold weather?

Yes, especially now because its winter. But it's my handicapped child who is sick more often than the others.

What is usually wrong with him?

He first gets a cold and then it goes into his chest. He cannot cough well, so I can hear the phlegm gurgling in his chest as he breathes in and out.

If you get a chest infection and have phlegm sitting in your chests, how do you get rid of it?

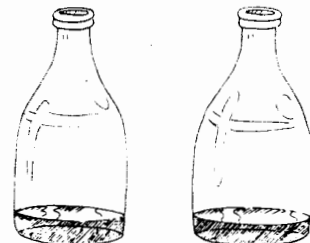
I cough. The phlegm is then coughed up and then I feel better.

Where do you think this phlegm comes from?

It comes from the chest.

When a person gets a chest infection, phlegm is produced and accumulates in the air sacs at the bottom of the chest.

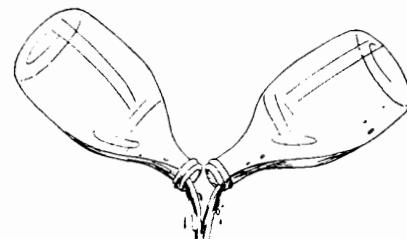
Look at these two milk bottles that I am holding in front of my lungs. These symbolize my two lungs. Each one has a small bit of green coloured liquid at the bottom, to illustrate a bad chest infection.



What is the easiest way to get this liquid out of these bottles?

Turn them upside down.

Yes. So if you see a person with a bad chest infection, turn her on her side, with her head lower than the bottom of their lungs. This is the easiest position from which the phlegm can drain out of the lung on the top.

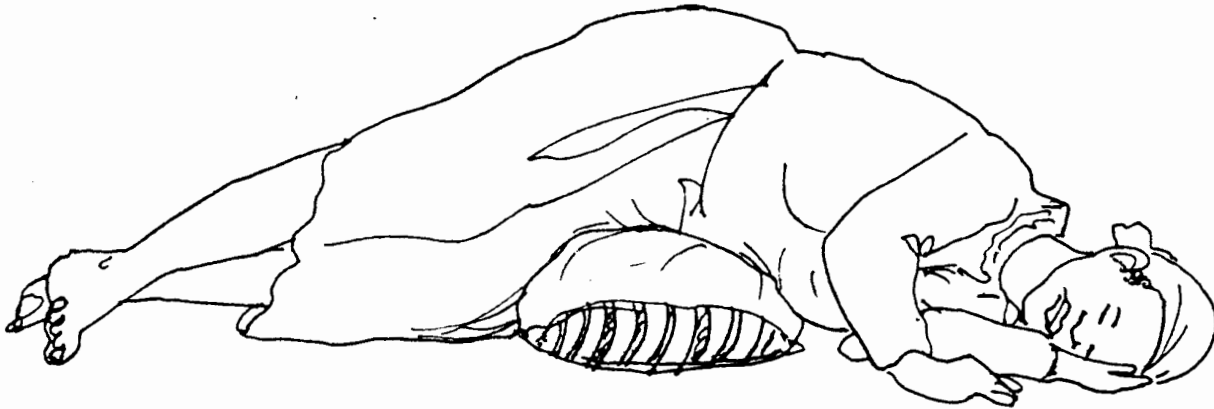


To drain the other lung what position must the person lie in?

She must lie on her other side with her head lower than her chest.

If I had something thick like mayonnaise in this bottle, how could I get it out more quickly?

With the bottle turned upside down, hit the bottom of the bottle again and again.



If someone has a chest infection and the phlegm is thick and sticky and doesn't come out that easily, we can clap them regularly on the side of their chest and this helps the phlegm to come out more easily.

If you clap the chest with your hand cupped, then it is not painful. It is also more comfortable if the person keeps on a jersey or vest.

To recap: what is the way you get rid of phlegm in your chest?

By coughing.

Yes. So it is very important to encourage people who have chest infections to cough.



