First Edition

Management of Children with Deafblindness with Cerebral Palsy

Feeding, Oromotor Skills and Self-Care Skills

sense International (India)

Working with deafblind people throughout India

Resource and Information Unit

Acknowledgement

Over the years of working with deafblind children and adults, Sense International (India) has witnessed enrolment of many children with Sensory Impairments having associated condition of Cerebral Palsy in its partner projects. Management of children with associated Cerebral Palsy along with deafblindness is often perceived as a challenging task by many of the special educators and parents. This created the need to edify and update the skilled and valuable human resources about management of these children. This booklet gives step by step instruction of management of feeding, oromotor and selfcare of children with Cerebral Palsy and deafblindness. The pictorial illustrations will help families and teachers of deafblind children to provide basic need based support to deafblind children having the associated condition of Cerebral Palsy.

We thank all deafblind children and their educators and parents for putting forth the need for this information material.

The contents in this booklet is informative and also looks attractive because of the illustrations. We thank Mrs. Viji Dayan for the same.

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Preface

Children with deafblindness experience a range of associated conditions like cerebral palsy, mental retardation, autism, epilepsy, etc. Deafblind children with the associated condition of Cerebral Palsy become the subject to orthopaedic and other functional complications, such as limitations of movement, scoliosis, joint instability, bowel and bladder dysfunction, dysarthria and dysphagia, and altered growth and nutrition. The physical and psychological consequences of compromised mobility and independence, difficulties with communication, altered appearance, and chronic illness may also require identification and specific intervention.

Cerebral Palsy along with deafblindness creates more difficulties in the life of individuals by limiting their ability to learn, explore and express themselves in their immediate environment. Thus, it is very important to identify these associated conditions, correct them and facilitate the maximum improvement in a child.

Children with deafblindness and Cerebral Palsy may also have problems with oral motor control and feeding. They can be defensive to certain textures of food. Their other self care skills can also be affected because of the combination of deafblindness and Cerebral Palsy.

This booklet gives activities to improve self help skills, feeding and also activities to reduce drooling. Since each child is different, the reader will have to modify the activities given based on individual child needs and skills even though the techniques remain the same.

Though utmost efforts are being made to ensure that the information in this booklet is complete and accurate as possbile. This text should be used only as a general guide and not as the ultimate source of writing and publishing information. The purpose of this book is to educate the reader and can in no way be taken to reflect the views of the European Union.

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CHAPTER 1 - INTRODUCTION

SELF-CARE SKILLS

Children have a drive to be independent and do things on their own. This is a healthy part of normal child development. As children grow, they learn to do more and more tasks. Self- care tasks are some of the most important tasks learned by children as they mature. When children practice self-help skills such as feeding and dressing themselves, they practice their large and small motor skills, gain confidence in their ability to try new things and build their self-esteem and pride in their independence.

There are five main types of self-help skills:

- Feeding
- Dressing
- Toileting
- Bathing
- Brushing and grooming (combing hair, washing hands and face, applying make-up etc.)

TYPICAL DEVELOPMENTAL SEQUENCE OF SELF-CARE SKILLS

Feeding

Approximate age	Eating Skill
0 - 3 months	Solely breast and/or bottle fed. They have oral reflexes for suckling and swallowing.
4 months	Loss of sucking reflexes. Sucking becomes intentional
5 - 6 months	Cereals and pureed foods introduced
8 months	Mashed foods introduced Munching (up and down jaw movements develop. Visually or tactilely accepts spoon and opens mouth to accept spoon Drinks from a cup with lots of spilling

Approximate age	Eating Skill
6 -9 months	Holds a bottle with both hands
10 months	Uses upper lips to clean food off the spoon. Takes a small piece of biscuit to mouth by self
12 months	Drinks from a cup, spilling still present Mashed food with lumps introduced Takes a bite off a biscuit Rotary movements of the jaw
12-15 months	Holds a cup with both hands. Moves spoon to mouth but spills.
15- 18 months	Coarsely chopped food Chews well without significant spilling of food
2 years	Swallows liquid from a cup without spilling. Able to feed self with with pieces of rotis and dosa's from the plate. Also able to eat rice balls from plate
2-3 years	Uses spoon without spilling
3 years	Eats the same food as the rest of the family.
3-5 years	Eats by himself/herself

