



GETTING TO KNOW CEREBRAL PALSY

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



Module 6 Feeding 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.

Funders

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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 6

FEEDING YOUR CHILD

PLANNED OUTCOMES

When you have finished this workshop:

- **You should understand some of the difficulties that a child with cerebral palsy may experience during feeding, and be able to explain these to a family/community member.**
- **If your child is not independent in eating then you should be able to work out how to make feeding her easier and more enjoyable for both of you.**
- **If your child has some independence in eating then you should be able to teach her to eat more independently.**
- **You should know when to ask for help with feeding your child, if needed.**
- **You should understand the link between chewing and speech development.**

Feeding Your Child

Feeding is one of the first abilities that a child usually develops to meet her needs.

But many children with cerebral palsy have feeding difficulties, which can sometimes be severe.

Let's look at what the feeding difficulties of a child with cerebral palsy might be.

List of feeding difficulties:

- Difficulty controlling her head:
 - Her head is floppy and she struggles to keep it upright
 - Her head is stiff and pushes backwards

- Difficulty controlling her body
 - She cannot sit by herself and struggles to keep her body upright
 - It is difficult to hold her body upright when feeding her as she pushes back or struggles to keep her body still

- Difficulty controlling her mouth/lips/tongue
 - She struggles to close her mouth
 - She struggles to chew her food
 - She struggles to swallow / takes a long time before swallowing her food
 - She chokes / coughs a lot when eating
 - She pushes the food out of her mouth again with her tongue
 - She struggles to eat what other children her age are eating and only eats soft food

- Difficulty eating on her own
 - She struggles to hold things and bring them to her mouth

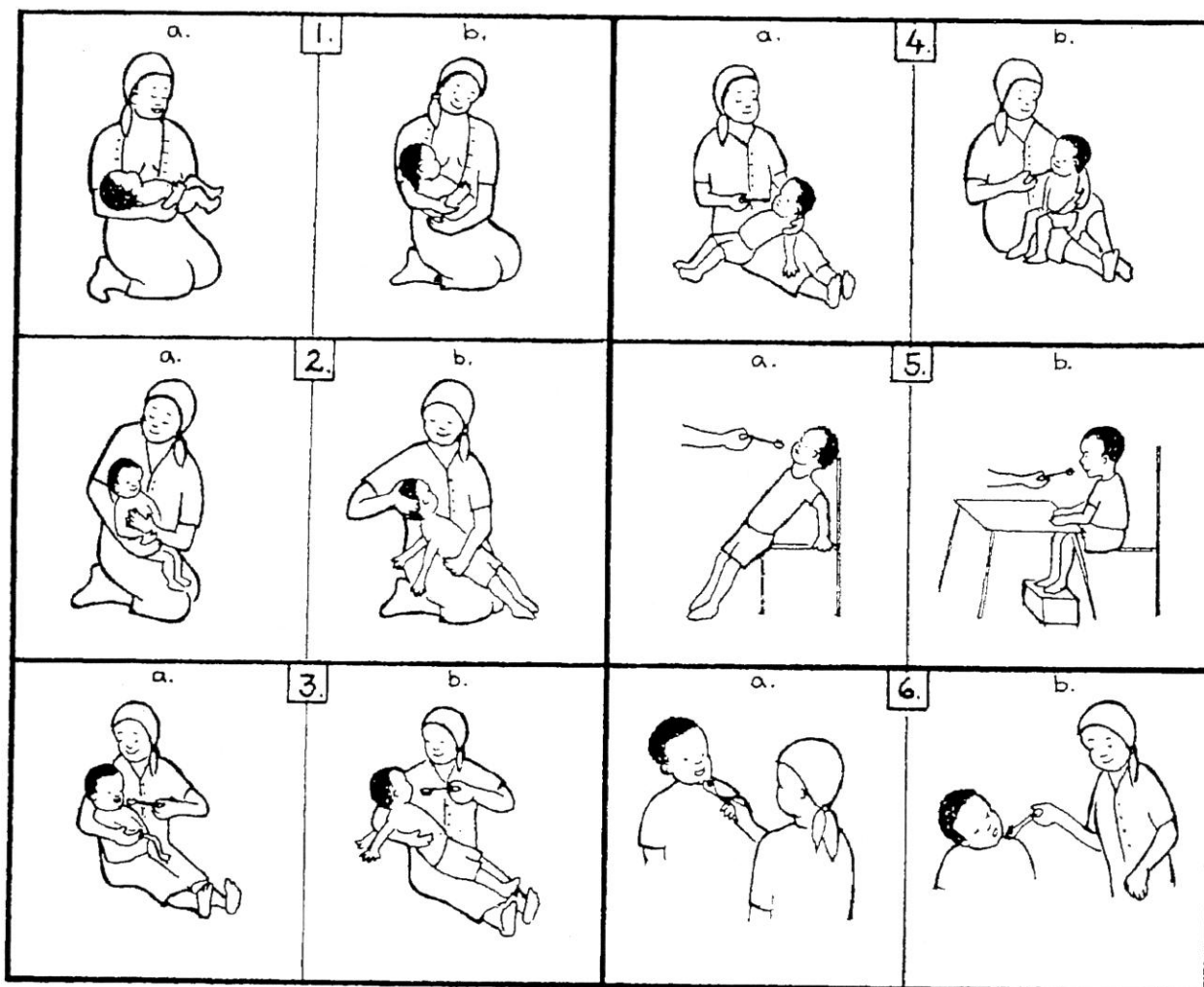
Think about what difficulties you may have when feeding your child. Do they fit under one or more of these headings?