Helping a person to clear their chest.

- * Lie the person on one side, with their head lower than their chest.
- * Clap the upper half of the chest with a cupped hand.
- * Sit the person up and get them to cough.
- * Lie the person on the other side, with their head lower than their chest.
- * Clap the side of the chest that is now uppermost with a cupped hand.
- * Sit the person up and get them to cough.

B. Adults and children.

When you do this with children, you can lie them over your knee.

Adults, however, will have to be positioned with cushions.

C. Practical session.

Each R.W. then practised this positioning, clapping, and getting adults and children to cough.

IV.7. FEEDING CHILDREN WITH CEREBRAL PALSY

Aims of this session:

1. To learn the correct position in which a spastic child should be sat for breastfeeding, feeding and drinking.
2. To learn how to hold a child so as to control their head, jaw and swallowing.
3. To learn how to feed and give drink to a brain damaged child, to provide the child with a chance to develop control over her feeding, drinking and swallowing.
4. To learn how best to feed a floppy and athetoid child.

Note:

This session deals predominately with the feeding of spastic quadriplegic (tight) children because this is the most common problem. The final section deals with feeding children with hypotonic or athetoid cerebral palsy.

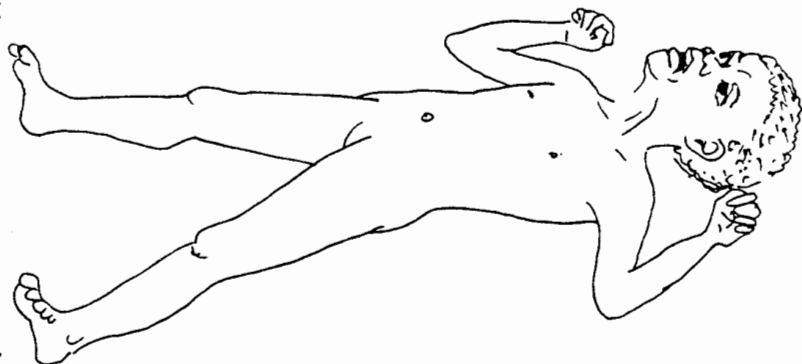
1. Feeding tight children.

A. Difficulty with eating.

The position of the whole body of a brain damaged child who is tight or spastic is abnormal.

If they lie on their backs what do you see?

- * *the head is pushed back*
- * *the shoulders are pulled back*
- * *the hips are pushed forwards*
- * *the knees turn in*
- * *the feet point downwards.*



It is not just the arms, legs and trunk that are in an abnormal position, the whole body is affected. The mouth, lips and jaws are not normal and do not move normally.

The three biggest problems that spastic children have in feeding are:

- The body is in a poor position.
- The jaw is tight.
- The tongue pushes the food forward.

B. Problems with swallowing.

Spastic children find it difficult to swallow.

Try to swallow sitting in the position that a spastic child sits in, with the head tilted back.

Is it possible to swallow in this position?

No, it is impossible to swallow with your head back like this.

Push your jaw forwards and try to swallow like this. Is it easy?

No, not at all. Your jaw has to be back so that your teeth are one on top of the other before you can swallow.

Spastic children either have their jaws clamped closed, biting the bottom lip with the top teeth, or wide open. Try to swallow with your mouth wide open, or biting your bottom lip with your top set of teeth. Is it easy?

No, not at all, it is difficult. Your lips have to be together and closed to swallow.

The tip of the tongue is down behind the teeth in spastic children.

Is it easy to swallow with the tip of the tongue behind the teeth?

No, not at all.

Make your tongue hard, as the tongue of a spastic child is. Is it that easy to swallow with a hard tongue?

No, not at all.

