



GETTING TO KNOW CEREBRAL PALSY

A learning resource for facilitators, parents, caregivers,
and persons with cerebral palsy



Module 3 Positioning Your Child

Cerebral Palsy Association (Eastern Cape)

The Cerebral Palsy Association (Eastern Cape) was established in Port Elizabeth, in 1955. The primary mission of the Association is to encourage, assist and care for all persons affected by cerebral palsy, and assist them to attain their maximum potential and independently integrate into the community. The Association is a registered Non-Profit Organisation, and is affiliated to the National Association for Persons with Cerebral Palsy in South Africa.

The Association presently operates from its own premises in Port Elizabeth. It has a permanent staff of three part-time and five full-time employees, ably assisted by a network of volunteers. The Association is directed by an Executive Management Committee of 12 members, who are elected bi-annually and serve on a voluntary basis.

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About Hambisela

Parents and caregivers are in the front-line of caring for individuals affected by cerebral palsy and assisting with their treatment. Historically, individuals in rural and under-developed areas had no or limited access to skills and training to assist them with skills development. This very often compromised the level of primary care and therapy that individuals affected by cerebral palsy could obtain in these areas.

To address this problem and improve the level of daily care available to individuals affected by cerebral palsy, especially in rural and under-developed areas, the Cerebral Palsy Association (Eastern Cape) identified a need to transfer skills to parents and caregivers through the following measures:

- Develop training programmes in basic skills for parents and primary caregivers of individuals affected by cerebral palsy;
- Present these training courses to parents and primary caregivers;
- Facilitate specialized therapy training for nurses and sisters from community clinics;
- Develop the pool of specialized therapy skills in the Eastern Cape, especially in rural areas;
- Offer supplementary therapy to individuals from schools in the Eastern Cape, to supplement the reduction in therapy support from schools.

In 2005 the Cerebral Palsy Association initiated the Hambisela project as Center of Excellence in Therapy for Cerebral Palsy, to develop and promote excellence in therapy for cerebral palsy through community-based programmes.

Hambisela is based at the Association's premises in Port Elizabeth. Hambisela has developed a series of 7 training modules in the "Getting to know Cerebral Palsy" series, each comprising a Facilitator Manual, an Activity Pack, course display material, and a Trainee Handout. Hambisela is using this series as a primary resource to develop the skills of parents and caregivers of children with cerebral palsy in the community.

Getting to know Cerebral Palsy: List of Modules:

Module 1: Introduction

Module 2: Evaluating Your child

Module 3: Positioning Your child

Module 4: Communication

Module 5: Everyday Activities

Module 6: Feeding Your child

Module 7: Play

MODULE 3

POSITIONING YOUR CHILD

PLANNED OUTCOMES

When you have finished this workshop, you should be more confident to position your child with cerebral palsy, and be able to show others in your family or community better ways to position your child, or other children, with cerebral palsy.

Positioning Your Child

Picking up and carrying and washing and feeding a child with cerebral palsy can be very difficult for you, the carer. Everyday activities can become major events.

Look at the following pictures:

Question: *Can you point out some of the difficulties you have with handling and positioning your child in any of these pictures?*







How you handle and position your child influences what she can do and how she develops.

Good handling and positioning

Question: *Why do you think good positioning is important for a child with cerebral palsy and her caregiver?*



GOOD HANDLING AND POSITIONING:

- **helps to make eating, drinking, playing and communicating easier for your child**
- **makes it easier for you to care for your child**
- **is the basis for all activities that you do with your child**
- **helps to prevent disabling positions**
- **is worth learning more about, with a therapist if possible**
- **should be used with your child all the time**

Poor handling and positioning

Question: *What problems and difficulties do you think might happen with poor handling and positioning?*



POOR HANDLING AND POSITIONING:

- **will hinder your child from developing;**
- **will make it more difficult for you to pick up, carry and handle your child every day;**
- **can cause problems such as:**
 - **Pressure areas** – Due to pressure from the outside on to a body part, blood is prevented from flowing easily through the muscles of that part and then sores develop. These begin with dark red or purple areas. Sores like these don't tend to get better quickly as the blood flow is not good.
 - **Contractures** – If a limb stays in one position for a long time, the muscles get shorter and the joint becomes stiff – this is called a contracture.
 - **Deformities** – Even if you care for your child really well – keep her clean and dry and free from pressure areas, feed her well, etc – the pull of the muscles when the child spends long hours in any one position, can cause the child to become deformed. Her back can become crooked and twisted, and her hips can move out of place or dislocate.