We may need to look at all these difficulties when trying to help feed a child more effectively.

POSITIONS FOR FEEDING

Look first at positioning your baby/child. (What do you remember about positioning?)

Look at these pictures, and choose which you think is the best position for feeding, from each pair. Can you say why you choose one position rather than the other?



You can check your answers on the last page of this module.

REMEMBER

- **Be sure your child is in a good position before you begin feeding her!**
- **The position you use will make feeding either easier and safer, or more difficult and unsafe.**
- **It is especially important that the head and neck are in a good position for feeding to make swallowing easier and safer.**
- **You can play with your child in these positions too – that way she gets used to the position before you try feeding her, and you also get comfortable with using these positions.**

GOOD POSITIONS FOR FEEDING YOUR CHILD

Here are some pictures of different ways to help your child get into this good position. Let's look at how the caregiver manages to put the child in a good position by using the **checklist**:

CHECKLIST: GOOD POSITION FOR FEEDING

HEAD & BODY:	Straight and upright; back of the neck must be long
SHOULDERS & ARMS:	Forward
LEGS:	Hips bent

Now let's look at some specific positions.

If you're sitting on a chair, couch, or bed to feed:



- Make sure that you are comfortable, with a cushion behind your back and another under your supporting elbow.
- Keep your upper arm firmly against the top of her **head**, and not behind her neck. Make sure you can see your elbow.
- Hold your child's bottom firmly between your legs so that she cannot push back.
- Raise your leg that is supporting her knees by putting a box under your foot, and use your other leg to make her **back straight**.
- Bring her **arms** forward so that her **shoulders** also come **forward**.

If your child's back is very rounded, it may help if you raise your leg that is behind her back even higher than the other leg.



If you are sitting on the floor to feed:



- Try to sit in a corner so that you can rest your back and your supporting arm.
- Keep your upper arm firmly against the top of your child's **head** – not behind her neck. Make sure you can see your elbow.
- Her **shoulders** and **arms** are **forward**.
- Put a cushion under your raised knee to keep yourself comfortable and to keep her **back straight**.
- Make sure your child's bottom is well between your legs so that you can keep her **hips** firmly bent.

- For the bigger child, or for one who pushes back very strongly, try resting her bottom firmly on the floor and then push her legs up towards her chest.
- Place your leg firmly across her feet to hold them flat on the floor.



Extra hints for positioning in this way:

- If your child is sinking down too far between your legs, try putting a firm folded towel under her bottom
- Make sure her shoulders are really well back and supported. Remember her back must be straight, not rounded
- If her back is still too rounded, slip a folded towel over a piece of board behind her back to give her something to lean against