To summarize, swallowing in a spastic child is difficult for the following reasons:

- *The head position* - the head pushing back.
- *The position of the jaw and lips* - they are not closed, the bottom lip tends to be bitten in by the top set of teeth or the mouth is wide open.
- *The position of the tongue* - The tip of the tongue is down behind the teeth.
- *The hardness of the tongue* - The tongue cannot roll the food back, from the front to the back of the mouth. The food gets jammed against the roof of the mouth.
- *The movement of the tongue* - The tongue pushes food forward, and cannot turn the food from side to side.

To swallow we need:

- * the head to be in a good position.
- * the jaw must be back.
- * the lips must be closed together.
- * the tongue must be able to move the food from side to side in the mouth.

C. Problems with breast feeding.

Nowitness, was it easy for you to breast feed Nkosinathi, your handicapped child?

No, not at all. Firstly I struggled to hold him to my breast as he would push back with his head and his body, and his arms and legs would get stiff. He also didn't suck and swallow easily.



When you feed your child, the position he is in can make it more difficult to feed him.

If a child with cerebral palsy lies on his back, what happens?

He pushes back.

If he pushes back, he will get tighter. Sucking and swallowing will be more difficult. It is more likely that he will choke.

Did you ever try to push Nkosinathi's head forward?

Yes, I used to try to push it towards my breast. It didn't help though, as then and even now if I push his head forward, he just pushes back his head even more.

To breast feed a child with cerebral palsy the head must be forward so that he can swallow more easily. The baby must be half sitting and not lying, with the hips bent. Keep the shoulders forward by pushing firmly on the chest.

Did you stop breast feeding Nkosinathi?

Yes, I did. I didn't think of expressing milk to give to him as we talked about in the session on breast feeding. Even if I had, I don't know how long I would have kept it up for, as it takes a long time and is so messy.

How did you give him milk?

In a bottle.

Could he suck the bottle and swallow the milk easily?

No, not at all. I had to cut a bigger hole in the teat, lie him down and then pour the milk into his mouth.

Did this work well?

No, not really. He often used to choke and he is still not able to suck.

With Nkosinathi's head pushing back it is very difficult for him to swallow, just as it is difficult for us to swallow with our heads back. He should be positioned with the head slightly forward. By pushing gently on the chest, bring the shoulders forwards and keep the hips and knees bent. This will encourage him not to push back, so that he can swallow better.

If the teat has a small hole in it how must the child get milk?

He must suck.

If the teat has a big hole, does he need to suck?

No, the milk just pours out.

By cutting the teat to make the hole bigger, Nowitness can now just pour the milk into Nkosinathi's mouth. Nowitness said though that the problem with this is that he chokes. Nkosinathi has no control over the milk that is pouring into his mouth, he chokes often and will not learn to suck properly.



2. Preparing the child to feed.

A. Helping the child develop jaw control.

If we give the child a chance to learn how to control his mouth, particularly his jaw, then sucking and swallowing, spoon feeding and drinking from a cup will be improved.

To learn how to teach a child jaw control we practised on each other, working in pairs.

- One person sat in a chair, the other stood at her side facing her. (At 90 degrees to the person in the chair.)
- The person who was standing put her arm around the head of the person in the chair, being careful not to push on the back of the head.

- Her hand then clasped the jaw of the person sitting in the chair.
- The index finger was then put on the bone of the jaw:
 - * pushing the jaw backwards (not down)
 - * pushing the bottom lip up, as this is necessary for swallowing.
- The third finger is put under tongue, to help the tongue move.
- The other fingers are lifted away from the child's face.



B. Preparing the child's mouth.

This is to make the child's mouth less sensitive so that reaction to a finger, spoon or food in the mouth is minimized.

The child is held in a good position so as to reduce the spasticity.

- Using her right index finger, the person holding the child, moves the finger in a semicircle on the top gum, from the middle to the left. This is done firmly and not too fast. It is done 3 times. Then the lips are closed and the child is encouraged to swallow by the 3rd finger of the left hand moving from forwards to backwards.
- In exactly the same way the finger is moved along the right side of the top gum and on each side of the lower gum. In each case it is done 3 times and then the child is encouraged to swallow.
- A spatula is put into the mouth of the child and the tongue gently pushed down for the count of 3. This is done 3 times.