And as children with disabilities gain access to wheelchairs, they very often spend long hours poorly positioned in the wheelchair, and still unable to move themselves. And they still develop a crooked back and other disabling deformities, including eventually breathing difficulties due to the chest space being so crooked and confined.

You can see this in some of the pictures on pages 5-7.

That's the bad news bit.

Now let's look at positioning your child, and what you can do to improve her position.

HOW TO POSITION YOUR CHILD

- 1. Learn helpful ways to move your child**
 - **if she is stiff you need to loosen her first**
 - **you can't force her into a position, and expect her to stay there**
 - **ask a therapist how to do this.**

- 2. Try to get your child into the best position that you can.**
 - **aim for 'ideal positions' or 'normal alignment'**
 - **she may not be comfortable in a new position at first. Persevere, and ask advice from a therapist if she continues to be uncomfortable.**

- 3. Change her position often, about every 30 minutes**
 - **or better still, encourage her or help her to change it**
 - **remember, if you leave a child in one position for many hours, her body may gradually stiffen into that position**
 - **she needs to be in a variety of helpful positions**

In the next section we will be looking at specific positions, both those that are „poor“ positions, and suggestions for „helpful“ positions. For each position, we will use this checklist (see diagram below) to help us decide in an ordered way whether the child is in a poor or helpful position.

CHECKLIST

Head and body

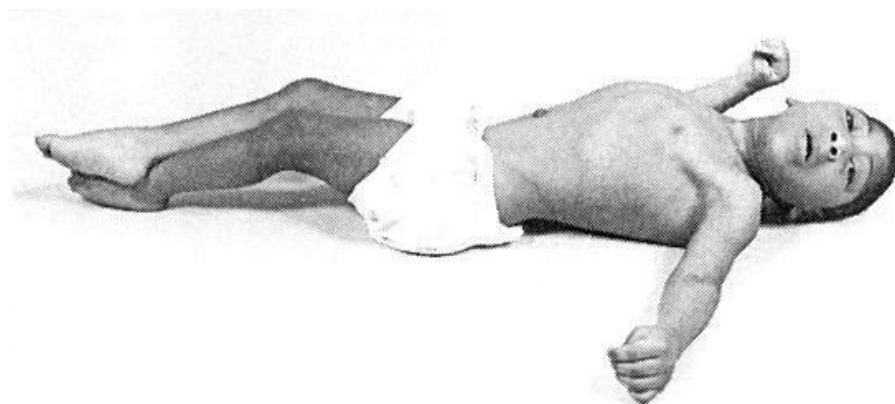
Legs and feet

Shoulders and arms

LYING

Supine (on her back)

Poor position

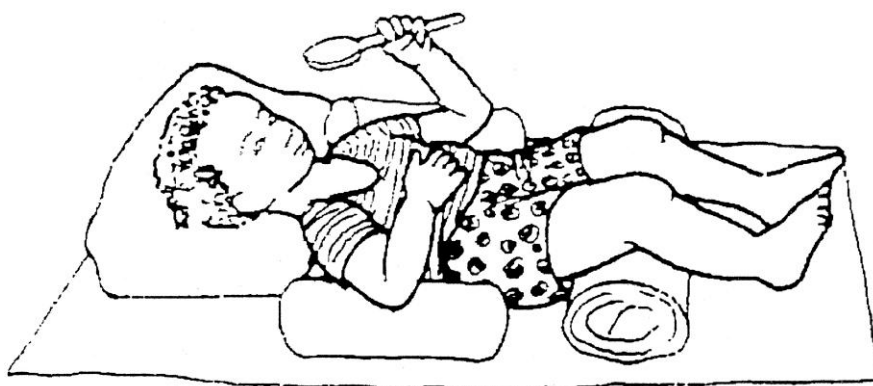


This is a poor position because:

- Head pushing back and turned to one side
- Hips turning in causing legs to cross (scissor)
- Feet are pointing down, which means she can't get them flat if she is sitting.
- Hands and arms away from body
- Hands fisted and closed

Helpful positions

This is a helpful position because:



SUPINE CHECKLIST

Head and body

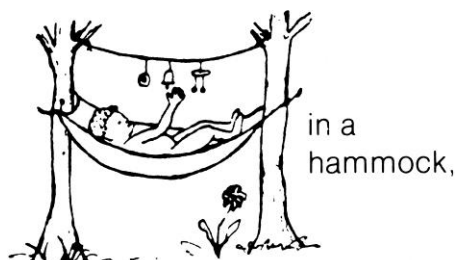
- If she can move her head on her own, make sure it is comfortable
- If she cannot move her head on her own, make sure it is in the middle and comfortable
- Her body (spine) must be straight – support on her sides if needed with a rolled up towel to keep her straight

Legs and feet

- Bend her hips – this helps to release tension in her lower back which is often arched, and it helps to relax stiffness in her legs. Place support under her knees to keep hips bent (not under her feet)
- Keep her legs open and uncrossed – use a pillow between if needed
- Feet should be as close to a standing position as possible – if her feet push down, talk to a therapist about the need for an ankle/foot orthosis

Shoulders and arms

- They should be forward and supported, especially if her arms pull back. This position also helps to relax her upper back, and allows her hands to open more easily.

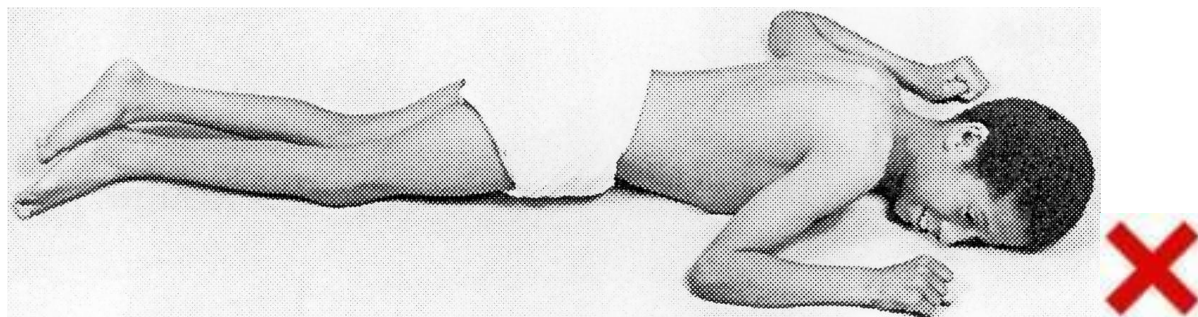


- Lying in a hammock can help to relax tight muscles.
- Babies/small children can „hang“ in a large towel (held by two adults) to relax tight muscles.



Prone (on her tummy)

