

**Part 2:**

**Supporting  
the Child –  
*General  
Principles***

# Considerations for Specific Age Groups

# Children of All Ages

## 1. Hygiene

It is especially important to maintain hygienic practices when supporting children with disabilities, as they can be particularly vulnerable to infection.

- Ensuring a clean environment for playing and eating
  - Keep all play and feeding areas clean – wipe surfaces with a *clean* cloth
  - Avoid dirty toys in the child’s mouth
  - Ensure cooking equipment and utensils are clean before using
    - Rinse in *clean* water and dry them in the sun
  - Wash your hands before cooking and eating
- Preparing your child for eating
  - Wash yours and your child’s everyone’s hands
    - Make sure the water comes from a flowing source
    - Use soap or ash
    - Dry hands in the air or with a paper towel – avoid shared towels
  - Wash your child’s face before eating as well as afterwards
  - Clean your child’s teeth before eating as well as after in drinking water



## 2. Participation in daily life

It is important that your child participates in daily life as much as possible. Try to involve them in what you are doing around the house or outside. If they are too young to help, then make sure they are sitting in a supported position, watching you. Talk to them whilst you are doing your housework. Take your child shopping with you – show them things in the street and the shops, encourage other people to communicate with your child.



# The importance of a daily routine

Following a routine of daily activities is the most effective way for a child to help develop his/her practical life skills.

The way parents support a child in each daily activity needs to change as their skills develop.

***Work with the parents to help them choose specific activities of the daily routine to focus on. Use the parent interview form in the appendices to help them decide. And then move onto others. It is easier that way, rather than trying to work on everything at once. Make sure they choose activities that the child will be able to make some progress in quite quickly, to keep everyone motivated.***

## **Before, during and after each activity:**

- Communicate directly to the child to prepare them for every activity (using all forms of communication necessary).
- To encourage independence, ask the child what he would like to do and see how it can be planned.
- Take time for the child to relax (reduce tone) in a stable position before starting an activity – this may be in lying, side lying, sitting or standing etc.
- Keep movements smooth when supporting an activity – the child will relax if you support and guide them to do an activity.
- Break activities up into small steps, encouraging the child to do just one part of the activity to begin with, if the whole activity is too difficult.
- Teach one step at a time. It can help to teach the last step first, and slowly work backwards e.g. with dressing.
- Praise the child for achievements and improvements – if the child gets frustrated, try make the activity easier or turn it into a game if you can.
- Give the child every opportunity to do activities on his own and in his own time.
- Make sure the daily routine is followed consistently by the mother and other carers and discuss how the child is doing.

# Setting up the routine

## Have you prepared the equipment or materials for the activities?

<b>Mobility</b>	<p>Are the shoes and supports ready to use?</p> <p>Are the <i>walker</i>, crutches or wheelchair nearby?</p>
<b>Positioning</b>	<p>Are the chair, standing frame, cushions, blankets, rolls or wedges nearby?</p>
<b>Communication</b>	<p>Is there a safe and quiet area ready to use?</p> <p>Do you need any visual materials to help you to communicate?</p>
<b>Play or Educational Activity</b>	<p>Is the space ready to play in? Is it clean?</p> <p>Do you need any specific type of materials to work with e.g. to promote individual and group play or activities, working on recognition, choice, numerical or literacy skills or listening to music etc?</p> <p>Is it age appropriate?</p>
<b>Eating and drinking</b>	<p>Are the chair (supportive seat) and table ready to use?</p> <p>Do you have a soft spoon and an unbreakable dish?</p> <p>Do you have a bib/cloth to catch extra food and dribble?</p> <p>Is everything clean?</p>
<b>Dressing</b>	<p>Is there a safe area to lie or sit to use for dressing?</p> <p>Are the clothes ready and chosen by the child?</p>
<b>Washing</b>	<p>Is there a safe area to lie or sit to use for washing</p>
<b>Toileting</b>	<p>Is there a special clean toilet seat to use for toileting?</p>

# Babies and Young Children (Birth – 2 years)

***The healthcare worker's role is to support families in providing the best environment in which their children can develop.***

***The early years are also a time for healthcare workers to identify babies/young children who are developing differently from others.***

Early concerns that a parent or carer may have for a child who is not developing like others their age:

- Sleeping too much or sleeping too little
- Difficult to settle when held
- The body of the child is too floppy (almost slips through your hands) or stiffens when handled
- Difficulty while feeding – feeding very slowly and not gaining weight; coughing/choking while feeding







When a parent has concerns which the healthcare worker feels are valid, she should refer the child for a detailed assessment with a specialist/specialist team, where available.

***The healthcare worker's role is to guide the family on how to support their child to develop to its best ability throughout the normal activities of the day and on how to ensure the child is included, as far as possible, in the normal daily life of the family and community.***

The healthcare worker needs to:

- Listen**
- Support**
- Work with the family to look for solutions**

## General priorities: babies and young children

<p><b>Movement and posture</b></p>	<p><b>Encouraging movement and good positioning helps the child develop in all ways!</b></p> <p><b>Good positioning may also help limit future problems with posture (<i>postural deformities</i>)</b></p> <p><i>Postural deformities</i> (limb contracture, hip dislocation and spinal deformity) are common secondary effects if a child has cerebral palsy. They can result in pain, increased deformity, inability to sit, and general difficulties with daily living. Children with severe physical difficulties (i.e. cannot sit without help by 18 months of age) are at risk of hip dislocation.</p>
<p><b>Changing positions</b></p>	 <p>The child's position should be changed regularly to minimize stiffness and the development of future problems with posture.</p>
<p><b>Sitting</b></p>	 <p>To support sitting, sit behind the child and support them on both sides of their body.</p>
<p><b>Standing</b></p>	 <p>Try to keep the child's body straight when lying, kneeling and standing.</p> <p>Providing supported and <i>symmetrical</i> standing, at the age children normally learn to stand, helps the child to grow straight and can reduce problems with their hips. It also helps to strengthen the muscles and bones of their legs.</p>
<p><b>Playing</b></p>	 <p>Have suggestions on making home toys. Explain why this is important for the child's development and show the family how to play with their child. For example, hang toys within the child's reach and play turn taking games like peek-a-boo.</p>
<p><b>Communicating</b></p>	<p>Encourage parents to talk to their child before and during any activity – showing them the objects involved, and explaining what you are going to do together. Tell parents to encourage their child and praise them for any response they give. It doesn't matter if they don't understand what the parents say. Remind parents to do things slowly, gently, and not to rush or force the child.</p>



## The daily routine: explain to the parent....

### Carrying

Carry the child in a *flexed* position and fairly upright. This helps to keep the child safe.

Hold the child close to your body, both for safety and also to protect your back.

This position will also help the baby to practice holding up their head.



### Mealtimes – eating/feeding

For breast/bottle feeding – find a supportive position in a calm and relaxed environment.

If they can manage, babies should be exclusively breast fed for the first 6 months of life. Encourage the mother to respond to early cues like sucking, cooing and restlessness to offer the next feed.

Once the baby is 6 month old, they should be fed in a more upright position, using recommended complementary foods which have a high nutritive content (Appendix).

Hold the child, *flexed* at the hip, sitting fairly upright, to help them to swallow. Make sure the head is straight and with the chin tucked in a little.

Talk to your child and make frequent eye contact.

Follow the child's cues (e.g. look for signs of wanting more or not managing and wanting to stop/take a break). Make mealtime a pleasant experience.

If the baby is finding it hard to suck, you can try to give them milk from a medicine cup. Don't pour the milk in, but place the edge of the cup against the child's lips and allow them to 'draw it in'. Expressed breast milk should be the first choice of food.

If your baby is failing to grow, it is important to see a specialist and get advice on early weaning. Follow local guidelines on hygiene and ensure the food is nutritious.





As soon as the child is ready, encourage self-feeding, using a spoon or fingers (depending on the type of food). *(Reassure the mothers' concerns about making a 'mess' – it is part of the learning process).*

Start by encouraging the child to touch the food then take their fingers to their mouth. Then support them in feeding themselves with a hand over theirs ('hand-over-hand'). Again, be mindful of the need for good hygiene.



## Bathing

Support the baby on your lap to wash them or use a bowl or small bath with a small amount of tepid water in it.

Put a cloth under the baby to make the bath less slippery.

Support the baby's head out of the water with an arm.

Bath time is fun time. Play with the water and sing songs.

Dry the skin with soft pats – look for spots or marks which may suggest something is rubbing the skin and might need care.



## Toileting

Changing pants or nappies is an ideal time for gaining eye contact, playing and talking to your child. Communicate using your facial expression and a soft voice to help the baby relax.

As the baby learns to sit up with help, prepare for toileting using a potty or small bowl. Hold child on each side of the hips – see the picture.

This activity is good practice for the child to learn to sit on their own.



## Undressing/dressing

Find a safe and soft position to place the child in when they are being undressed or dressed. Talk softly about what is happening. This helps the child to anticipate what is coming next, for example, by asking “Where is your vest?”. Pause for the child to look at their arm or move it up. Smile and praise the behaviour.

Encourage the child to get involved in dressing and undressing themselves with you.



## Sleeping/resting

Create a safe sleeping place (a cot/bed) where the baby is at no risk of falling out or being injured.

If the baby is *unable to move* and usually stays in the same position, position them into different positions from time to time, using cushions and rolled up towels.

With cushions and towels, support the child to lie with the knees and hips a little bent. This encourages them to be less stiff.



## Going outside

It is important to try and take your baby with you wherever you go e.g. to the fields, to the shops. A sling (see the picture) can be very useful because the child is carried close to the adult and it can help the child develop head control.

Talk to your child about what is happening around them, and encourage other people to talk to the baby.



## Play

Playing with another person is the most valuable activity for babies and young children.