Dressing

Approximate age	Dressing Skill
10 months	Helps pull a leg from a pants leg or an arm from a sleeve.
12 months	Co-operates with dressing (holds out arms and feet) Pulls off shoes and removes socks Pushes arms through sleeves and legs through pants
18 months	Can put on a hat, unzip a large zipper, and remove an unbuttoned button-type shirt.
24 months	Removes shoes if laces are untied Helps pull down pants Finds armholes in overhead shirt Puts on shoes with only a little help.
30 months	Removes pull down pants with elastic waist Assists in pulling on socks Puts on front button shirt Unbuttons large buttons

Approximate age	Dressing Skill
3 years	Puts on overhead shirts with minimal assistance Puts on shoes without fasteners Zips and unzips jackets Buttons large front buttons
3 ½ years	Finds and differentiates between front and back of shirt inconsistently Buttons series of three or four buttons Dresses with supervision
4 years	Zips jacket zipper Laces shoes Consistently identifies the front and back of the garment
5 years	Ties and unties knots Dresses unsupervised
6 years	Closes back zipper Buttons back buttons

Toileting

Approximate age	Toileting Skill
10 months	Child indicates when wet or soiled
12 months	Regularity of bowel movements
15 months	Child sits on toilet when placed there and supervised (short time)
18 – 21 months	Regularity of urination
24 months	Indicates the need to go to the toilet Daytime control with occasional accidents
30 months	Child tells someone he or she needs to go to the bathroom Child seats self on toilet
34 months	Child goes to the bathroom independently
3 years	Child may need help with clothing Attempts to wash after toileting
4- 5 years	Completely independent

Brushing, Bathing and Grooming

Approximate age	Brushing, Bathing and Grooming Skills
1 ½ - 2years	Imitates and enjoys brushing.
2 years	Wipes nose and mouth on command Applies soap on the tummy
2 ½ years	Brushes front teeth with side to side stokes Combs hair with forward strokes Attempts to pour water during bathing Washes hands when assisted
3 – 4 years	Wets brush and applies tooth paste Bathes with supervision Washes and dries hands with supervision
5- 6 years	Bathes and brushes teeth with minimal supervision Combs hair

CHAPTER 2 - SELFCARE SKILLS IN CHILDREN WITH DEAFBLINDNESS AND CEREBRAL PALSY

Deafblindness is a condition which poses many unique challenges to the individual. Cerebral Palsy along with deafblindness creates more difficulties in the life of individuals by limiting their ability to learn, explore and express themselves in their immediate environment. Children with deafblindness and Cerebral palsy may have problems with oral motor control and feeding. They can be defensive to certain textures of food. Their other self care skills can also be affected because of the combination of deafblindness and Cerebral Palsy.

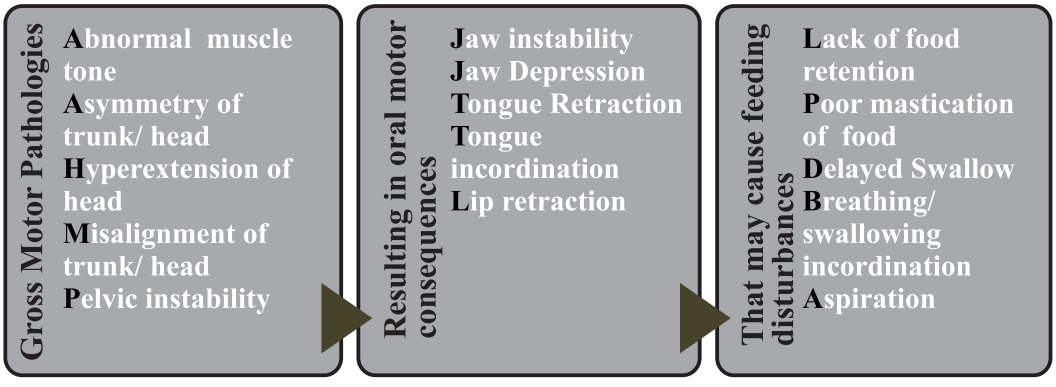
This booklet gives activities to improve self help skills, feeding and also activities to reduce drooling. Since each child is different, the reader will have to modify the activities given based on individual child needs and skills even though the techniques remain the same.