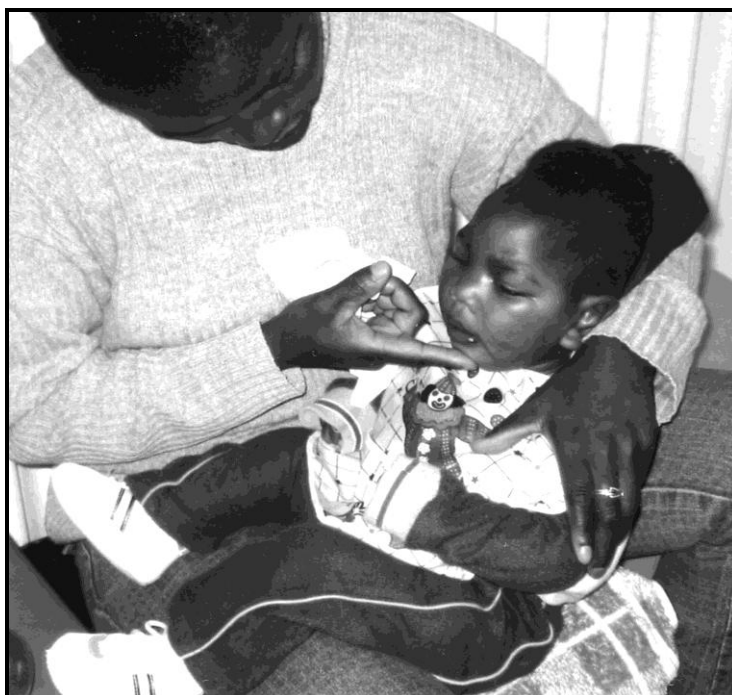
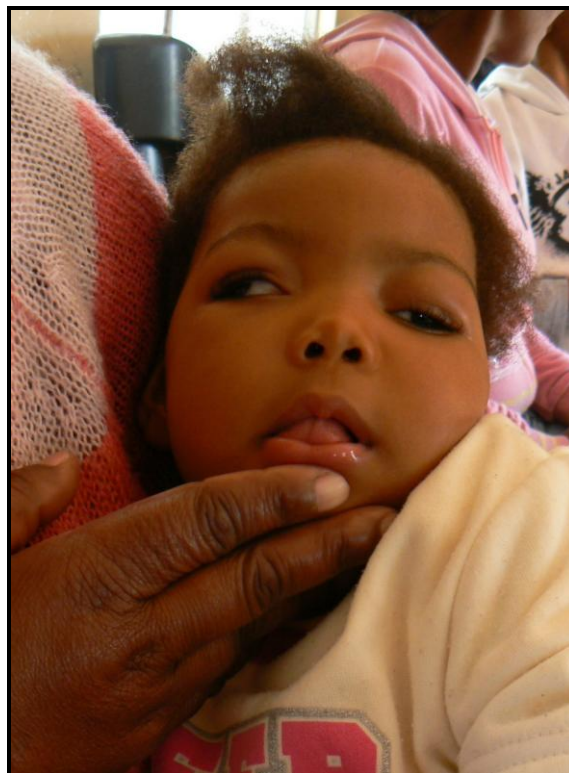
Or your child may have a proper positioning and seating buggy, which is ideal to use when feeding her.



- A buggy like this can give your child all the body support that she needs, leaving you free to concentrate on your feeding technique.
- But make sure she is correctly seated and positioned, as you have been shown.
- It's no good having equipment and then not using it properly.
- Positions for feeding the child on her mothers lap are likely to be very difficult with older/bigger children, and are more suitable for younger children.
- For those older / bigger children, use of a proper positioning buggy will probably be the only way to achieve a good feeding position.

HELPING HER TO SWALLOW

Other than keeping her in a good position, swallowing can also be improved by helping to close her lips.



HELPING YOUR CHILD SWALLOW

- **First make sure she is sitting with you in a good position as discussed before.**
- **Give special attention to the position of her head and neck. The head is upright and straight with the back of her neck long.**
- **Now place two fingers, one on her chin and one under it. To help close her lips when the food is in her mouth, roll her bottom lip up with your finger to meet her top lip to help her close her mouth.**
- **The finger under her chin is only there to stabilize your hand, so if you find it difficult to do it like this, you may also use only your thumb or index finger to close the lower lip with a rolling action (as demonstrated in the first two pictures)**
- **Be careful not to push her head back, but keep it upright with the back of her neck long, especially when she swallows! This position makes it easier for her to swallow and helps to prevent choking.**
- **At first she may push against your hand, but once she gets used to it, it should help her control the movement of her mouth and tongue.**
- **Be sure not to push her head backwards, but keep it bent forward slightly.**
- **Try to keep your hands in this position for as long as possible during the feed. She will respond better to constant, firm pressure than you putting your hands on and off.**

Try this lip closure on yourself first, to get your fingers in the right positions. You may want to try it on someone else in your family before you try it with your child. When you try any new feeding technique with your child, try the new way for 5 – 10 spoonfuls, then go back to your usual way. This is until you and your child get used to the new way.