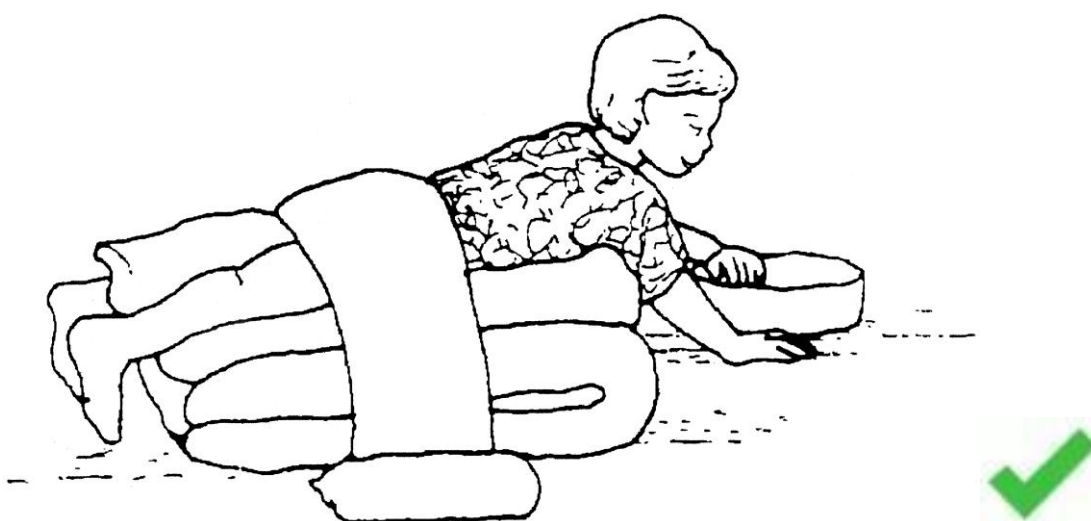
Poor position



This is a poor position because:

- Body is not even, because her head is turned to breathe
- There is no muscle work
- She can't see anything
- Legs may be crossed
- Hands are in a fist
- She can't do anything

Helpful positions



PRONE CHECKLIST

Head and body

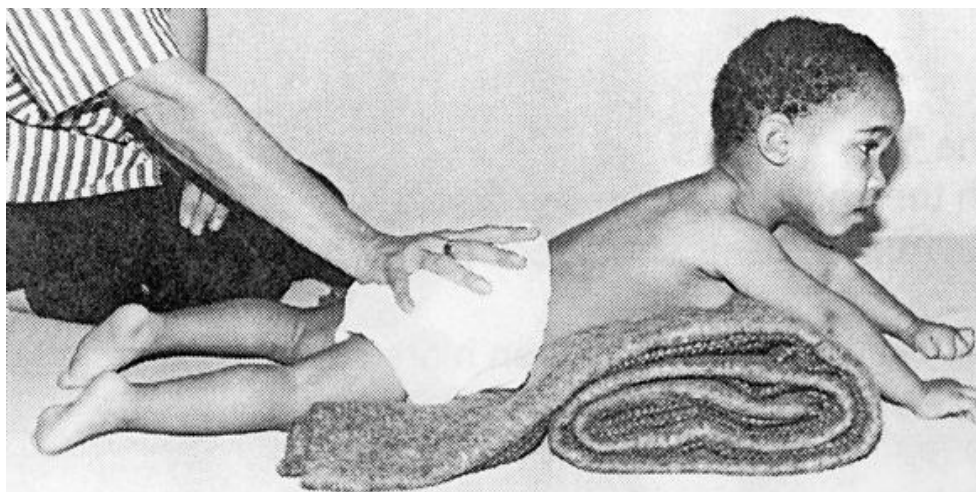
- In a straight line
- Encourage her to lift her head and look at something in front of her on the floor. This is a good time to get a sibling, also lying on the floor, to play with her

Legs and feet

- Straight – push down on her bottom from side to side in a rocking motion to help her straighten her hips
- You can put weighted bags over her hips

Shoulders and arms

- Her arms should be in line with or slightly in front of her shoulders (make sure the pillow or towel she is lying on comes all the way up to her armpits to help keep her arms forward)
- If possible, encourage her to open her hands and push down on them (you may need to gently open them out for her; if too stiff to stay open, keep helping her each time you use this position)



MOST IMPORTANT about this position is that it is not for all children!

Be careful when using this position for children who are always pushing back strongly with their heads. It is possible that it will reinforce the pushing back of the head, while the child is not actually learning to use her arms or control her head.