DEVELOPING SELF CARE SKILLS IN CHILDREN WITH DEAFBLINDNESS AND CEREBRAL PALSY

FEEDING

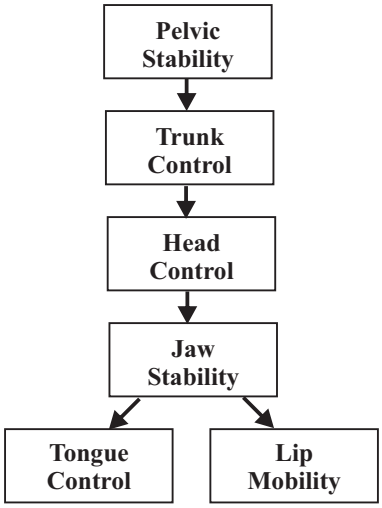
➲ ***Causes of feeding disturbances in children with Cerebral Palsy***

Abnormal muscle tone; asymmetry, hyperextension and misalignment of the head and trunk and pelvic instability can result in oral motor consequences like jaw instability, tongue incordination etc which can lead to problems in feeding.



➲ Positioning

The first thing to consider while feeding a child with Cerebral Palsy is positioning the child. The child should be seated on a firm surface with stable pelvis.



- While breast/bottle feeding position the baby so that the head is slightly forward

DO

Fig. 1(a): *Positioning the baby with head slightly forward*

DON'T

Fig. 1(b): *Avoid feeding the baby in this position*

- Keep the spoon/ bottle in front and not from above or sideways. Giving food from above causes the head to press back and the body to stiffen. This makes swallowing difficult. Touch cues can be used for children with deafblindness

DO

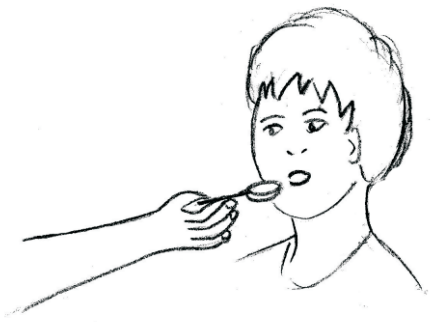


Fig. 2(a): *Keeping spoon in front*

DON'T

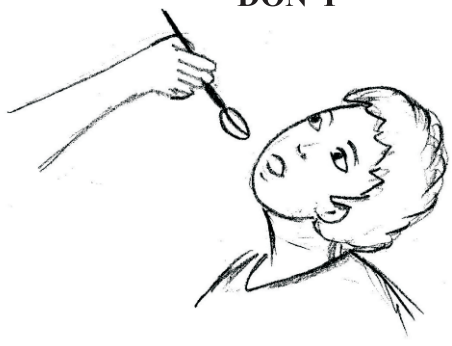


Fig. 2(b): *Do not give food from above*

Checklist for Proper Positioning of the Child with C.P. for Feeding/ Swallowing

- Is the child upright?
  - Chair seat and back should be at 90° and child maintained upright
- Is he/ she symmetrical?
- Are the hips, knees, and feet in 90° flexion?
- Are the feet stable?
  - Feet should be on the floor with ankle at 90° . If not, foot support should be provided
- Is the pelvis stable?
- Is a well- positioned, tight seat- belt being used?
- Has a solid table surface been provided?
- Is the head in a chin tuck position?
  - If not, check the above items
  - If a chin tuck position cannot be attained through postural alignment, then oral control, which is explained later in this booklet, should be administered

DO

Fig. 5(a): *Proper positioning of a child with C.P. for feeding*

DON'T

Fig. 5(b): *Improper positioning of a child with C.P.*

If an adapted chair is not available at home and school, the child can be positioned in the corner of the room or using a corner stool

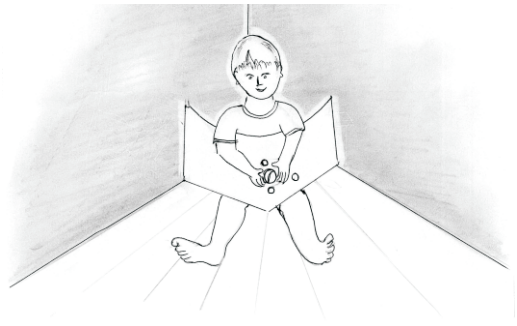


Fig. 6: *Seating a child in the corner of the room*

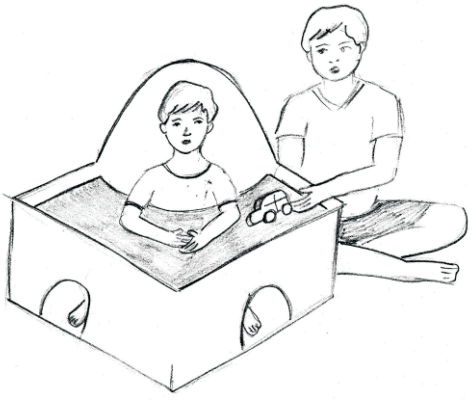


Fig. 7: *Positioning a child using the corner stool*

➲ Activities to do before feeding

The first thing to do before feeding a child with C.P. is to normalize muscle tone of the cheek and tongue

- ❍ Hypotonia: If the cheek and lip muscles are floppy and loose (hypotonia), the following technques can be used.
  - Tapping or quick stretch of cheeks and lips. Pull both corners of the lips and release them suddenly.