While the person in the chair swallowed, the person standing controlled the swallowing with their index and third finger.

3. Helping the child to eat and drink.

A. Spoon feeding a brain damaged child.

We watched Nowitness feeding Nkosinathi with a spoon.

Nowitness held Nkosinathi with his head tilted back, his body pushing back, his legs tight and straight and his arms tight and bent.

She used a big spoon to feed him and spooned the food as quickly as possible into his mouth.

She puts the food into the very front of Nkosinathi's mouth and scraped it off against his top teeth.

He seemed to push the food out of his mouth with his tongue.

Every now and then his jaw clamped closed and he bit the spoon.

She kept wiping his face and mouth clean with the big spoon.



Nowitness, is feeding your child an easy process?

No, not at all.

Do you think Nkosinathi enjoys being fed?

No, he seems to be frightened of being fed and as Nowitness brings the spoon closer to him, he withdraws and pushes back to get away from it.

Does the food go in easily?

No, as she puts the food in his mouth, he pushes it out with his tongue.

He often vomits up the food that he has just been fed.

It also makes him cough so that he vomits up some of the food.

Sometimes he bites on the spoon which must be a very uncomfortable feeling.

Is it only Nowitness who feeds her handicapped child like this?

No, nearly all the mothers at this centre whose children have a problem with feeding, feed their children like this.

Is Nkosinathi in a good position to eat and swallow?

No, he is lying down, pushing back and is very tight.

How can we improve this?

- Sit him up properly so that he isn't half lying down. Do this by bending him at the hips first.
- Turn his arms and legs and put them in more natural positions so that his arms are no longer bent and his legs no longer straight and sticking out.
- His head must be held so that it cannot push back, using the method that we had learnt earlier, with one arm round his head controlling his jaw.



What did you notice as Nowitness brought the spoon towards him?

He seemed terrified of being fed, he withdrew and pushed back.

Why do you think he is terrified of being fed?

- * *Being fed isn't a pleasant experience for him.*
- * *Often it makes him cough and vomit.*
- * *He is also not in control of what is happening at all.*
- * *Food is spooned into his mouth when his mother thinks he is ready and not when he feels ready for it.*

When feeding a child with brain damage, giving the food from above the child's head often causes the head to press back and the body to stiffen. This makes swallowing difficult.

Giving food from the front helps to minimize the tightness and makes swallowing easier.

Having improved Nkosinathi's position, we then did the exercises to make his mouth less sensitive. Then holding his jaw in the position so that he could learn jaw control, we fed him, using a teaspoon.

Why do mothers use big spoons?

More food can be put in the child's mouth, so it is quicker.

A big spoon should never be used, only a teaspoon may be used.

Only a small amount of food must be put on the teaspoon. The teaspoon must be put right in the mouth and pressed down on the tongue.

By doing this the tongue will be encouraged to stop pushing forwards and the child will be able to use his lips better.

A metal teaspoon must be used, not a plastic one that can break.

The food must not be scraped off on the top teeth. The child's jaw and swallowing will have to be controlled as before.

Ensure that the mouth is closed as you take the spoon out.

B. Finger feeding.

Children who have severe feeding problems and

- do not swallow well
- clamp their teeth onto the teaspoon
- push the food out with their tongue,

may need to be fed with a finger until they have some control over their feeding and swallowing.

Their jaw must be controlled with your other hand.

- only small amounts of food put into his mouth
- the finger put right into the mouth and then moved to the side where it was removed against the cheek.

Less food must be put into the mouth. This is less frightening for the child and he does not feel out of control.

The food was put far back into his mouth, this makes it more difficult for him to push the food out with his tongue, and is easier for him to swallow.

By putting the food in the side of the mouth, the tongue and cheeks were encouraged to work.