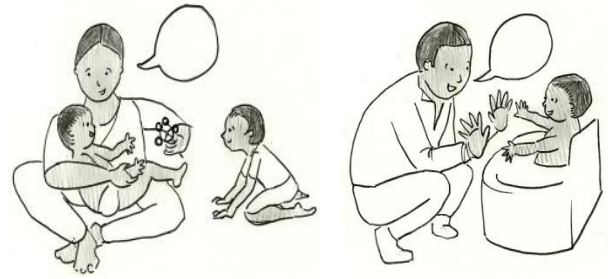
Playing with/exploring their bodies also very important.

Use a range of positions.

Make sure that all toys, whether home-made or bought, are safe.

Make sure the child can reach the toys. Help the child to touch them and explore them.

Watch carefully to see which toys get a strong response from the child – a laugh, a smile or a movement towards it or away from it!



# Teenagers

***A key role of the healthcare worker is to encourage a young person to continue to be as independent as possible.***

## Priority areas

- **School – life skills and work skills**
- **Social activities with peers**
- **Work**
- **Physical and Communication needs**
- **Self-care skills e.g. eating and drinking, toileting, dressing etc.**

From 13-18 years the healthcare worker has a key role in supporting the young person with a disability and their family in their transition to adulthood.

The disability is only part of the person and it is important to consider other aspects of the young person when working together?

**With regards to the patterns of development**, it is important to note that as the young person gets older, physical abilities may change or deteriorate (due to strain, poor posture, overuse of the muscles and joints, and emotional stress) and their capacity for learning new things slows down. Young people with **severe** cerebral palsy will notice the greatest physical changes. This does not mean that they cannot learn new skills for work, but it is important to take these factors into consideration and find ways of compensating through *functional support strategies*.

As the young person with a disability transitions to adulthood, changes in their body and its functions will also need to be addressed. This is particularly important in young girls who will need to be prepared for their menstrual period.

This can be a challenging time for a young person and the healthcare worker has a vital role in supporting this process.

It may be useful to break down your work into 2 sections:

### **A. Working with the young person with a disability**

The healthcare worker needs to:

- a) Listen**
- b) Support**
- c) Identify 2 key problems or difficulties and make an action plan together with selected targets.**

The young person has to adjust to the emotional and psychological impact as well as changes within themselves. Often their quality of life changes and the individual will need a lot of support to adjust to this. This may often be influenced by the local situations and the acceptance of a young person with a disability within their community.

## B. Working with the young person and their carer(s)

Before, during and after each activity a) look at your action plan and targets – talk through the activity b) listen to the discussions from both sides and suggest or agree to activities c) choose the activity – see how it goes d) provide support where needed to the young person or carer e) take time.

***The care and support provided by the family and others changes as their child grows up and they often start to give up as the future for their child as a young person looks difficult. The healthcare worker can be very helpful in this period – motivating, providing ideas and making things happen for the young person.***

## Priorities for teenagers according to level of disability

Main focus		
Level 1	Level 2	Level 3
Main focus is on education and preparing for work	Main focus on socialisation and adjusting to any changes in <i>mobility</i> .	Main focus is on facilitating involvement in daily life and maintaining quality of life.  For individuals with cerebral palsy, focus also on handling and positioning – aim to maintain good <i>posture</i> in lying and sitting, and adjusting to changes in mobility. Help the family and carers to physically manage a longer and heavier individual.

Suggested activities		
Level 1	Level 2	Level 3
Daily living skills	Follow a routine of personal hygiene, toileting, dressing etc.; maintain a healthy eating and drinking regime and try to maintain a good weight.	Have suggestions for home modifications, aids and equipment (see Appendices) to support any changes e.g. supportive seating, modified cutlery, rails on the walls, ramps into the house etc).
Participation in family and community life	Ensure that the young person is involved in family and community life and not living in isolation.	Prepare families on how they will support their disabled child within the family and the community – encourage families and the young person to discuss any concerns and face any issues.
Maintain mobility and strength	Maintain their mobility in sitting and standing; work on balance and help to reduce any increasing fear of falling; finding ways to <i>transfer</i> as independently as possible and to keep walking with appropriate assistance.	Look at ways of supporting families and the young person on how to deal with other people’s comments as their youngster grows into adulthood.
Keep active – for general health and wellbeing, and for participation in social activities	Encourage the young person to be involved in community activities (e.g. education, sports, peer to peer groups etc). As the healthcare worker, you may be the main persons outside his family that he or she meets. You may become a trusted friend.	Work with the young person to identify what goals he or she would like to accomplish in the next year e.g. visit friends regularly, be involved in cooking etc.

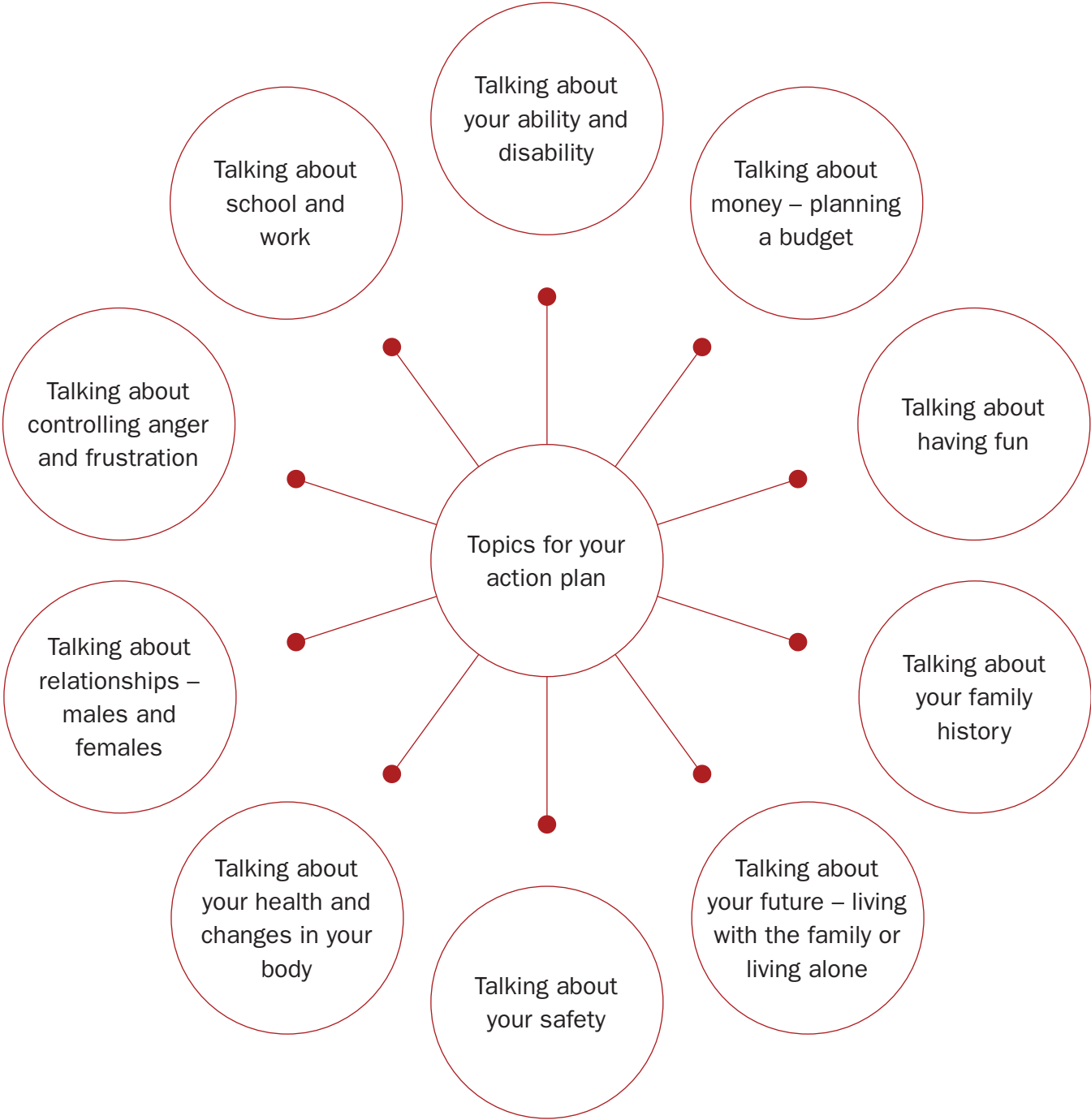
It becomes more important, as a young person grows up, that they feel believed in, respected and accepted by others.

***A family healthcare worker has a key role in reducing the negative attitude and prejudice towards a young person with a disability by listening and encouraging them to take the lead in decision making.***

***A family healthcare worker has a key role in eliminating barriers which often stop a young person with a disability from leading a fulfilling life.***



Here are some suggested topics for conversations and planning with a youth with a disability:



Each of these suggestions can be made into an action plan, as shown in the table of ‘suggested activities’ above. When planning, it is important to also consider information from other relevant sections of the manual.



# Considerations for Specific Conditions

# Cerebral Palsy

## Priorities according to level of disability

### Level III

**Movement and positioning:** Provide opportunities to encourage head and body control and use of hands in well-supported sitting. The child will need a supportive chair and standing frame.

**Communication:** Use *Total Communication* methods to help the child understand the adult (facial expression, hand gestures, sounds, objects, pictures) and to help the child show the mother what they need/want.

**Eating and drinking:** Make sure the child is in an upright symmetrical position for feeding and that their head is well supported. Give soft food that is easy to chew and swallow. Make sure it contains the full range of nutritious ingredients with extra oil for energy. Explain that the child should be fed small amounts at each meal and given a minimum of 3 meals and 2 snacks per day. Small amounts of water should be given **throughout** the day (minimum 1 litre). Encourage the mother to talk with their child, feed carefully and sensitively, and to make this an enjoyable time.

### Level II

**Movement and positioning:** Provide opportunities to encourage independence in sitting (the child may need pelvic/trunk support so that they can use their hands). Help the mother create opportunities for the child to stand supported, and to walk with support.