Side lying

Helpful position

SIDELYING CHECKLIST

Head and body

- Head supported on a pillow so her chin is level (in the middle, with her head and spine in a straight line)
- Give good support at her back, from the top of her head to her feet

Legs and feet

- Keep her bottom leg straight
- Support her top leg bent at her knee with pillows or blankets so her knee is level with her hip – this is important to help prevent injury to her hip (dislocation)
- Bending one leg and keeping the other straight helps to relax the stiffness in her legs

Shoulders and arms

- Her lower shoulder and arm must be brought forward so they are not trapped underneath her
- Keep both arms forward to bring her hands together – encourage her to use her hands by playing a game with her, or putting a toy nearby for her to touch and reach for.



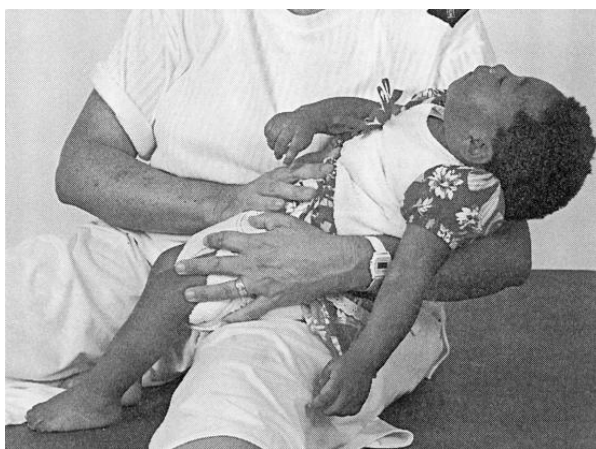
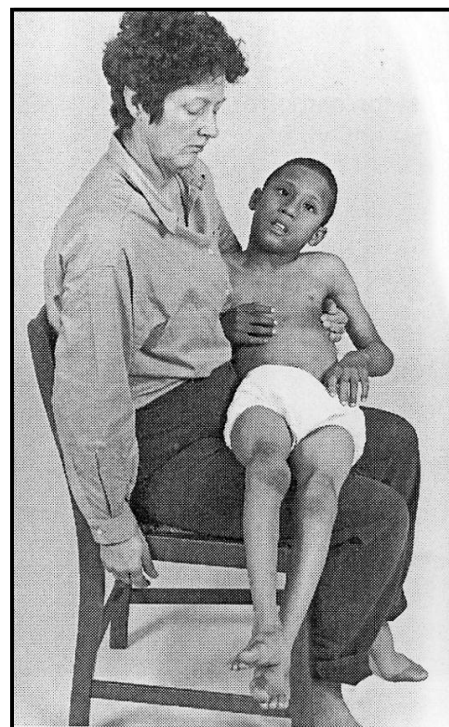
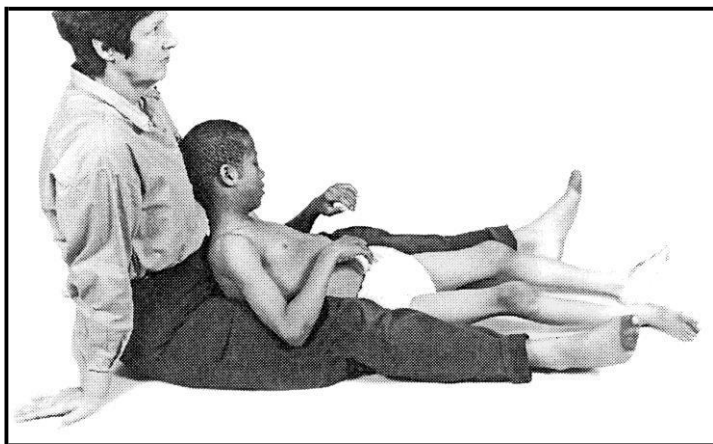
During the day this position should be changed from one side to the other, or to another position, every half an hour.

This is also a good position for a child to sleep in.