When Nkosinathi clamped his teeth closed, they didn't clamp closed on a metal spoon but on a finger. This is sore (of course) but is not as painful or frightening for Nkosinathi as a metal spoon.

It is much easier for the child if the mother uses her finger, although this might be slower.

The food we used was stiff pronutro (otherwise it didn't stay on a finger).

C. Drinking.

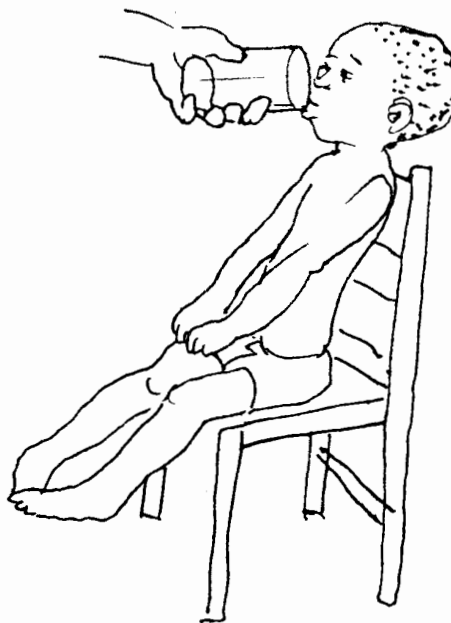
Nowitness, could you show us how you give Nkosinathi something to drink?

Nkosinathi's head tilts back, his body pushes back, his legs are tight and straight and his arms tight and bent.

Nowitness then forces the cup between his teeth and tilts it up.

Nowitness, can you see how much liquid you are giving Nkosinathi at each mouthful?

No, the cup is in the way, but I know when to stop tilting the cup up, when the water runs down the sides of his mouth.



Is it easy to try to swallow with a cup between your teeth.

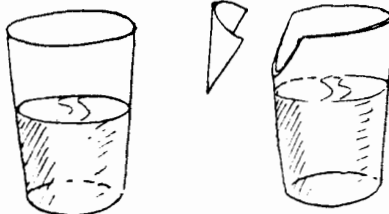
No. Your teeth and lips need to be closed to swallow.

To teach the mother to help the child to drink some ultramel, we first corrected the position of the child as we have already described.

We then did the following:

We cut a semicircle out of the plastic mug on the opposite side from which Nkosinathi was going to drink so as to enable the mother to see how much ultra-mel she was giving Nkosinathi at each mouthful and to prevent him from tilting his head back to get the liquid.

A little ultra-mel was put in the cup and mixed with water, but it was still fairly thick.



- The cup was then put on top of Nkosinathi's bottom lip. It was not put between his teeth. The cup was tilted up until the ultra-mel was just touching Nkosinathi's lips.

- He then started to make sucking movements with his lips and then swallowed.
- His mother helped him swallow using her third finger under his jaw, pressing up against the tongue and moving from forwards to backwards.

This was then repeated.

All the R.W.s then had a chance to practise:-

- a) Preparing the children's mouths for feeding.
- b) Feeding.
- c) Drinking.

4. Children with athetoid or hypotonic cerebral palsy.

In the session so far we have focussed on tight children, those with spastic quadriplegia. Children who are floppy (hypotonic) and those with strange uncontrollable movements (athetoid) also have eating problems.

When dealing with either of these two groups of children, the most important thing to ensure is that they are sitting up with their head in a good position, so that swallowing is made easier.