SPOONFEEDING

HINTS WHEN SPOON FEEDING:

- **Make sure she is in a good position**
- **Make sure the food is not too sloppy – it's easier for your child to deal with a small amount of firm food on the front of the spoon**
- **Give the spoon from the front, not from above or from the side**
- **Keep the spoon flat and press down firmly on her tongue**
- **Wait for her to close her mouth, or help her to close her lips**
- **Remove the spoon quickly, keeping it flat. Don't pull it out against her top teeth**
- **Maintain the pressure to keep her mouth closed, and let her tongue do it's job**
- **Let her enjoy eating and not be afraid of it**

CHEWING

Question: *When should I start to give my baby solid food?*



Babies with cerebral palsy should start eating solid food at the same time as babies who don't have cerebral palsy.

Question: *Why do you think we learn that it is good to give our children more solid food? Maybe you feel that feeding her soft food is easier for you?*



Babies need to learn to chew to help develop control of the movements of the tongue, cheeks, and lips, which is **very important for the development of talking.**

Lets look at tongue movements as an example:

- When drinking liquids and eating sloppy food the tongue only moves backwards and forwards to suck. This is the way a baby moves her tongue to eat. If an older child still moves her tongue like this to eat, it is because she has never learned to make any other tongue movements.
- When eating solid food the tongue has to move sideways to move the food to the teeth to be chewed, and again to the back of the mouth for swallowing. So the child learns and practices much more control over the movements of her tongue, which will help her when having to control different tongue movements needed for chewing, swallowing and talking.



HINTS TO TEACH HER TO CHEW

- **Make sure you are both in a good position to start with**
- **Put a small piece of solid food such as a little cube of cooked potato or other vegetable between her teeth and the side of her mouth and toward the back.**
- **Approach with the food from the middle and below so that she doesn't throw her head back to look at the food.**
- **Do not push the food into her mouth – pull the corner of her lip out, work your finger gently along her cheek first, and then only slide the food in with your thumb.**
- **She may need help to keep her mouth closed while she chews. Just roll her bottom lip up gently to help her close her mouth (look again at the pictures 6.12 a-c). This will also encourage her to swallow.**
- **Do not make chewing movements for her.**
- **Do not try to get her to open and close her mouth as if she were biting.**
- **Put food in one side, and next time in the other.**
- **Once you are managing with cooked vegetables, progress to a piece of brown bread. Leave the crust on. Do not use white bread – it causes constipation.**

This method of feeding is more helpful than feeding with a spoon. It can get messy but is really a good way to help her learn to chew. It may take a long time initially, but as she gets used to it and better at it, feeding will begin to go more quickly.

DRINKING

Question: *Have you noticed what your head does when you drink from a cup?
When does your head move?*



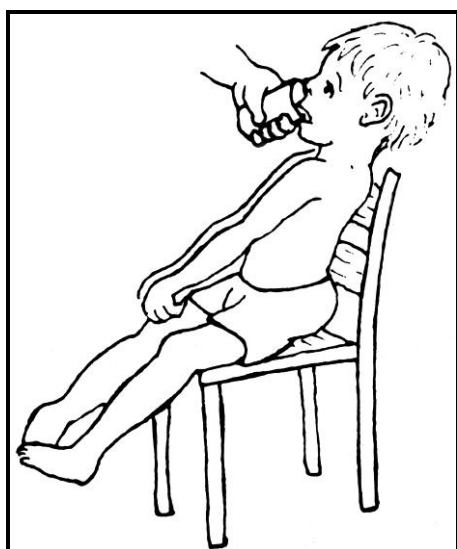
To drink from an ordinary cup, you need to tilt your head back, especially when you get down past the middle of the cup. Try it.

Question: *What happens to your body when your head moves?*



You are able to keep your body in an upright position when tilting your head back.

Question: *What happens to your child's body when she tilts her head back?*

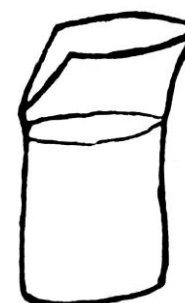


For a child with cerebral palsy, this tilting the head back may cause her whole body to stiffen backwards.



Cut out a piece of the cup which will fit around her nose – this way she won't have to tilt her head back when drinking, especially for the last few sips.

(Hint: Use a plastic cup, not paper or polystyrene. Try to find a plastic cup with no "bumps" on the sides, just a smooth cup with a rim at the top.)



The most important point for drinking is to get the **lips closed**.

When drinking, if your child cannot close her mouth, help her by holding your fingers as discussed for swallowing, and roll up to close her lips.