Sitting with a caregiver

Poor positions



These are poor positions because:

- Her head is hanging backwards, or to one side, or just leaning against the caregiver
- She is just lying, and not sitting on her bottom
- Her hips are not bent, and wrong muscles are working
- Her hands are not free to do anything
- Her arms aren't helping her to sit
- She is not able to do anything with her hands

Helpful positions

SITTING WITH A CAREGIVER CHECKLIST

Head and body

- If she cannot hold her head upright, make sure she is sitting up straight with the head and her back supported.
- If she can hold her head upright, use your hands to support her chest and/or hips just enough to help her stay up straight and control her head.
- She should be working her muscles to move her body and keep it upright

Legs and feet

- Bend her hips to at least a right angle – this will help keep her back in a good position and help stop her from pushing backwards and sliding off your lap. If possible, have her feet supported.

Shoulders and arms

- Her shoulders should be slightly forward so that her arms and hands are in front of her body, and she can explore objects and her own body.



It is also important for your child's development to be given an opportunity to practice using the muscles she needs to balance in sitting. Play a game with her, or help her explore her own body, toys, or other objects. This shows a more active way of playing with your child in a good position.



Sitting on a chair or buggy or on a couch

Poor positions



This is a poor position because:

- Her head is pushing back, and she tends to slide herself out of the chair
- Hips are too straight and stiff
- Shoulders are not supported, and are either pulling back, or pushed too far forward
- She leans sideways and is not stable
- Leg problems can develop from twisting of leg bones



Helpful positions

SITTING ON A CHAIR OR BUGGY OR ON A COUCH CHECKLIST

Head and body

- She sits upright with her back straight and her head upright
- Her buttocks are all the way to the back
- If she has a lap strap, make sure it is tightened firmly enough to stop her from sliding down in the chair

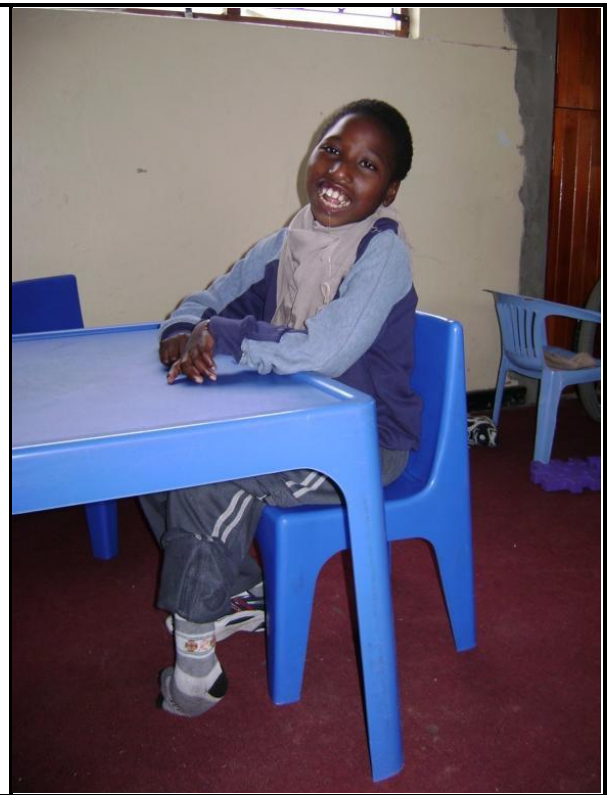
Legs and feet

- These must be supported

Shoulders and arms

- These should be supported slightly forward and in front of her body.