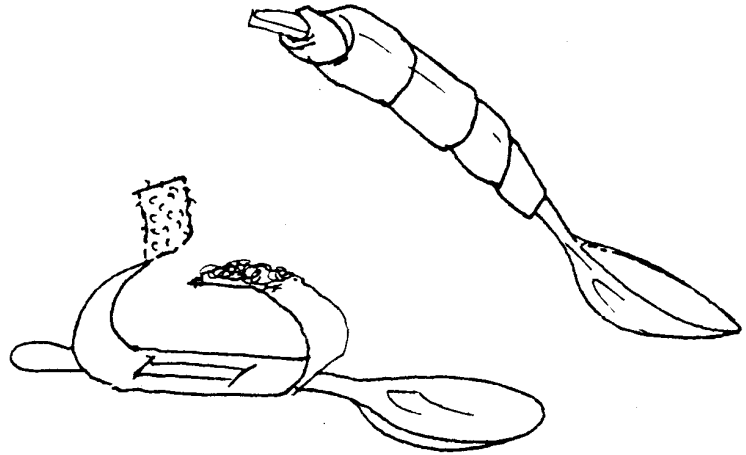
These children will often have to be secured in a good position with their

- shoulders strapped back against the chair.
- hips strapped back so that the hips are at 90 degrees.
- feet on the ground, a foot strap may be needed to keep them here.
- hands and arms supported on a table in front of them.



The child should be encouraged to feed himself:

- spoon handles can be adjusted for gripping using a velcro strap or increasing the size of the handle



- a cup with 2 handles will encourage the child to drink with both hands



- he should keep his elbows on the table for extra support.



IV.8. TOY MAKING WORKSHOP

Aims of this session:

1. To learn how toys can be made from bits and pieces that are often thrown away.
2. To gain an understanding of the principles of normal development as they relate to play.

Teaching aids:

Different items to make different toys. These are listed under the respective toy.

1. The principles of normal development.

We have already done a session on normal development in which we talked about stimulating children. What were some of the points that relate to playing?

- A child must be in a normal, good position before she can play.
- Children take time to respond and learn. Handicapped children take even longer to respond and to learn.
- Children learn to do things by doing them again and again and again. A child needs time to repeat things.
- Children are easily distracted, therefore play with one toy only at a time.
- Children can learn about life through play. Play can be used to help them learn to do daily activities.
- Children first learn to do big movements and then learn to do smaller more precise movements with their hands and fingers.

2. Different toys that can be made.

A. Rattles.

Materials used: Plastic bottles, pebbles, paint.

Method: Paint the different bottles.

When these are dry fill them with pebbles, so that the pebbles cover the bottom of the bottle.

Put the lid on. The bottle sounds like a rattle if it is shaken.

How could this help a child?

- A rattle can be used to attract a child's attention. When it is shaken a child will turn her eyes and head to look at it. We can use a rattle to work for head control in a child.
- A smaller bottle put inside a child's hand which is very tight, can keep her hand open and give her the chance to have something in the palm of her hand.
- If a child can shake the rattle it could help her develop hand control.



If we take the lid off and empty out the pebbles, the child will have a chance to develop finger control as she picks the pebbles up and puts them back into the bottle.

B. A different kind of rattle.

Materials used: Bottle tops, wire and masking tape.

Method: A hole was made in each bottle top, using a hammer and nail.

A circle of wire was made.

The bottle tops were threaded onto the wire circle.

The circle was closed with masking tape.

This sounds like a rattle when it is shaken.



How could this help a child?

- A rattle can be used to attract a child's attention. When it is shaken a child will turn her eyes and head to look at it. We can use a rattle to work for head control in a child.
- This rattle can be put in the tight hand of a handicapped child. She will then have the chance to have and feel something in the palm of her hand.
- If a child can shake the rattle it could help her develop hand and wrist control.

C. Mobiles.

Materials used: Wire coat hanger, string, toilet rolls, wool, colourful pieces of material, koki pens, glue.

Method: Decorate toilet rolls to look like people, using the wool for hair, the pieces of material for clothes and the koki pens to draw faces.

Hang 3 or 4 pieces of string from the wire hanger.

Attach the toilet rolls to the pieces of string.



Hook the hanger from a hook so that it hangs where the baby can see it.

Many different things can be used to make a mobile, pieces of wood, egg shells, yoghurt cups.

How could this help a child?

- Hang it up so that the child has to lift up his head to look at it. It is then being used to help the child develop head control.

D. Play-dough.

Materials used: Flour, water, salt, food colouring and oil.