**Communication:** Use *Total Communication* methods to help the child understand (hand gestures, objects, pictures) and to help the child show the mother what they need/want. Encourage the mother to talk to their child through playing.

**Eating and drinking:** Make sure the child is in an upright position for feeding. Give food that is easy to chew and swallow but that is also nutritious. Encourage the child to be involved in feeding itself (hand over hand). Make sure they drink enough water – small amounts throughout the day (minimum 1 litre). Encourage the mother to make this a fun time for communicating with their child.

### Level I

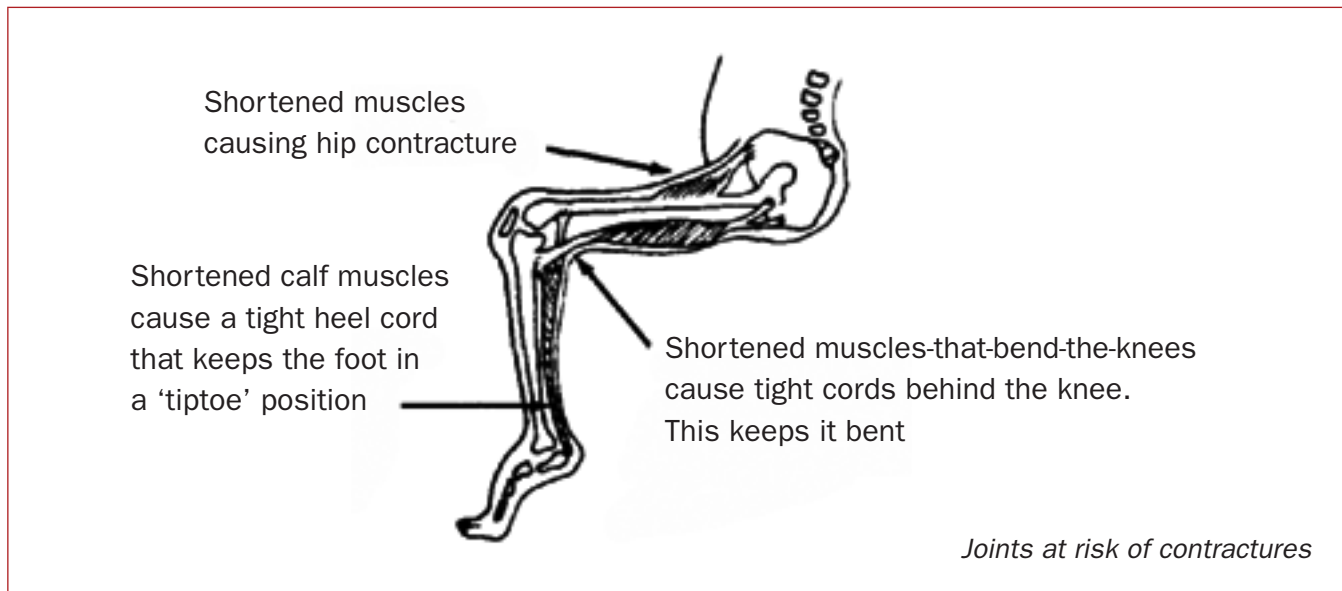
**Movement and positioning:** Encourage the mother to provide opportunities to develop independence and balance in standing and walking.

**Communication:** Encourage the mother to help their child to be aware of their own speech and the need to talk slowly so others can understand. Show the mother how to encourage the child to use all forms of communication where necessary.

**Eating and drinking:** Make sure the child is eating food that it will not choke on (crunchy, hard, chewy). Encourage self-feeding and tell the mother not to worry about the mess.

# Contractures

Contractures are a shortening of the muscles e.g. at hips, knees, ankles or shoulders, wrists and elbows, spine. As the child with spastic cerebral palsy grows, the muscles do not always grow enough, or they may grow differently, so become imbalanced.



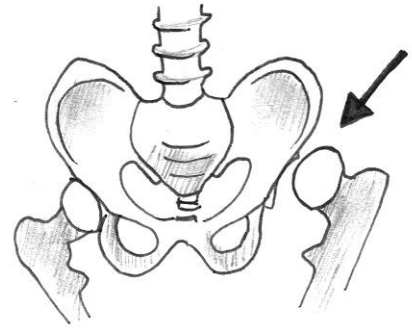
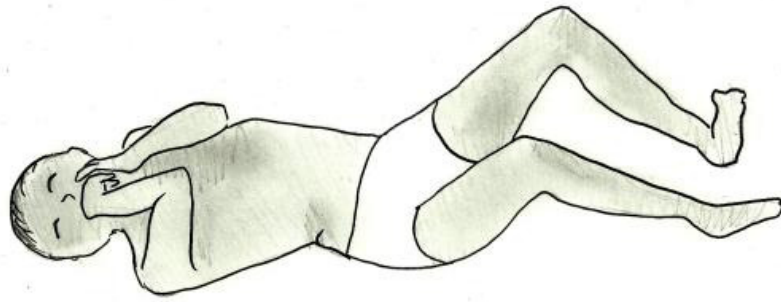
**Issues:** Contractures cause deformities and pain. Contractures are made worse by poor positioning and inactivity. Muscles and joints remain more flexible when they are used throughout the day.

**Solutions:** Even in a person with minimal spontaneous movements, creating a daily routine which involves using different positions throughout the day (side lying, sitting, standing etc.) will keep the limbs active.

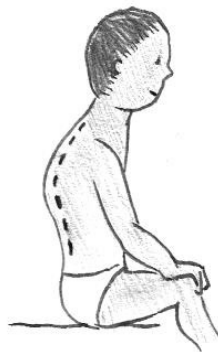
**Your role is a) to anticipate contractures and deformities before they happen, b) if the contracture is already identified, to try to stop it getting worse or help to reduce the degree of deformity, c) to find a more comfortable position to relieve the pain.**

## Most common deformities caused by contractures and loss of movement:

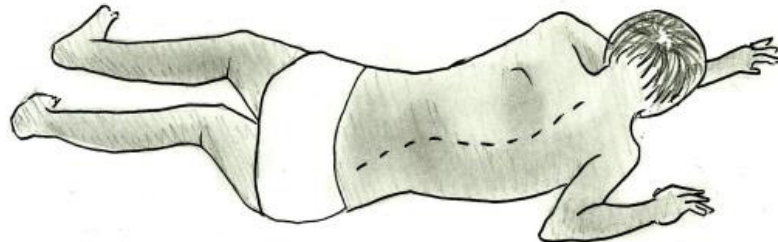
- **Hip dislocation** – the child cannot move his legs normally and take weight on them



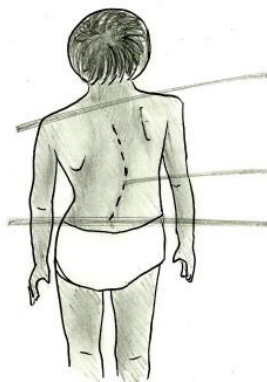
- **Forward curvature of the middle part of the spine** – the child is not able to sit up straight



- **Arch in the lower back** – the child is not able to use the abdominal muscles or to compensate for the hip which cannot straighten



- **The spine adopts an S shaped curve of the spine (scoliosis)** – can cause problems for breathing and digestion

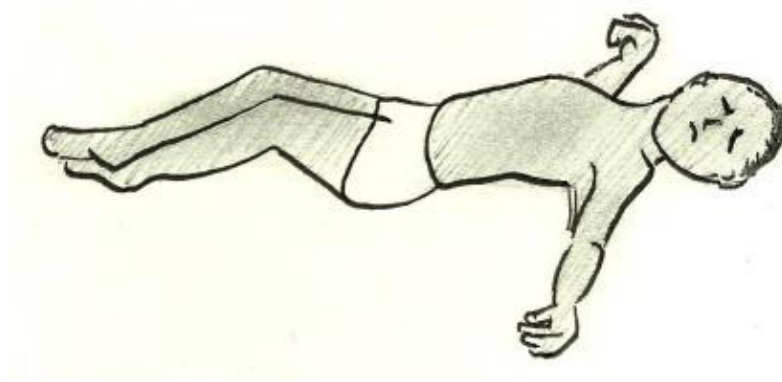


*Asymmetrical shoulders*

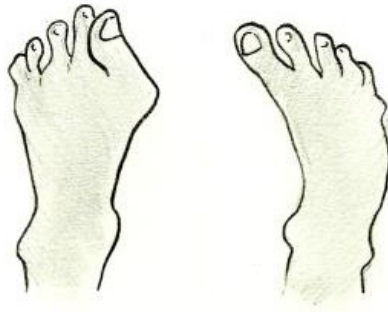
*Curvature of the spine*

*Even hips (at risk of contracture and becoming asymmetrical)*

- **Knee – flexion deformities**



- **Foot deformities** – with foot turning in or out ('valgus' and 'varus')



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## **Pain: understanding how pain can affect the child's daily activities**

There may be times when you visit a child with disabilities, when they seem unhappy or disinterested in your visit. This may be due to many things, such as being hungry, not feeling well, lying or sitting in soiled clothes or very often it may be due to pain somewhere in their body. However, if a child with cerebral palsy has problems with communication, carers often do not often understand or know how to interpret their behaviour, which may be indicating that they are in pain.

Many children, especially those with severe cerebral palsy, may make groaning sounds and facial grimaces or may be lethargic and irritable, as well as having irregular sleeping patterns. These are often interpreted as signs of pain, which is not always correct. It is important therefore to understand each child and take time to observe their behaviours.