Sitting on the floor

Poor positions

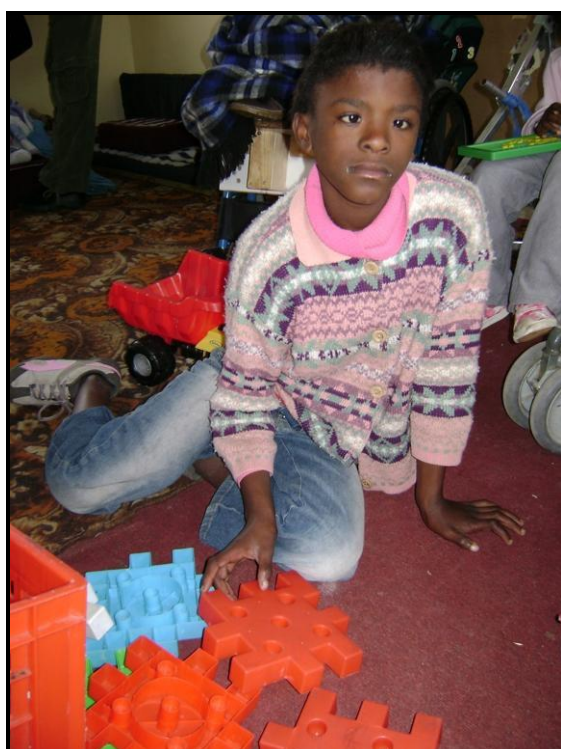
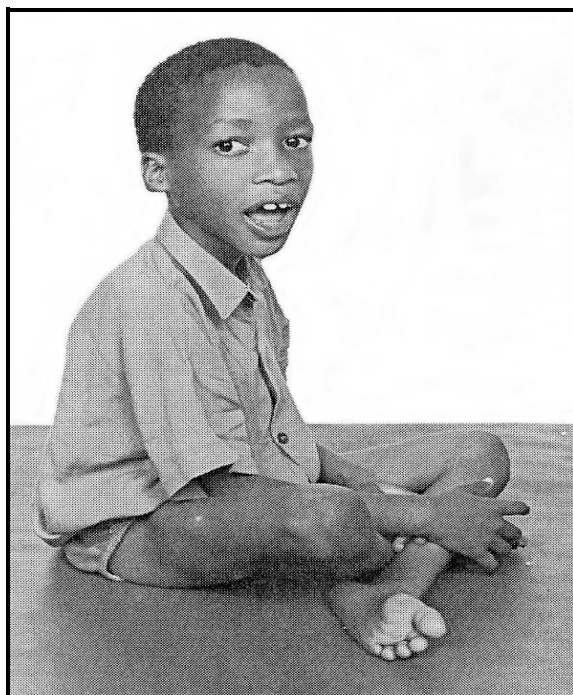


- This position can hurt the knees and hips and hips of the child.
- She does not need much control to sit like this, so she does not need to learn to or practice balancing her upper body over her pelvis.
- She does not learn to develop a good sitting balance if she is always in this position. She may therefore never learn to sit with good balance in any other sitting position.



Therapists generally don't like your child to sit in this position. However, if it is the only way that allows your child to be independent in sitting, then it should probably be allowed. But do not let her sit in this position all the time.

Helpful positions



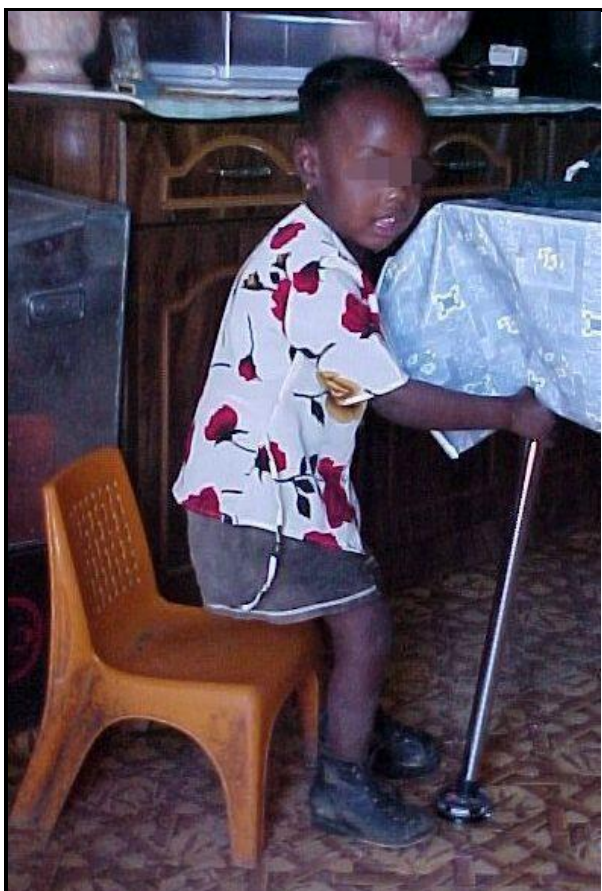
- She can sit independently with legs crossed
- She should sometimes sit with legs straight, not always bent (beware of contractures)
- Sitting with her back in a corner helps to keep shoulders forward and head level
- Her hands are more free to do something
- What about sitting on her side? First one side, and then the other.