Method: Mix in a bowl: 1 cup flour, 1 teaspoon salt, 1/2 cup of water, 1 tsp food colouring.

Work these together using your hands until you have a well mixed ball of dough.

Pour a small amount of oil onto your hands and work this into the dough.

Keep adding oil bit by bit until the dough has no crack in it.

This will need to be kept cool or in the fridge.

How can this be used to help a child?

- In playing with this dough a child will have a chance to move and develop co-ordination of her fingers.
- She will also have a chance to be creative and make different things, animals, beads or anything else with the dough.
- If children with tight hands and fingers can have their fingers opened a bit, dough can be put inside their hands so that they get a chance to feel it.

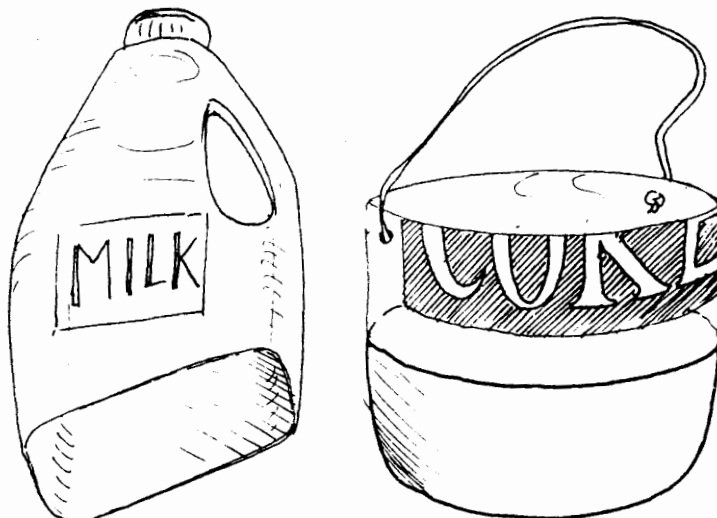
E. Bucket and spade.

Materials used: Empty plastic 2 litre coke bottle, empty plastic 2 litre milk bottle, scissors, a thick needle and a piece of string.

Method:

To make a spade to dig in the sand, cut the milk bottle at an angle.

To make a bucket, cut the coke bottle in half. Make 2 holes with the thick needle on opposite sides to attach a loop of string as the handle.



How will this help children?

- It will encourage a child to play in the sand, encouraging them to become aware of different shapes and filling a container.
- Co-ordination will also be encouraged as they have to fill the bucket with sand from the spade.

F. Water toys.

Materials used: Empty plastic 2 litre coke bottle, empty plastic 2 litre milk bottle, scissors, a thick needle.

Method:

Cut the coke bottle in half.

Pierce holes in what was the bottom of the bottle, with the needle, so that when a child fills it up, water spouts out of each hole.

The other half of the bottle which has the lid on can have the lid taken off and be used as a funnel.

How can this help children?

- By playing with water and these toys they will become aware of filling and emptying containers.

G. Balls.

Materials used: Foam chips, old stockings, string.

Method:

Put a knot in the bottom of a stocking.

Fill the stocking up with foam chips.

Pack down the foam chips until the stocking is ball shaped.

Tie a knot in the stocking, and then fold the stocking back on itself, to make it more firm.

Tie the stocking closed with a piece of string and then cut it off.

How can this help children?

- They will learn eye hand co-ordination by catching and throwing the ball.

IV.9. WELFARE ASSISTANCE

Aims of this session:

1. To know the different grants that exist, who can apply for them, where they should go and what information they need to have with them.
2. To be aware of the various institutions that help handicapped people.

1. Application for identity book and grants.

A. Identity book.

It is essential that a person have an identity book (I.D. book) if they want to apply for a welfare grant.

To apply for an I.D. book, the person concerned must go to the local administration (Regional Service Council) office. They need to have:

- 2 passport size photographs of themselves
- their birth certificate
- R2.00
- proof of residence in Cape Town for 5 years.