Fig. 8: *Quick stretch of the lips*

  - Vibration: Vibration can be applied on the cheek muscles using a vibrator. However, it should be done with caution while stimulating face if the child has epilepsy.

- ❍ Hypertonia: If the cheek and lip muscles are tight and spastic (hypertonia), the following techniques can be used.
  - Deep & firm pressure using a downward stroking motion
  - Massage the gum symmetrically, one quarter of the mouth at a time

Fig. 9: *Massaging the gums symmetrically*

- Move the hands symmetrically towards the mouth

Fig. 10: *Massaging the face symmetrically towards the mouth*

- Massage inside the cheeks, using fingers in a circular motion

Fig. 11: *Massaging inside of the cheek*

- To promote lip closure
  - Quick stretch

- Chin tuck
  - Keep the neck slightly flexed

- **Tongue thrust**
  - Tongue Thrust refers to an elongated tongue where the child keeps the tongue out but has difficulty withdrawing back into the mouth. In such a situation, apply firm pressure with your finger or the ball of the spoon on the tongue in a backward direction

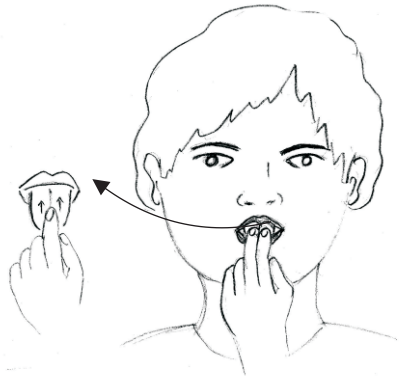


Fig. 12: *Applying backward pressure to the tongue*

  - Use jaw control techniques which will be explained later to keep the mouth closed

- **Retracted tongue**
  - If the tongue does not extend beyond the lips, apply firm pressure in a forward direction

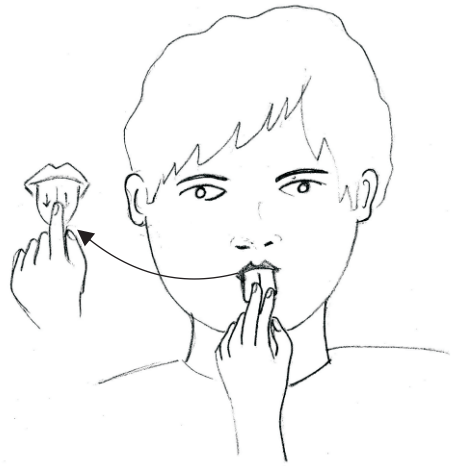


Fig. 13: *Applying forward pressure on a retracted tongue*

❍ **Activities to facilitate tongue movements**

Use honey/ sugar syrup or jam or something that the child likes. Lemon extract (squash) is also very useful

- Forwards
- Sideways
- Over the upper lip

Fig. 14: *Forward tongue movement*

Fig. 15: *Lateral tongue movement*

Fig. 16: *Tongue pretraction over upper lip*

➲ **Activities to do during feeding**

❍ Breast/ bottle feeding

If the child does not suck, or is not able to coordinate between sucking, swallowing and breathing, the following techni

- Massage cheeks
- Cheek support i.e. applying firm pressure o the cheeks

Fig. 17: Check support

- Insert and pull out the nipple from mouth
- External pacing, where mother removes the nipple from the child's mouth after she sucks 2-3times.

❍ Jaw or Oral control techniques

Oral control can aid mouth closure, inhibit oral reflexes, and facilitate jaw, tongue, and lip movements for feeding, while limiting abnormal movements such as jaw protraction and extension. If the child cannot control his jaws and close his mouth or munch (up and down movements of the jaw) or chew (rotatory movement of the jaw), jaw/ oral control techniques should be used. These techniques can be provided from the side or from the front.

- From the side: : Oral control given from the side allows the feeder greater influence over the movements of the oral structures.