Always ask yourself – is there another position that my child could be sitting in, which is a more helpful position, but also gives her as much function and independence as possible?

STANDING

Poor position



- She has stiff leg muscles (one or both legs), so she can't stand on flat feet with her knees and hips straight
- Her balance isn't good enough to „let go“ to do something with one or both hands
- She has to hold on for support
- All she can do is stand there, with her hips and knees bent



Functional position



- Her balance is not difficult in this position
- Her hips and knees are in a good position, helping to keep her feet flat
- Her shoulders and arms are forwards
- She no longer needs to hold on for support
- Her hands are now free to do something
- Look at her smile!



STANDING FRAME CHECKLIST

Head and body

- Her back is straight – if her body leans to the left or right, put a rolled up towel on either side of her in the frame to keep her body straight
- Her hips are facing the front – adjust gently if necessary
- Her shirt is covering her tummy so that her skin is not touching the Velcro in front

Legs and feet

- Her feet are firmly on the ground (including her heels), her toes are facing forward, and her feet are not falling in or out
- If you can easily move her feet, she is not putting enough weight on them. Loosen the frame, and let her fall more onto her feet before easing her into standing again and closing the frame. Recheck her hips and feet
- If the child's feet are in a very poor position, she should only stand once she has been assessed for, and is using, orthotics

Shoulders and arms

- Her arms should come forward onto the tray, which should be at about nipple height.
- It is good if she pushes on her arms, or uses them to touch a toy or object she likes on her tray.

Standing is very important for all children above the age of 1 year (this is when children without disabilities will usually start to stand). This includes those children who do not even try to or cannot stand by themselves at all.

WHY STANDING IS IMPORTANT:

- **For the development of normal stable hips. If a child never stands her hips do not develop well and are weak and can easily dislocate as she gets older, causing pain and other problems.**
- **For the development of strong bones. A child who never stands, has weaker, less dense bones that can more easily break.**
- **For stretching the muscles of the legs, to prevent contractures and deformities.**
- **It is good for breathing and blood circulation.**
- **It assists the emptying of the bladder and bowels.**
- **Weight bearing can help to reduce stiffness and uncontrolled movements in the legs.**

Remember rather use a more helpful position than a poor position, even if you're not doing anything with her.

REMEMBER

- **It's not really possible to be doing something with your child all the time. So you need to leave her in one position or the other at various times.**
- **Instead of leaving her in a poor position, guide her into as helpful a position as you can. You need to try different positions with your child, and see what helps, or what works for her.**
- **If you have access to equipment like buggies and positioners, then use them. Ask your hospital to get the most helpful items for your child.**
- **If you have access to therapists at your clinic or hospital, discuss how best your child can benefit from a combination of positioning and specific therapy, some of which you as caregiver can do.**

Sources and References

Ideas from many sources have helped us to develop the Hambisela programme. The following material and references have been particularly helpful, either as sources or as inspiration on how to present training, and we gratefully acknowledge their use.

In many cases we have been given permission to use photographs. Where permission could not be obtained, the faces have been re-touched in order to protect identity.

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Acknowledgements

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