- Caregiver's right hand controls the liquid level in the cup.
- Because of the cut-out, the caregiver can see the liquid level and the child's lips.
- Caregiver's left hand (with watch) is helping to control position of her head, and closing her lips as needed.
- The caregiver does not remove the cup between sips.
- She holds the cup firmly in place, but makes sure she gives time for a swallow between sips.

HINTS FOR DRINKING

- **Make sure you are both in a good position to start with**
- **Give special attention to the position of her head and neck. The head is upright and straight with the back of her neck long.**
- **Tilt the cup so the liquid just touches her upper lip, and wait for her to do the sipping movements.**
- **Help her to close her lips, if needed.**
- **Don't take the cup away after each swallow – this can cause her to push her head back or her tongue out.**
- **Hold the mug firmly in place, but make sure you give time for a swallow between sips.**
- **Don't be in a hurry to give her normal liquids in the mug. First get her used to thickened liquids – like custard, soft porridge, fruit puree or yoghurt. These are easier for her to handle because they flow more slowly and she is less likely to panic or choke.**

BRUSHING TEETH

Question: *Why do you think it is especially important to clean the teeth of your child with cerebral palsy?*



- The child has limited or poorly controlled tongue movements so the tongue cannot be used to collect pieces of food that remain between the teeth.
- Chewing stimulates blood flow to the gums. If a child only eats soft food and is not chewing there is less blood circulation to the gums which can make them unhealthy.
- Some medicines prescribed for children with cerebral palsy may affect the teeth and gums, making it even more important to keep the mouth clean.
- The child who drools a lot does not swallow properly and has an open mouth most of the time. This allows germs to collect in the mouth.
- Some children with cerebral palsy are very sensitive in their mouths which makes it difficult to clean their teeth well. So extra care is needed.
- If the child is starting to brush her own teeth, but does not have good hand function and cannot rinse her mouth well, the teeth may not be properly cleaned

We see that a child with cerebral palsy is very much at risk of developing problems with her teeth and gums.

Therefore, you should clean your child's teeth carefully after every meal and after sugary snacks and drinks!

Question: *What specific steps would be helpful when cleaning the teeth of a child with cerebral palsy?*



SPECIFIC HINTS FOR TEETHCLEANING IN A CHILD WITH CEREBRAL PALSY

- **Make sure that you and your child are in a good position before starting. Pay special attention to the position of her head and neck.**
- **Rinsing is very difficult for many children with cerebral palsy. You could use a syringe to help rinse out the mouth.**
- **You may have to bring her body forward so that the water can run out.**
- **It is easier to use a small bowl for spitting out and rinsing, rather than a fixed basin.**
- **Giving firm pressure on the cheeks towards the lips could help the child to spit out.**
- **If there is any area with problems like pain or sensitivity, do those first so it can get done while your child is still relatively relaxed.**

FACE CLEANING

Question: *Do you need to wipe your child's face often?*



Some children with cerebral palsy need to have their faces cleaned often. This can be because of drooling or food spilling out of the mouth when eating.

We have learned in this module how important it is for a child to learn to close her lips. It is important for swallowing and chewing.

It will help your child to learn to close her lips if cleaning her face is done in such a way that it gives her the feeling of a closed mouth. This can also help to teach your child to swallow her saliva instead of letting it dribble out.



HINTS FOR FACE CLEANING:

- **Use firm pressure on the cheeks and lips using a dabbing movement – not wiping.**
- **Always dab towards the mouth. It is as if you are helping to close the lips.**
- **Dab from the left and right side of the mouth. Then the chin and lower lip. Then the upper lip.**
- **Tell your child to swallow when you are doing this.**

TOWARDS INDEPENDENT EATING

Question: *How do I encourage my child to eat more independently?*



You want to encourage your child to learn to be more independent in eating. To prepare for this, encourage her to play, taking her hands and toys to her mouth. If her balance is poor, she will need special seating to help her. But don't let her special seating become a prison.

If your child is developing some head and trunk control, reduce the support that you give, but make sure she still keeps a good sitting position.