    - Right handed feeder uses the index and middle fingers of the non dominant hand, i.e. left hand
    - Stand or sit on the right side of the child
    - Non dominant hand must go around the back of the child's head
    - Index finger placed midway between the lower lip and the bottom of the chin.The middle finger and the index fingers work in tandem to maintain proper tongue and jaw positioning
    - Middle finger is placed under the chin. The middle finger and the index fingers work in tandem to maintain proper tongue and jaw positioning

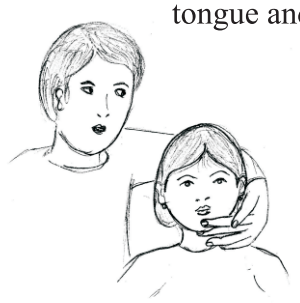


Fig. 18: *Jaw control technique from the side*

- From front: Front oral control permits eye contact between the child and the feeder but offers less oral control. It should be done with the non dominant hand.

  - Hold thumb, index finger and middle finger 90° to each other

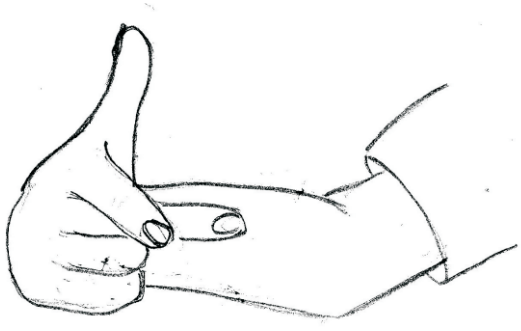


Fig. 19: *Positioning of the mother's / therapist's fingers for jaw control*

  - Thumb is placed on the chin
  - Middle finger is placed under the chin
  - Index finger is placed over the jaw joint.

Fig. 20: *Jaw control technique from front(3 -jaw chuck)*

Checklist for Oral Control

- Front Oral Control
  - Sit in front of the child or infant for eye contact
  - Use non- dominant hand
  - Thumb on chin
  - Middle finger under the chin
  - Index finger over the joint
- Side Oral Control
  - Right handed feeder sits on the left side of the child
  - Use non- dominant hand
  - Index finger on chin
  - Middle finger under the chin
- Don'ts
  - Don't exert too much pressure
  - Don't push the child into extension

➲ Activities to develop munching and chewing

- Work on tongue movements and jaw control
- Cut potatoes/ carrots into long strips and cook it
  - Keep it inside the mouth, over the molars and not in the front
  - Use jaw control techniques and help the child in up and down movements of the jaw
- Cut mangoes/ apples into a small piece and cover it with a clean cloth
  - Keep it inside the mouth, over the molars and not in the front

- Use 3 jaw chuck and help the child in up and down movements of the jaw
- The juice that comes out will be a reward to the child

❍ Once the child is able to bite and munch/ chew soft food, shift to little hard food like biscuit. Initially it can be dipped in water/ milk and later can be given as such

❍ Later, give hard food like murukku, chakli, sev, papad, gathiya, farsan, chivda, peanuts, khakra, rotis etc.

➲ **Swallowing:**

Swallowing can be facilitated by using the following techniques.

❍ Cold stimulation is given to the tongue and the soft palate

❍ Take an ice cube and rub slowly for 3- 4 times in a circular manner over the cheeks, tongue and soft palate. Wipe away excess water.

❍ Jaw support

❍ Positioning neck in slight flexion

❍ Brushing the neck as shown in *Fig.21*

Fig. 21: *Brushing the neck to facilitate swallowing*

- Stimulate the neck and apply slight pressure over supra sternal notch (bottom of the neck).

Fig. 22: *Applying pressure over the suprasternal notch to faciliate swallowing*

Management of oral defensiveness

Some children with deafblindness and Cerebral Palsy are known to have oral defensiveness.

- Picky eater based on textures, temperatures of food and new flavors.
- May gag at times or only desire to eat pureed foods
- Difficulty sucking, chewing, or swallowing
- May have frequent choking incidents
- Avoids spicy, extra sweet, sour, or salty foods
- Oversensitive to toothpaste and mouthwash and dislikes going to the dentist

Points to remember while managing oral defensiveness

- Activities to desensitise should be splaced in the context of play
- Activities to desensitise should be self guided as much as possible
- Activities to desensitise should be introduced gradually

- Always acknowledge the child's physical cues of discomfort through
  - Verbal response
  - When appropriate, withdrawal of oral stimulus

Desensitisation activities should be done between meals and just before meals.