**Ask the carer questions so that you can get answers for the following:**


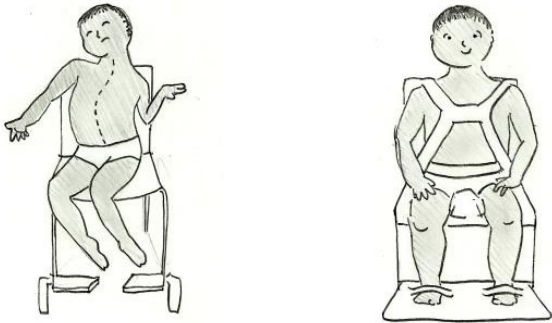

- *Do you think the child has pain? (Yes/No)*
- *How do you know this?*
- *Do you know what triggers the pain e.g. sudden movement, noise, pressure or fatigue?*
- *Does the pain last for a long or short time?*
- *How does the child themselves try to stop the pain e.g. moving position, stretching, asking for help etc.?*
- *What have you tried to help the child to manage their pain?*

If you can find some of these answers, then you can help a child with cerebral palsy manage their pain.


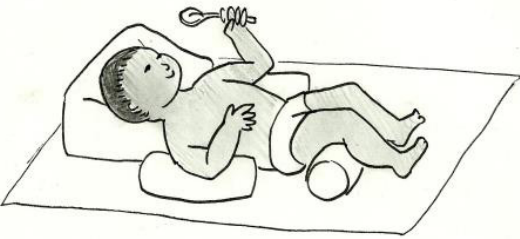
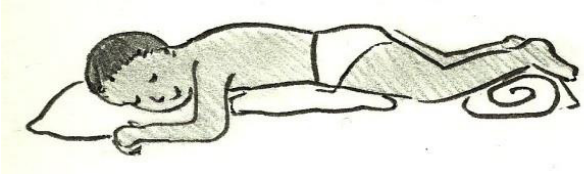

The parent needs to have a good knowledge of how the child communicates when he is in pain, so that they can judge when the child needs to change position etc.

***Your role is to help the child manage their pain or help the child find a solution:***

- ***Encourage carers to place their child into a series of comfortable and functional positions which also provide a sustained joint stretch over a longer period. E.g. using a wedge, a good chair, or a standing frame.***
- ***The more active a child is – the less likely they are of getting contractures – so for some children activities are the most useful way of helping.***
- ***Think of WHY the child may be in pain. Look at the checklist on the next page, which gives some solutions to try and help the child feel more comfortable.***

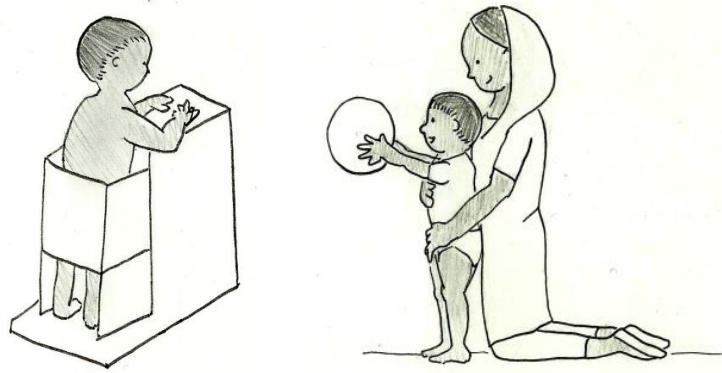
Common causes of pain and discomfort	Solutions
<p>Has the child been lying in the same position for a very long time?</p> <p>This creates stiffness in joints and loss of joint flexibility.</p>	<p>Change position every hour between different lying and sitting positions. Check for pressure areas on the bony parts of the body and stop the child from lying on those areas.</p> 
<p>Is the child sitting in a way which is not balanced (straight)?</p> <p>Sitting <i>asymmetrically</i> (not straight) in a poorly fitting chair – creating new or increased back pain.</p>	<p>Make sure that the chair fits the child so that he or she is sitting in a good position. Make sure the chair or table are not digging into their legs or chest. Also check that the belt is not digging in and if possible is padded.</p>  <p style="text-align: center;">Sitting <i>asymmetrically</i>                      Sitting straight</p>
<p>Has the child got dislocation of the hips?</p> <p>Living with a hip dislocation – creating loss of joint function and an increase in muscle spasms</p>	<p>Make sure that when the child is moved from one position to another, it is lifted under the hips and not picked up by the legs.</p> 



Common causes of pain and discomfort	Solutions
	<p>When lying, make sure that the dislocated hip is well supported (e.g. avoid the leg being bent over across the body). If a child stands from an early stage, they are less likely to get a hip dislocation.</p> 
<p>Does the child have very tight muscles and joints? Increased muscle tone and spasm – resulting in tight muscles and joints.</p>	<p>The following positions can all reduce tone:</p> <ul style="list-style-type: none"> <li>• Positioning in <i>supported lying</i> (lying with the head lifted slightly, the shoulders supported and the legs a little bent)</li> </ul>  <ul style="list-style-type: none"> <li>• or in supported <i>prone lying</i> (lying on the front over a rolled blanket)</li> </ul>  <ul style="list-style-type: none"> <li>• in <i>sitting</i> (supported by a person or a chair with hips bent up, and shoulders made rounded)</li> </ul> 

Common causes of pain and discomfort	Solutions
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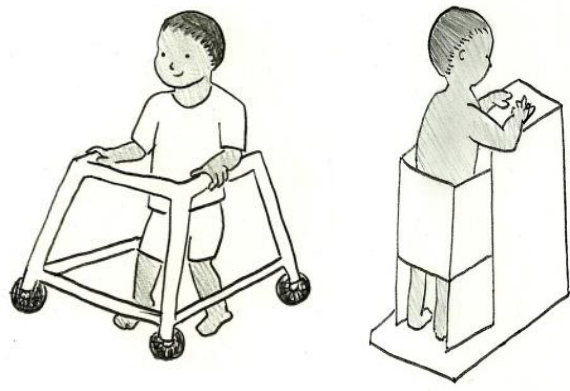
- in *supported standing* (standing supported leaning forwards, or in a standing frame)



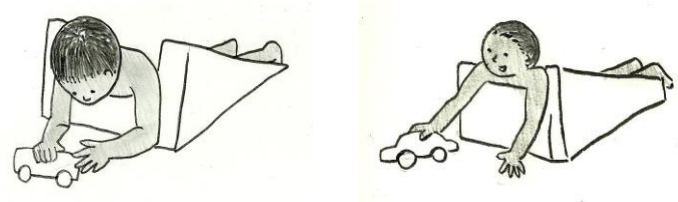
Does the child seem to be in pain when they stand or walk?

Standing and walking on the child's weak hip, knee and ankle joints – creating increased joint pain and muscle fatigue.

Reduce the amount of time the child is standing or walking and use an aid, such as a supportive standing frame, crutches or a walker.




Try to do exercises together to strengthen the trunk, and leg muscles e.g. (i) prone lying on a wedge pushing up on the arms and lifting up the head.



(ii) sitting down and standing up, using the legs and arms.



Common causes of pain and discomfort	Solutions
<p>Does the child seem in pain after exercise or activity?</p> <p>Extra effort and over exertion – causing fatigue and anxiety.</p>	<p>Work together to set up a daily routine that makes time for rests and drinks or snacks, as required.</p> <p>Make sure the child knows what you want them to do and that they want to do it.</p> <p>Make sure the task is within their abilities, and if not, provide more physical support or change the activity.</p>
<p>Is the child in pain during stretching exercises?</p>	<p>Some carers carry out a routine of stretching exercises on the child’s legs and arms. If these are carried out incorrectly they can cause pain, for example, if the limb is pushed straight when it is not ready to do so, or the joints are <i>over-mobilised</i>. Stretches are <b>not recommended</b> any more. <b>Good positioning</b> is the current method to manage the child.</p>
<p>Does your child experience discomfort during eating and drinking?</p>	<p>Make sure that the child is sitting in the correct position for feeding and that the food is of the correct consistency to be swallowed easily. Give small mouthfuls and feed SLOWLY (see detailed guidelines on eating and drinking in section 3).</p> 

# Positioning

**Sitting a child with cerebral palsy in a way that facilitates good posture can be extremely difficult. For some children, a well-fitting, supportive chair helps maintain a good posture and minimizes contractures. Often a child with severe cerebral palsy needs a lot of help to sit well. Here are some tips:**

## Helping to find the right way to position and seat a child

- 1:** Talk with the child whilst assessing their position in the chair. Enquire about what makes them most comfortable (though this may not be what is best).
- 2:** Consider how to keep the pelvis right back in the chair (use a pelvic strap). Ensure that the seat is not too deep or too wide and that there is a close fit at the sides of the pelvis to keep it straight within the chair (if necessary use padded blocks, a rolled or folded cloth or towel for this).
- 3:** Consider how to support the spine and trunk (e.g. chest strap, cloth/towel up the sides and tray for the child's elbows).
- 4:** Consider how to help the feet to be placed flat (e.g. foot support, with or without foot straps).
- 5:** Consider how to support the child's head, especially during mealtimes (e.g. cushion attached to a high chair back or head rest). Aim for symmetry in both sides of the body).

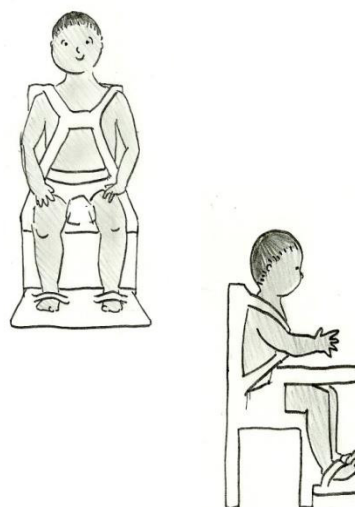


The child here is sitting in an unstable position and has problems keeping his balance and being comfortable. The lack of support makes it difficult to carry out any daily activities and increases the chance of contractures and deformities.