HINTS TO ENCOURAGE YOUR CHILD TO EAT MORE INDEPENDENTLY

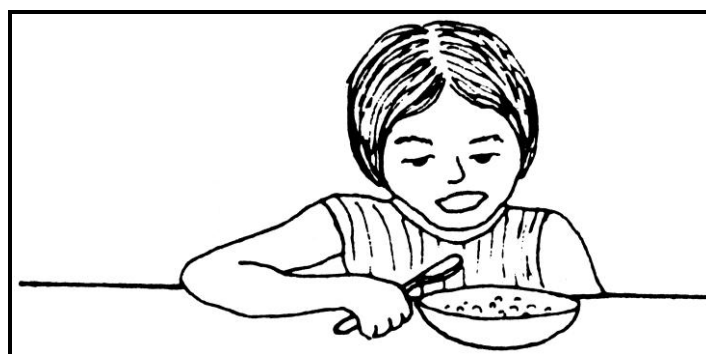
- **In the beginning, guide her hand to help her learn to feed herself**
- **Put a biscuit in her hand, guide it to her mouth, and see what she does with it...you might be surprised at how much she manages to feed herself**
- **Don't stop her putting her hand in her food and trying to feed herself**
- **Put a wet face cloth under the bowl to stop it slipping on the table as she holds it**
- **Try bending the spoon so the food still comes towards her at the right angle**
- **Put some padding round the handle to make it easier for her to grip and hold the spoon**

These pictures give some ideas how you can help your child to feed herself:

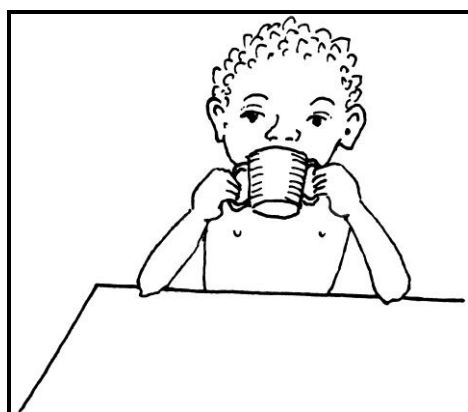


Let her rest her elbow on the table if it gives her more control.

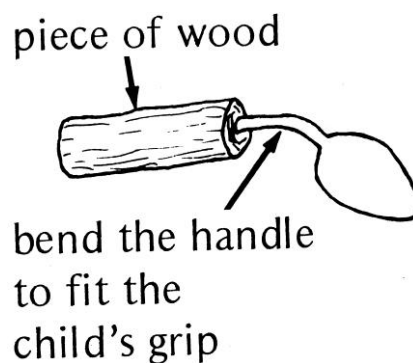
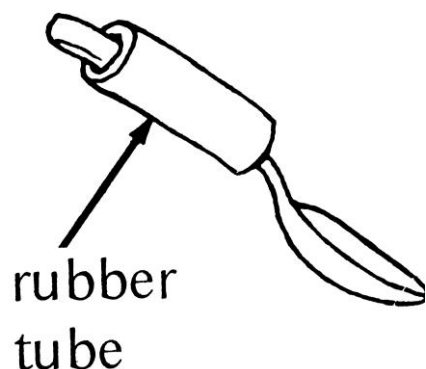
Lifting the table up on blocks may also give her more control. The table and therefore the bowl of food, is now closer to her mouth.



If she has difficulty controlling a cup with one hand, try using a cup with two handles.



Making a spoon easier for her to manage might increase her independence.



Question:

Is there going to be a mess when your child learns to eat by herself?



Yes, yes, yes.

Does it matter? Well, it's more work for you.

But ask yourself this – do I still want to be feeding my child when she is 21?

Perhaps I should let her make a mess now, and maybe she won't need to be fed when she is that age.....

Remember, all children mess when they are learning to eat. Children with cerebral palsy may mess more, but it is part of learning and developing control.

Answers to positioning quiz

1. b.



Child held upright to make lip closure and swallowing easier. It is very difficult to swallow with your head back.

2. a.



Don't force head forward. Cradle base of head in your bent arm using same arm to bring child's arm forward. Use your other hand to press firmly on child's sternum.

3. a.



Support base of head in bend of your arm. Hold child's arms firmly forward. This, and pressure on sternum (mentioned in 2), help to reduce extensor pattern.

4. b.



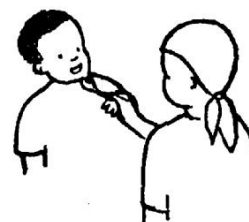
Use your legs to support child in a good, upright position with child's hips and knees flexed.

5. b.



While sitting, hips and knees should be flexed at 90°. Arms should be forward with tray as support. Feet should be supported.

6. a.



Give food from the front, slightly below. Ensure child's head is symmetrical. This makes eating and swallowing easier.

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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