Desensitisation between Meals

- Encourage the child to explore his/ her own mouth with his/ her own hands
- Introduce rubber toys dipped in fruit juices to oral play
- Massage the gums with a tooth brush dipped in pureed food
- Stimulate different areas of mouth with different degrees of pressure
- Rub child's gum with a warm wash cloth
- Allow the child to suck or chew on the wash cloth
- Blowing bubbles and making sounds to desensitise the oral area

Desensitisation before Meals

- Using a warm washcloth around and inside the mouth
- Firm rubbing and deep pressure applied to cheeks, outer lips, inside the mouth, gums and tongue
- Sustained firm pressure to the upper palate
- Massage the gums and cheeks with therapist's finger inside a nipple

Texture Grading

Texture grading involves giving the textures which are most tolerated by the child. Slowly it is graded to the least tolerated texture. This should be done along with the desensitization activities given above.

The various stages of texture grading can be as follows:

- Pureed, smooth foods as first solids
- Gradually increase texture with food with lumps
- Textures within any one meal should be varied from least tolerated to most tolerated
- Soft foods that have cohesion when chewed provide increased sensory input. E.g. boiled potatoes.
- Biscuits: provide chewing and dissolve quickly

E.g. Texture grading for fruits and vegetables can be done as follows:

Step 1: Strained fruits and vegetables
Step 2: Mashed bananas; mashed potatoes
Step 3: Fork- mashed soft fruits without skin, fork-mashed well cooked vegetables without skin, and boiled potatoes without skin
Step 4: Soft, ripe, fresh fruits; well cooked vegetables cut in small pieces
Step 5: Vegetables of increased textures (steamed carrots, cauliflower); soups with well- cooked vegetables
Step 6: Raw or dried fruits; raw vegetables; vegetables with skin (corn, peas), chunky soup

- Self feeding: The steps for facilitating a child to eat by self can be graded as follows

  - Food balls from hand
  - Food balls from plate
  - Mixed food from plate. Use a bowl, so that the child can scoop the food against the side
  - Mixing food
  - Serving

- If the child cannot use his fingers adequately to eat by self
  - Modified spoon
    - Built up spoon, if the grasp is weak

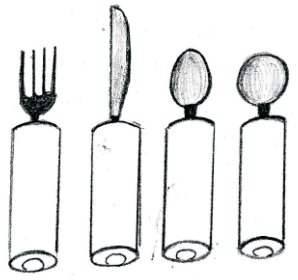


Fig. 23: *Built up spoon, fork and knife*

- Bent spoon, if the child cannot turn his hands

Fig. 24: *Bent Spoon*

- Universal cuff, if the child cannot hold a spoon

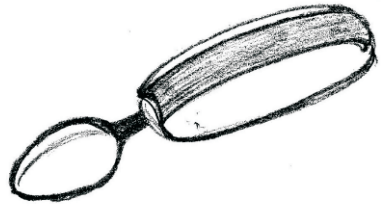


Fig. 25: *Universal cuff*

- If the child has poor elbow movements
  - Keep the lap board higher
  - Rocker bottom

Fig. 26: *Rocker bottom for a child with poor elbow control*

Drinking

The child should be off the feeding bottle by two years of age.

- Positioning
  - Same as in feeding
- Use a tumbler with a rim

Fig. 27: *Tumbler with a rim*

- If the child has tongue thrust, avoid using sippy cups
- If the child cannot control the cup with one hand, use a cup with two handles

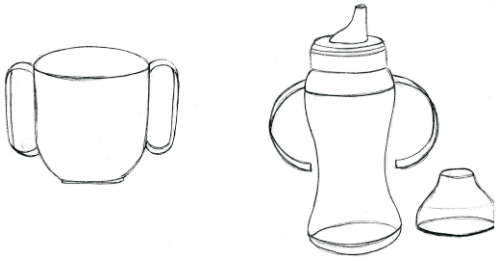


Fig. 28: *Cup with 2 handles*

- Start with a small amount of water and gradually increase the quantity
    - Slowly move on to controlling the cup with one hand

DROOLING

- **Causes**
    - Posture / poor or inadequate head control
    - Decreased sensory awareness. Child is not aware that he is drooling
    - Impaired swallowing
    - Hyper salivation
    - Tongue thrust
    - Inadequate tongue movements
    - Inadequate lip closure
    - Hypotonia / hypertonia of cheek muscles
    - Inadequate jaw closure / jaw control
    - As a behavior problem

- **Management**
    - Facilitate head control and posture, tongue movements, jaw control and swallowing as mentioned earlier
    - To normalize tone
        - Massage cheek, tongue, gums and lips as described under feeding
        - Icing over cheeks, gums and tongue. Take a small cube of ice and massage the cheeks with it in a circular manner for 30 seconds. Do not wipe away the water, but just blotch it with a cloth
    - Impaired sensation
        - Alternate between cold and hot temperatures over the perioral area (around the lips)
        - Do not wipe the drool away. Always use a soft towel to just blotch it.