This child has

- feet on supported surface (with foot straps)
- a pelvic strap and chest strap to encourage sitting upright
- a tray table but he is still twisted at the pelvis which will be bad for his spine



This child is looking even more relaxed and symmetrical in a chair with

- foot straps
- a seat that fits on the sides
- a pelvic strap and chest strap to encourage sitting upright
- a head rest to keep the head upright
- a pommel between the legs

## Exercises to help healthy development:

*Weight-bearing* activities in supported standing are another important way to help the child with cerebral palsy to develop healthily. It prevents the development of contractures in the foot, knee and hip and allows the child to use their hands whilst being supported in a stable position. Supporting the child in a standing position, using a standing frame or other method, is therefore an important part of their day.

**Note:** If the child already has contractures, this may not be possible, and may cause a lot of discomfort.

Weight-bearing helps the formation of the hip joint in a younger child; it improves bone density (strength of the bones) and helps to prevent hip dislocation. It also help the child to learn to place their feet flat on the floor – which is essential if the child is going to be moved easily ('transferred') and with less carrying from one position to another (e.g. enabling toileting).



***As you build up the daily routine with a child with cerebral palsy, there are many things to look into.***

***You need to decide together with the carer and the child, what are the priorities to help build the daily routine.***

***Find out where you can get special seats and equipment made.***

For information on how to make low-cost equipment for the home, visit  
**<http://www.paperfurnitureenterprise.com>.**

You can also contact **[info@maits.org.uk](mailto:info@maits.org.uk)** to request training in this.

# Social Communication Difficulties (SCD) and Autism

## Overall priorities for children with social communication difficulties (SCD) or autism

- Encourage parents to try to understand their child. What are their child's abilities or strengths? How can they support these skills?
- Persuade parents to do fun things together with their child. Suggest things they can do together which encourage the development of interaction, communication, physical and self-care skills through play.
- Help the parents identify what activities the child enjoys and see how they can teach skills through doing these. (E.g. if they like to collect small objects, help them to tidy away after mealtimes).
- Use visual support for communication as much as possible (objects, gestures, pictures). The child may prefer to use non-verbal methods of communicating.
- Help the parents to make a time table for their child's day; encourage them to ensure that the day is structured and predictable by keeping to the same routine and preparing the child for any changes that need to be made to it.



# Priorities according to level of disability

## Level III

- For most children with social communication difficulties (SCD) or autism, creating a predictable routine is most important as it will help them to understand what is going on and what will happen next.
- Help the parents to use real objects and single words to communicate what is happening. For example, at mealtimes parents should give or show their child a bowl and say “food”. The parent needs to learn the little signs that show how the child is feeling and how they express what they need (e.g. when they need a drink or sleep). Help the parent to support the child to tell them what they need/want by teaching them simple hand gestures (e.g. raising the hand to the mouth to show that they need a drink)
- It is important to be realistic with parents. Expect small changes in the development of skills over a long period of time. For example a child at this level may learn to pass a ball to another child or adult but not to catch a ball. These children are likely to show signs of stress (usually behaviours, for example pushing you away) if they are asked to do something that is too hard for them.

## Level II

- Help parents to set up and follow routines as far as possible, e.g. routine for bedtime, breakfast time and going to school time.
- Children and young people at this level will need hand gestures (signs) or pictures to help them understand what is happening or expected of them, in addition to being spoken to using simple phrases.
- Children will need lots of repetition of activities in order to learn key skills e.g. being able to follow a command. Do not assume that because the child has been told once they will remember.
- Recommend that the parents give the child additional time to understand what they are saying. Use hand gestures, simple speech and familiar objects (e.g. bowl, toothbrush) during the activity to help the child understand what to do.
- Tell parents to let the child know when they are happy with what they are doing by using simple words that describe what the child is doing e.g. ‘Good teeth brushing’.

## Level I

- Encourage parents to set up and follow routines as far as possible, e.g. routine for bedtime, breakfast time and going to school time. For older children this can include a routine for working. The child will need to hear simple, short phrases and sentences in order to know what is happening next or what they are expected to do.
- If the routine needs to change, the child needs to be told in advance of this change, so the change can be expected. Encourage parents to teach their child how to have a ‘back and forth’ conversation with others by ‘acting it out’ with them. Encourage parents to give their child opportunities to talk and play with other children in order to help them to learn conversation and play skills.



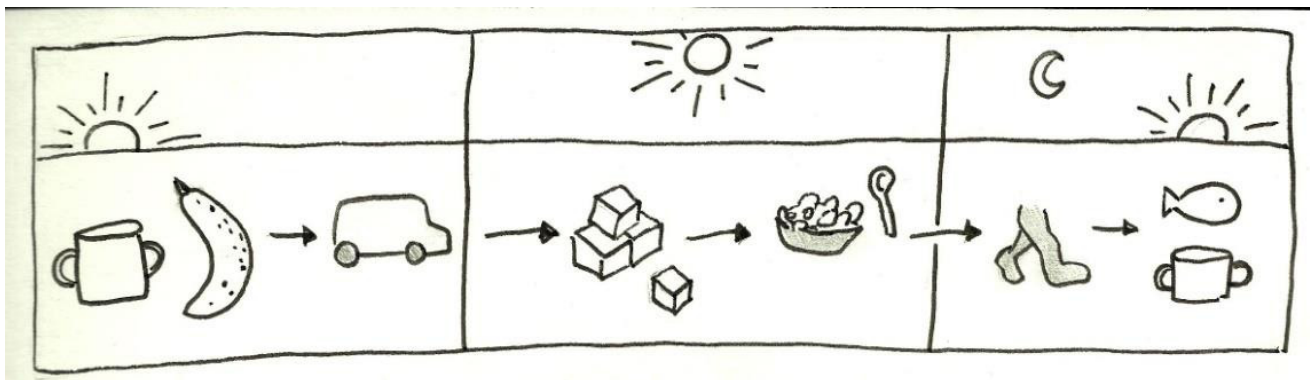
# Providing structure and safety

- **Be consistent**

Children with SCD or autism find it hard to transfer the information that they have learned in one setting (e.g. home) to other settings (e.g. school). Creating consistency in the child's environment is the best way to reinforce learning. For example, parents should make sure that everyone who has contact with their child knows the best way to communicate with them, and uses the same methods, including the same words.

- **Stick to a schedule**

Children with SCD or autism tend to do best when they have a highly-structured schedule or routine. Help the mother to set up a schedule for their child, with regular times for meals, going to the market, going to school, and bedtime. Explain that she should try to avoid changes to this routine. If there is an unavoidable schedule change, the child should be prepared for it in advance. Using a visual timetable to prepare the child for the beginning and end of every activity can also be reassuring for the child.



- **Reward good behaviour**

Encourage parents to notice when the child does something good, and to praise them when they act appropriately or learn a new skill (being very specific about what behaviour they are being praised for). Encourage parents to look for other ways to reward good behaviour, such as letting the child play with a favourite toy.

- **Create a 'home safety zone'**

Encourage parents to create a corner in the home where the child can relax, feel secure, and be safe. Visual cues can be helpful (coloured tape marking areas that are off limits, labelling items in the house with pictures). Parents should also make sure the house is 'safe', so that their child doesn't hurt themselves when they have a tantrum.

## Finding ways to connect

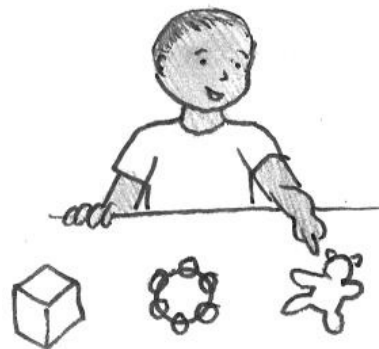
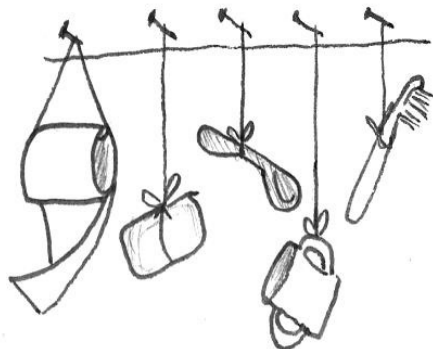
One of the main difficulties that children with SCD or autism have is their difficulty in connecting with other people. Help parents to understand that you don't need to talk in order to communicate and bond. Communication includes the way in which they look at their child, the way they touch them, and by the tone of their voice and their body language. Likewise, their child is also communicating with them, even if they never speak. The parents need to learn their child's 'language'.

- **Encourage parents to look for nonverbal cues.** If they are observant and aware, parents can learn to pick up on the nonverbal cues that their child uses to communicate. They need to pay attention to the kinds of sounds they make, their facial expressions, and the gestures they use when they're tired, hungry, or want something. Practice this with the parents.
- **Work out what the child needs, when they have a tantrum.** It is natural to feel upset when you are misunderstood or ignored, and it is the same for children with autism. Because they have weak communication signals which are often not noticed by adults around them, children with SCD or autism may get very upset. Having a 'tantrum' is their way of communicating their frustration and getting someone's attention.
- **Make time for fun.** Encourage parents to schedule time for play when the child is most alert and awake. Help parents to work out ways to have fun together by thinking about the things that make their child smile and laugh. Play is an essential part of learning.
- **Pay attention to the child's sensory sensitivities.** Many of these children are hypersensitive to light, sound, touch, taste, and smell. Some are 'under-sensitive' to sensory stimuli. Encourage parents to work out what sights, sounds, smells, movements, and tactile sensations trigger their child's difficult behaviours and what creates a positive response. Discuss this with the parents to find out what the child finds stressful, calming, uncomfortable and enjoyable. If parents understand what affects their child, they will be better at troubleshooting problems, preventing situations that cause difficulties and creating successful experiences.