They will initially be given a temporary document, and will receive their I.D. book later (up to a year).

B. Grants.

To apply for a grant the person needs to go to a social worker to help them to apply for a grant.

This may be done in the hospital, but there are also social workers at the day hospitals, Cape Mental Health, the Association for the Physically Disabled and the Advice Offices.

Grants are supposed to take 2 months, but they usually take much, much longer.

Grants are given out monthly at the Regional Services Council offices. The amounts given are guidelines and individual circumstances affect amounts.

Pensions and grants vary in amount depending on race. Pensions and grants for Blacks are less than those for so-called Indians and Coloureds, which in turn are less than those for Whites.

2. The various welfare grants.

A. Old age pension.

This is for old people who are no longer able to go to work and earn money.

- To apply for a pension, the person must have an I.D. book.
- Women over 60 can apply for pension.
- Men over 65 can apply for a pension.
- A Black pensioner gets R150 a month.

B. Disability grant.

This grant is for people who are so severely handicapped that they are unable to work.

- The person must have an I.D. book.
- The person must be more than 16 years old.
- The handicapped person must have a medical report from the doctor, explaining that the handicap is a long term problem preventing the person from working and earning a salary. The handicapped person has to be seen by the district surgeon.

Disability grants may be reassessed in case the person improves and can go to work again, eg. people with epilepsy.

A disability grant is R150 each month for Black people.

C. Single care grant.

This grant is for mothers of handicapped children who are unable to go out to work, as they have to stay at home to look after the child.

- The child must be between 3 and 16 years old.
- The mother must have an I.D. book and a medical report about the condition of the child, in which the child is certified in terms of the Mental Health Act to the care of a parent or guardian.

A single care grant is R117 each month for Black people.

D. Maintenance grant.

This grant is for families in which

- children are under 18 and at school
- the mother is single/widowed/divorced
- the mother not supported for 6 months
- a parent is in prison/institution
- a parent receives a social pension
- there are at least two children of the same father and a maximum of 4 children

Author

Marian Loveday
Physiotherapist



This training manual grew out of my work as the only physiotherapist working in a community of about 300,000 people. Given the overwhelming needs in this community, I determined my task to be passing on basic rehabilitation skills to people of the community. We defined the community we were working with as the community of disabled people, which included disabled adults and the mothers of disabled children. In each area in which we planned to work, a meeting was held with this community of disabled people. They chose from amongst themselves a person who would receive training and then work as a rehabilitation worker in that area. During my last years of work with the project, I completed a Masters degree in Maternal and Child Health, and for my thesis I completed a quantitative and qualitative evaluation of the rehabilitation project. I left the project in 1994 after ten years, and the work continued for a further ten years until the whole organization was forced to close due to a lack of donor funding.

In 1994, following political freedom in South Africa, my husband and I and our two small children moved to the Kalahari Desert near Botswana, where we lived in a rural area for 6 years. We lived at the Moffat Mission in Kuruman where my husband was the Director. Moffat Mission was David Livingstone's first home in Africa. There, I was employed by the newly established Northern Cape Department of Health as the District Health Manager of the Kalahari District. In this position, I was responsible for all the public health services within a defined geographical area which had three hospitals, fifteen primary health-care clinics, and seven mobile clinics.

Although we loved the Kalahari, our eldest daughter was diagnosed as having juvenile diabetes, and so for health and educational reasons, we left and moved to KwaZulu-Natal, another province in South Africa. During this time, I have been employed by Health Systems Trust, a non-governmental organisation, which strives to improve health services for all South Africans. Initially, I worked in a remote rural area supporting the local district health managers to implement an effective Primary Health Care system. More recently I have moved into health systems and operational research focusing on TB and the interface between TB and HIV.

In the years since 1994, I have continued to draw on the wonderful memories of that time working with disabled children and their mothers, as well as the lessons that were learnt in providing good health for all the people of South Africa.

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