- Hyper salivation
  - Frequent reminders to swallow
  - When drooling, show a mirror and ask him to swallow
  - Reward dry periods
- Some other activities
  - Blowing bubbles
  - Blowing whistle
  - Sucking through a straw

DRESSING

- **When helping your child put on clothing, put the more affected arm or leg into the clothing first. Move slowly, never forcing movements.**
- **Child who cannot stand, but has good sitting balance**

- Teach side push ups

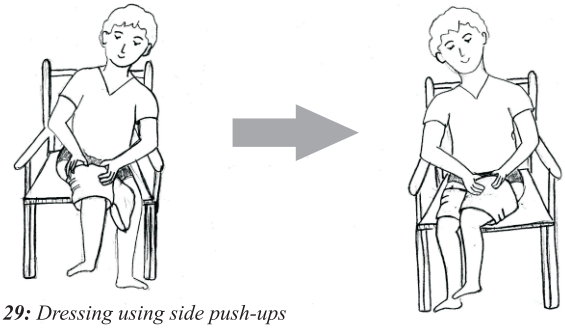


Fig. 29: *Dressing using side push-ups*

- Teach bridging, where the child lifts his pelvis up from the floor while lying on his back.

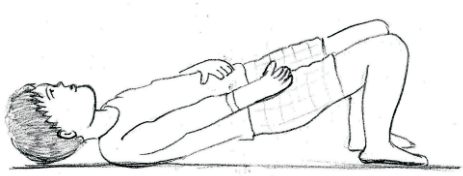


Fig. 30: *Bridging*

➲ **Child who does not have sitting balance**

❍ Teach rolling sideways

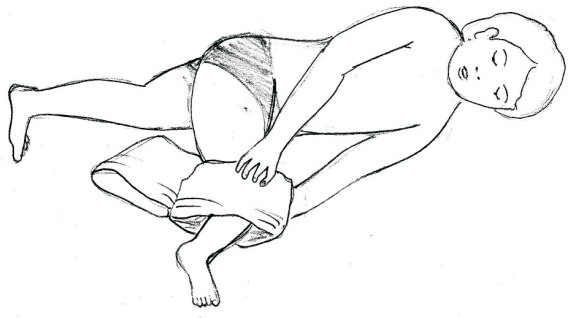


Fig. 31: *Dressing by rolling sideways*

➲ **Buttoning**

On a button board, large buttons

❍ Removing

- Remove half button
- Insert button into the hole
- Pull the buttons apart

❍

❍ Putting on

- Putting on half button
- Pulling button in, once it is kept in the hole
- Fully putting on the button

Once the child is able to remove or put on a button on the board, keep the shirt on the floor, and later can do it on self. If the child cannot hold the button, a button hook can be used.

➲ **Adaptations**

- ❍ Loops can be sewn inside the waistbands of pants and skirts to assist with pulling
- ❍ Elasticized waist bands
- ❍ Grasping surface of zipper can be increased by adding a metal ring or fabric loop
- ❍ Zipper openings may also be adapted with Velcro to minimize the fine dexterity demands of the task
- ❍ Selecting clothes with sleeves as loose as possible
- ❍ Buttoning can be avoided by selecting pull over garments
- ❍ Long handled reacher can be used when the child does not have adequate balance to stoop and reach legs

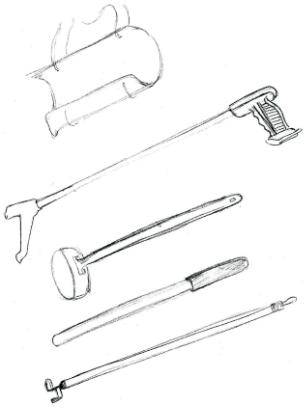


Fig. 32: *Long handles reachers*

- ❍ Button hook, to assist in buttoning

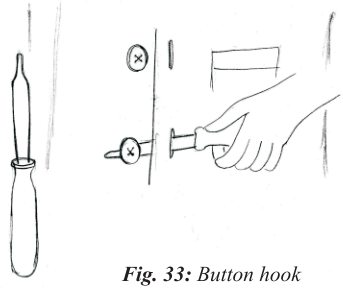


Fig. 33: *Button hook*

➲ COMBING

If the child cannot hold a long comb, use a round comb and make an elastic handle through which the child can insert his hands easily.