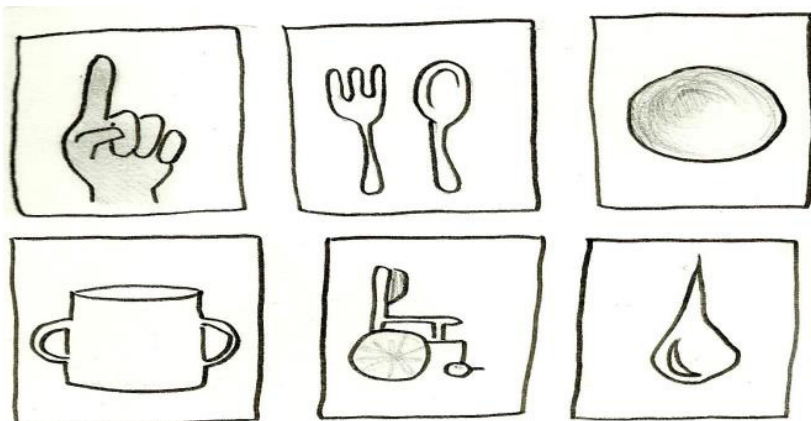
# Using visual support for communication



Use and encourage gesture



Encourage your child to use objects to show you what they mean



Encourage your child to use pictures to show you what they mean

# Profound and Multiple Learning Disabilities (PMLD)

You may meet children with more than one disability, who you feel are too difficult to work with. This section will give you suggestions on how the child with PMLD and the family can benefit from your support.

There is no accepted definition of profound and multiple learning disabilities, but it is commonly associated with severe developmental delay, significant physical and sensory impairments and with epilepsy.

This child needs considerable support for all their care. They can make some progress, but very slowly and to a limited degree. They will always need a high level of support and be dependent on others.

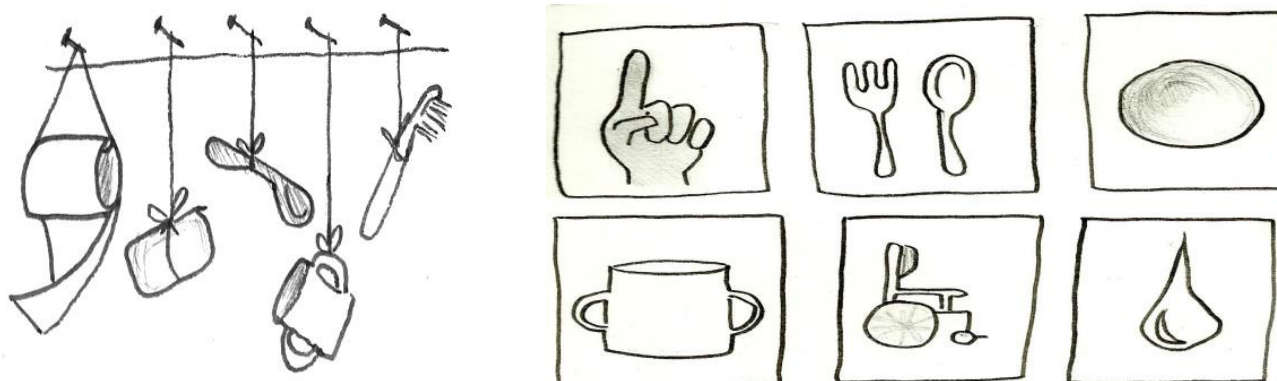
The way in which this child is supported by their carers is therefore extremely important and carer training is essential.

Most common difficulties	Suggestions to carers
Severe physical problems	Change the child's position frequently to prevent or reduce <i>contractures</i> and <i>deformity</i> . Try to find other people to help you with lifting and <i>transfers</i> .
Unable to walk	Use a special chair or a wheelchair.
Hearing and visual problems	Take time to communicate and guide the child.
Great difficulty communicating	Use ' <i>Total Communication</i> ' (see section on Communication).
Profound intellectual disability	Make activities short, simple and fun; repeat them over time.
Behaviours that challenge the family (examples needed)	Build up a daily routine and encourage positive behaviour (see section on Behaviour).
Epileptic fits (seizure)	During a seizure, lie the child in a <i>flexed</i> side lying position, make sure that their clothes are away from the neck and mouth, and that the child is comfortable. Sit nearby to comfort them. Do not put anything in the child's mouth. Get a doctor to review his medication.
Complex health needs or mental health difficulties	Recognise the signs of health problems e.g. chest infection, bladder infection, depression and seek medical advice.

**Ask the following questions to see if this helps to build up a plan with the parents:**

**Question 1: How do you communicate with your child?**

Do you know what your child wants by seeing what they are looking at? Do you help your child to understand what you mean by showing them or giving them the relevant object? Do you use hand gestures, a communication book, a communication board, or other?



Explain to the parents how they should help their child understand what is going on around them by encouraging them to look at, touch and smell things.





Parents should offer choices during daily living activities – i.e. by holding one item in each hand and asking the child which one they want, then watching to see which one the child looks at or points to. This is the first step to developing the child’s communication skills.



## Question 2: Do you know if your child has a friend?

- Often a child with PMLD finds it hard a) to communicate with people b) to make relationships.
- One of the most useful activities is to take them out (to the garden, the fields, the shops etc.) and watch to see what they like and dislike, and offer them new experiences.

## Question 3: What is the main difficulty for you in supporting your child?

- **Is it eating and drinking?** Observe the parent feeding their child; look at the positioning of the child to make sure they are sitting up, with their head slightly tilted forwards. Advise the mother to make the food soft rather than liquid and lumpy (see guidelines on Eating & Drinking in section on CP).
- **Is your child always soiling themselves?** Set up a toileting routine and make a chart for the parent to monitor their toileting habits. Check how much liquid they are drinking; if they become dehydrated they may need medical help.
- **Is your child difficult to dress?** Advise the mother to make sure clothes are one size bigger than needed, to make dressing easier. Find a position where the child is relaxed and can participate in the dressing e.g. side lying or half sitting.

It can be frustrating for a parent or carer to support a child with PMLD, but if you advise the parent to create a simple and well planned activity schedule, then the child with PMLD will have a better chance of making progress.

<b>Common difficulties in learning new things</b>	<b>Solutions for the parent/carer</b>
Difficulty remembering what has been taught	Make your instructions short and simple and repeat the same phrase and routine
Short attention span	Make activities short and direct, then rest and repeat
Under-developed coordination skills	Try to set up activities to develop coordination skills E.g. guiding the hand with the cup to the mouth in order to drink
Inability to apply skills to different situations	Break activities down into small sections – step by step approach
Difficulties with comprehension	Use <i>Total Communication</i>

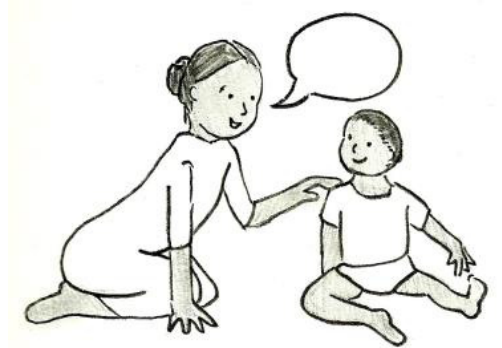
***One of the main aims of working with children with PMLD is to give them control over their lives – this is a challenge for the child and for the carers. A key point in working with a child with PMLD is to provide opportunities for them to indicate what they likes and to choose what they want to do in the day.***



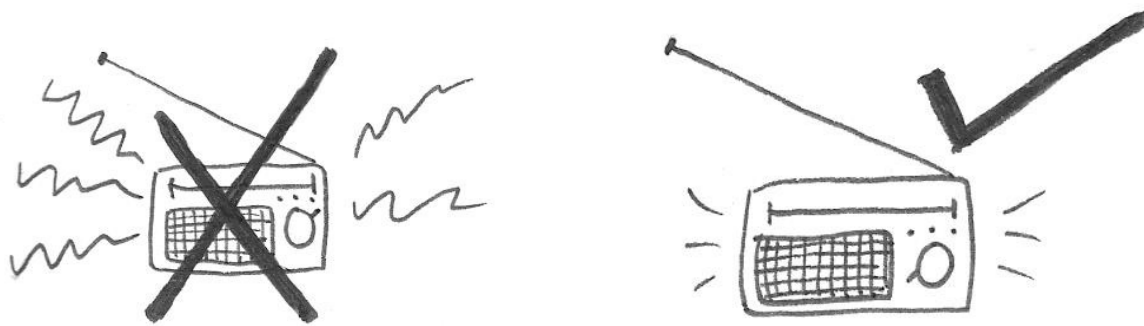
# Top Tips for Parents and Carers

# Children with a Hearing Impairment

- Get the child's attention first and give them some time to focus before you start to communicate with them.



- Talk to, or work with the child in a quiet room – turn off music or any other distractions.



- Sit closer to the child so that they can see and hear you well.



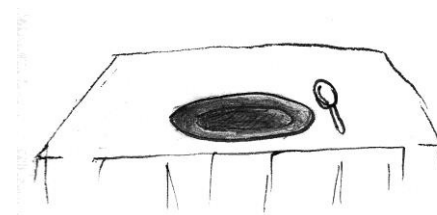
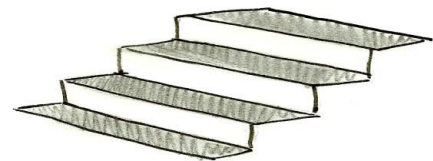
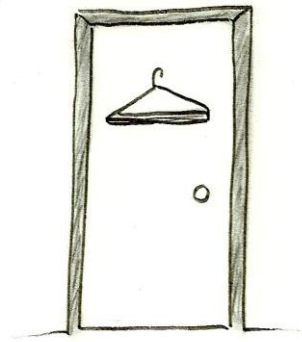
- Make sure there is good lighting so the child can see you well – it may be best for the child with hearing impairment to have their back to the light.
- If you are in a noisy place, encourage the child to turn their back to the noise or move away from it if possible.
- Do not try to talk to the child while eating or drinking as this will make it hard for them to understand you because they can't see your lips moving properly.