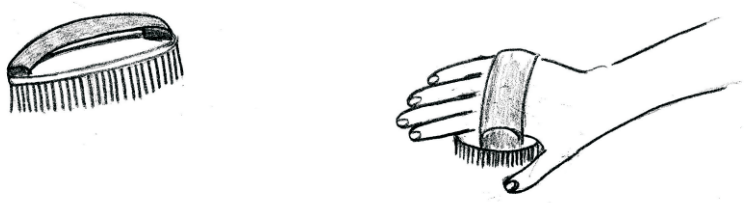


Fig. 34: *Round comb with elastic handle*

TOILETING

➲ If the child does not have any control and wets pants

❍ Collect a baseline data
For 5 days note the time in which child passes urine

Date	12	13	14	15	16
	6.00	7.20			
	6.30	7.50			
	7.15	8.15			
	7.45	8.45			
	8.30	9.15			
	9.00	10.00			

❍ Calculate the time interval. Then choose the shortest, most frequent time interval. In the above example it will be 30 minutes

- Make a schedule with half an hour interval from the time child wakes up. Mark the schedule as follows

  ✔ : passes urine in the toilet
  \- : does not pass urine
  x : accident, i.e. wets pants

	17	18	19	20	21	22
7.00	✓	x	✓	✓	✓	✓
7.30	-	✓	✓	✓	✓	✓
8.00	X	x	x	-	x	✓
8.30	X	✓	✓	x	✓	-
9.00	x	-	✓	x	✓	✓
9.30	-	x	x	-	✓	✓

- If the child does not pass urine, when taken to the toilet, try the following
  - Leave the tap open
  - Massage lower abdomen
  - Pour water over lower abdomen and legs
- If the child still does not pass urine, take him to the toilet after 5 minutes.
- If, the child has an accident, always take him to the toilet before changing his clothes. This will help them to associate toilet with passing urine and changing.

- Once the child is accident free, slowly increase the time by 10 minutes.

- If the child is accident free for a 2 hour schedule, start with indicating

  - By gestures
  - Sounds
  - Remember to reward the child for both indicating and passing urine separately.

- Cleaning after voiding

  - Child pours water while mother cleans
  - Child cleans while mother pours water
  - Child pours water and cleans simultaneously

- Modifications

  - If the child cannot squat
    - Toilet stool.

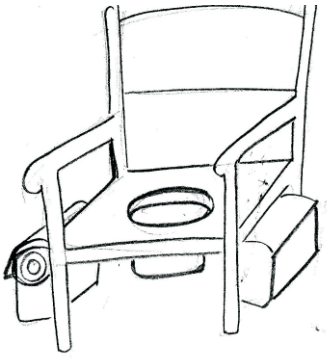


Fig. 35: Toilet stool

  - Child cannot reach backwards to clean
    - Long handled brush

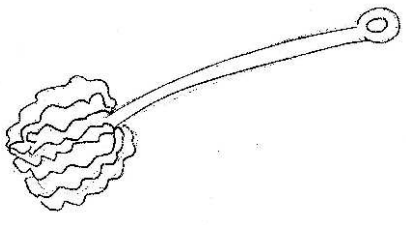


Fig. 36: *Long handled brush*

  - Child cannot grasp the mug and pour water
    - Hand shower can be used

BATHING

If the child cannot hold a soap, or if its slips from his hands

- Soap on a rope

Fig. 37: Soap on a rope

- Long handled brushes to reach back side, legs

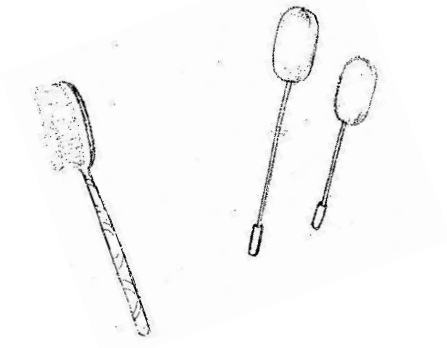


Fig. 38: Long handled brushes

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