- Do not cover your face or put your hands over your mouth when talking to the child.
- Try to make sure in group situations that only one person speaks at a time.
- Talk in a slightly louder, but normal voice – do not shout or talk too slowly as this will make it harder for them to lip read and make your voice harder to understand.
- Use short simple sentences or single words and repeat what you have said.
- If the child still does not understand, try saying it in a different way/using different words.
- Tell the child the topic you are talking about before giving information or asking a question (e.g. 'Talking about shopping' or 'Talking about mother').
- Choose a few words at a time that are useful and teach the child signs or gestures related to these words that can be used throughout the day (e.g. using the drink gesture every time the child has a drink). Once they understand these, introduce a few more different signs or gestures.
- Use objects, gestures and signs to show the child what you are talking about (*Total Communication*).



# Children with Visual Impairment

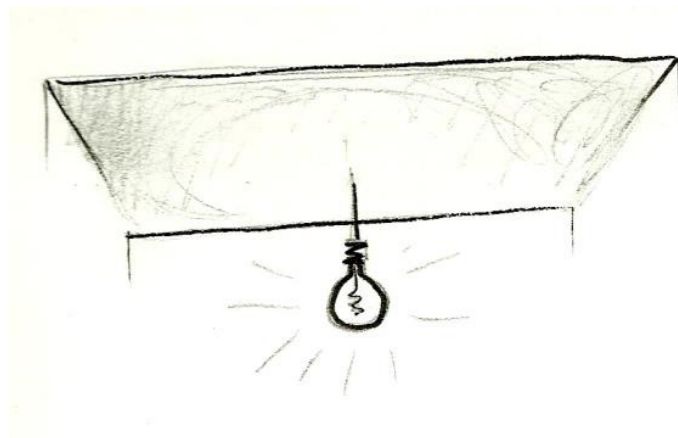
- Stimulate and encourage your child to use the vision that they do have. Even if they have very poor vision, they may be able to find a light/torch in a dark room.
- Your child will use many other ways to know what is happening around them:
  - They may know someone has come into the room or walked near them because of the movement of the air around them.
  - They may know it is dinner time because they can smell the food or hear the pots.
  - They may know what room they are in because of the rug on the floor.
  - They may know who is next to them because of their smell.
- Help to set up the environment so that the child has specific cues or hints to understand what is happening or where they are (e.g. put a different type of mat or rug on the floor in each room, hang a special door hanger on the door to their room or house, ask people to wear a specific perfume etc.)
- Conduct daily activities in the same way and the same order each time. Have a familiar routine so the child knows what is coming next. Always follow the same route when going from place to place and let the child feel objects along the way so that they know where they are going.
- Use simple short sentences or single words to talk about what the child can hear (e.g. birds, cars, people walking by, water, etc.)
- If the child has some vision, use colours that are contrasting (white and black, yellow and black, etc.) to help the child use what vision they have.
  - Paint the door frame a different colour from the walls so the child can find the door more easily.
  - Paint the edge of the steps a different colour from the floor so the child can find the door/steps more easily.
  - Give the child a black or dark coloured dish or bowl to eat their dhal or rice from.



- Use simple words and objects to tell the child what is happening or what you want them to do (e.g. give them a spoon to tell them it is time to eat and give them a jug to tell them it is time to wash).



- Try to keep objects and furniture in a usual place.
- Try to make sure the room/house is well-lit.

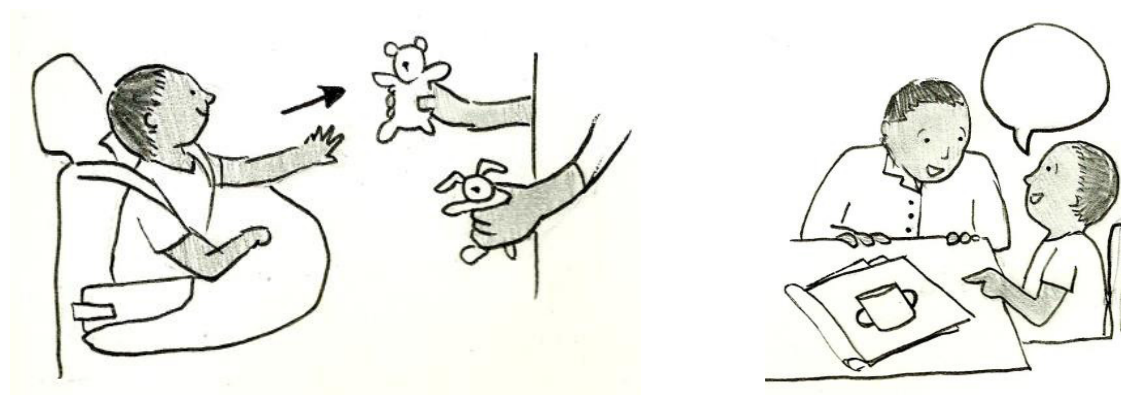


- Try to find out where the child's vision is best – is it looking left, looking right, looking up or looking down? Show things within their best range of vision. In group or social situations, it is best if only one person talks at a time. The person talking should say their name before speaking so that the child with visual impairment knows who is talking or who has come into the room.

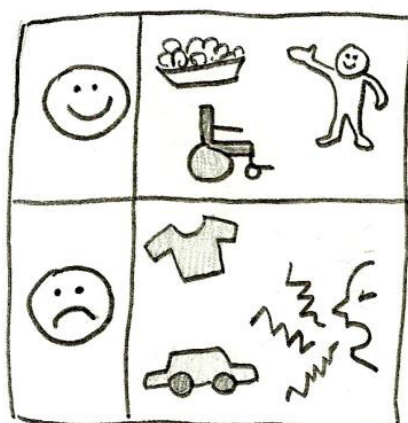
# Communicating with Children with Disabilities

Many children with disabilities have difficulties learning to understand and to speak. It is important to use a range of ways of communicating with your child from the beginning. You should accompany everything you say with hand gestures and lots of expression in your voice and face to support what you are saying. It also helps if you use objects and pictures to help the child know what you are talking about. This helps the child to understand you and also to develop their own ways of communicating. We call this **'Total Communication'**.

If the child finds talking very difficult, you can teach them to use objects and pictures to show you what they want and you can create picture books or picture boards that they can use with everyone.



You can also make a book (sometimes called a **'communication passport'**) explaining everything the child would like to say to people they meet. This is an example of the book they may take to school.





## About me

My name is Saraya, I am 7. I have some difficulties with walking and with my speech. I go to school with my brother.

I live at home with my mother, father and 3 brothers.

## What I like

Listening to stories.

Visiting my cousins.

Going to the shops.

Playing games at home.

Crisps and cake!

## What I don't like

People who ignore me.

Wearing school uniform.

Walking too far.

Crowded streets.

## How you can help me understand

Speak slowly.

Use short sentences.

Show me the thing you are talking about or a picture of it.

## How I tell you things

I use speech together with pictures in my communication book.

Please give me time and help me to use my book to show you what I mean.

## How I need to sit and how I get about

I need to sit at the front of the class in my special chair.

I need a walker to get around.

## Eating and Drinking

I need help with eating and drinking.

We can do it together, slowly, using a spoon and my special cup, taking small mouthfuls.

## Going to the Toilet

I will raise my hand to let you know that I need the toilet.

I need help to stand over the toilet.

# Severe communication difficulties: general principles

*Severe difficulties means communication may not be effective even with familiar people.*

**You are aiming (a) to learn how to communicate to your child what is happening (b) to teach your child to communicate their basic needs e.g. toilet, drink, food, sleep, comfort.**

## Understanding others:

- When you want to communicate something you need to get your child's attention first. Call their name and use a firm touch on the arm. Do this first and then give them an instruction.
- Avoid more than one person talking to the child at once.
- Use objects that are used in everyday routines to support your child to understand your words. For example, to let them know that it is time for sleep, give them their pillow or blanket and tell them "sleep".
- Use 1-2 words so that you will be understood and repeat these words.
- Try to use the same words for each routine.
- Accompany simple instructions with hand signals e.g. come, sit down, stand up, stop.
- Accompany your communication with appropriate facial expression and voice tone. This will help get the message across to them.
- Support other family members to do the same.

## Learning to communicate:

- Try not to do everything for your child. If you do, the child will not need to communicate at all. Give them encouragement and **time** to communicate in whatever way he is able. BE PATIENT; your child may just be able to blink or flick his hands to indicate what he or she wants.
- Encourage them to show the **intention to communicate**; look out for any change in your child's behaviour or expression which may indicate that he or she is wanting to tell you something
- Watch your child closely to learn how they are currently communicating with you through their behaviour. You will know already what they are doing to communicate e.g. frowning if they don't like something; smiling if they do. Children will be using non-verbal ways to communicate with you such as facial expression, body movements, hand-leading and simple vocalisations.
- Start by giving your child lots of opportunities to make requests for things by giving them choices of two items (e.g. foods, songs, play materials etc). For example, ask "Do you want **rice** or **chapatti**?" whilst holding the one food item in each hand. See where the child looks, or the expression on the child's face when each choice is offered in turn. Give them time.
- Interpret your child's response. Some children will look longer at the thing that they want and others will point to it. Interpret whatever your child does as their choice. Repeat the word of their choice i.e. "You want **chapatti, chapatti**". Your child will need to hear the word over and over in order to learn it. Give them time.
- If possible, teach your child to use their hands to communicate what they want. If you know your child wants a drink, encourage them to point to the cup or show them the hand gesture for drink, with your hand over theirs. Show them the cup and then give them a drink.

## Moderate communication difficulties: general principles

*Moderate communication difficulties means your child is able to communicate effectively sometimes or most of the time, with familiar people. Communicating with strangers is difficult.*

### Understanding others:

- Use objects to support your words (e.g. show a bowl to mean it is time for food, a ball to mean it is time to play etc.).
- Once your child is able to understand what the objects mean, you can use simple words and phrases e.g. “Let’s play ball”.
- Continue to accompany simple instructions with hand signals, facial expression and voice tone.
- Children at this stage need to practice listening and responding to simple instructions e.g. ‘Give the bowl to your father’ or ‘Go and sit on the small chair’. If your child does not understand, repeat again slowly and show with your hands what you mean.
- Help your child to develop their understanding of words by saying the names for what they see around them e.g. tree, house, bird, car, bike etc. Then you can play a game of ‘Find the tree, house’ etc. and then add a word e.g. ‘Find the red flower, the big chair’ etc. If your child is able to touch or point to the correct flower or the chair, give them lots of praise for good listening.

### Learning to talk or communicate with you and others:

- Continue giving your child lots of opportunities to make choices (of foods, songs, play materials etc.). For example, ask “Do you want **rice** or **chapatti**?” and encourage your child to touch or point to the one they want.
- Once they have made a choice, repeat the word for them “**chapatti**, you want **chapatti**”. Praise all attempts to say the word.
- Place foods and favourite play materials out of reach of the child so that they have the opportunity to learn to ask.
- If they take you to where they know their toy is, then you ask “What do you want?” If you know it is the ball, then you say “**ball, ball**, you want **ball**?” and encourage them to try to say the word before giving it to them.
- If your child is at the early stage of learning words and phrases, talk about what is happening. For example, if you are bathing the child, teach the words of the objects being used and describe what’s happening (e.g. “washing feet”). In this way your child will learn the words faster and know how words go together and then try to say them for themselves.
- If you are unsure about what your child is trying to say to you, ask them to try to use a different word or try to tell you the first sound in the word.
- If you are still not sure ask yes/no questions – “Is it about school?” “Is it something you want?” “Is it about a person?” “Is it about something that happened today?” “Can you show me?” Encourage *Total Communication* methods.
- If your child has difficulty pronouncing words, pick a list of 5 important words (e.g. things your child needs to ask for) and practice saying these words slowly, sound by sound until they are clear.

## **Mild communication difficulties: general principles**

*Mild communication difficulties means your child is able to communicate effectively with everyone but may need **more time** to understand others or to convey their message clearly.*

### **Understanding others:**

- Your child may have difficulty following long instructions (e.g. go to the shop and buy some flour and eggs). Help them to think about each part of the instruction. Your child may also need practice in listening carefully to the other person when they are having a conversation. Practice with your child listening to **simple** conversations e.g. Hello. What is your name? How old are you?

### **Learning to communicate:**

- Your child is probably saying words and phrases to communicate their needs (i.e. toilet, drink, sleep). You can help your child to make longer sentences by extending what they say e.g. If your child says “Baby sleeping” then you can say “Yes, baby sleeping on the bed”. This helps your child know what other words can go together to express an idea.
- If your child is saying sentences, help them to learn about the rules of conversation, for example, how to greet people (e.g. Hello! How is your family?), waiting for their turn to talk in a conversation, which topics of conversation are acceptable and which are not, and how to end a conversation.
- If your child asks the same questions over and over again (usually about what is going to happen next) try drawing a picture of the routine for the day and showing them (e.g. “First breakfast, then school”).
- Make plans together for the day, encouraging your child to ask and answer questions and make choices and decisions.
- Encourage your child to mix with children and adults to develop clear words and sentences and to become confident communicators.
- Remember that for children who have difficulties pronouncing words, there are some sounds that they may never be able to say. Do not push your child too much, punish them or be negative.

# Understanding and Managing Behaviour

## What is my child trying to tell me?



All children, including children with disabilities, communicate through their behaviour. 'Unusual' or 'difficult' behaviour of children with disabilities usually has a reason. It is a way of communicating or dealing with a situation. The first step is to try to understand the possible causes of the behaviour or what the child is trying to communicate.

### ***Example: A child bites his mother when she tries to encourage him or her to eat.***

#### **The reason may be that the child is:**

- Unaware of social rules
- Unaware of others' feelings
- Hyperactive (see ADHD below)
- Frustrated due to limited communication skills
- Feeling stressed by noises or smells
- Upset by the feel of the food on its hands or in its mouth
- Letting you know they need their 'special' plate

#### **It is helpful to think about a child's behaviour in 3 steps:**

- What happened just before
- What the child did
- The consequences of their behaviour (what happened afterwards which may be reinforcing or maintaining the behaviour)

For example:

1. The mother tells (or signals) the child to put their toy away
2. The child lies on the floor and screams
3. The mother picks up the toy and puts it away

The child's screaming and difficult behaviour is rewarded by the adult doing the tidying up. The child has learnt that if they scream they do not have to do what is asked. The next time the adult tells them to put their toy away they will be very unlikely to do it. In this case, it would be best to change the 'consequence' and for the adult to tidy up **with** the child, or make it a game by taking turns to put toys in a box. In this way the adult gets the tidying up done without a lot of conflict and the child learns the adult means what they say or sign.

Sometimes it is more helpful to change step 1. For example, if you observe that whenever your child is expected to eat with other children they throw their food on the floor, you could try feeding them in a quiet place away from others.

**When thinking about a child's behaviour, it is important to think about the following:**

- Is the child hungry, thirsty, tired?
- Is the child uncomfortable in their environment e.g. too hot, cold or noisy?
- Does the child have a sensory sensitivity? E.g. may find loud noises difficult OR want to make loud noises through banging objects.
- Is the child bored or frustrated?
- Is the activity they are doing too difficult for them?
- Do they want something to play with or to be with someone?
- Do they want an adult's attention?
- Who is the behaviour a problem for? It may be that the child's behaviour isn't really a problem but as a parent you find it embarrassing!

**Other possible strategies parents can use, depending on the purpose of the behaviour, when and where it occurs, and the level of the child's functioning:**

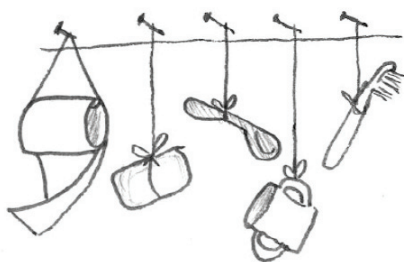
- Use distraction when you know a situation is potentially going to be difficult.
- Don't say 'No' all the time – think about what you are saying 'No' to, and if it is really necessary. Reduce the need to say 'No' by moving things, avoiding situations etc.
- Give your child warning of a change of activity. Tell them it is going to happen and use pictures to help the child understand, if necessary.
- Use words like 'first', 'then' (with pictures if necessary) e.g. first dinner, then ball.
- Keep language clear and simple.
- Talk and behave in a calm way yourself – children learn a lot about behaviour by observing adults.
- Give two choices rather than open choices e.g. 'Do you want milk or water?' Show the child the actual things – or pictures of them.
- Give lots of praise, smiles, hugs for behaviours you **do** want – you will then get more of this behaviour.
- Ignore behaviours you do not want to see.
- Teach the child to do something else that serves the same purpose but that cannot be done at the same time as the behaviour. E.g. teach your child to hit a cushion rather than other children.



# Understanding and Managing ADHD

Children with attention deficit hyperactivity disorder – ADHD/ADD are usually in a constant state of activity. This can be a challenge to adults. You may need to change your home life a bit to help your child. Here are some things you can do to help:

**Organize your daily routine at home.** Set up specific times for waking up, eating, playing, doing homework, doing chores, watching TV and going to bed. Show the routine by hanging objects on the wall in sequence, or drawing pictures to show the activities of each day. Explain any changes in routine in advance. Make sure your child understands the changes.



**Set up house rules.** Make the rules of behaviour for the family simple, clear and short. Rules should be explained clearly. It's important to explain what will happen when the rules are obeyed and when they are broken.

**Be positive.** Tell your child what you want rather than what you don't want. Reward your child regularly for any good behaviour—even little things such as getting dressed. Children with ADHD often spend most of their day being told what they are doing wrong. They need to be praised for good behaviour.

**Make sure your child understands you.** When you want your child to do something, first get their attention. Look directly into their eyes. Then tell your child in a clear, calm voice specifically just what you want. Ask your child to repeat the directions back to you. It's usually better to keep directions simple and short. For difficult tasks, give only one or two directions at a time. Then congratulate your child when he or she completes each step.

**Be consistent.** Only promise what you will deliver. Do what you say you are going to do. Repeating directions and requests many times doesn't work well.

**Make sure someone watches your child all the time.** Because they are impulsive, children with ADHD need more adult supervision than other children their age. Make sure your child is supervised by adults all day.

**Watch your child around his friends.** It's hard for children with ADHD to learn social skills and social rules. Watch them closely while they play. Reward good play behaviours often. Most of all, don't allow hitting, pushing and yelling in your house or yard.

**Help with school activities.** School mornings may be difficult for children with ADHD. Get ready the night before – lay out school clothes and get the book bag ready. Allow enough time for your child to get dressed and eat a good breakfast. If your child is really slow in the mornings, it's important to make enough time to dress and eat.

**Set up homework routine.** Pick a regular place for doing homework. This place should be away from distractions such as other people and television. Break homework time into small parts and have breaks. For example, give your child a snack after school and then let them play for a few minutes. Then start homework time. Stop frequently for short “fun breaks” that allow your child to do something enjoyable. Give your child lots of encouragement, but let your child do the school work. Focus on effort, not grades. Reward your child when he tries to finish school work. You can give extra rewards for earning better grades.

## Top tips:

- Take the time to listen to your children as much as you can (really try to get their “Message”).
- Love them by touching them, hugging them, tickling them, wrestling with them (they need lots of physical contact).
- Look for and encourage their strengths, interests, and abilities. Help them to use these as compensations for any limitations or disabilities.
- Reward them with praise, good words, smiles, and pat on the back as often as you can.
- Accept them for what they are and for their human potential for growth and development. Be realistic in your expectations and demands.
- Involve them in establishing rules and regulations, schedules, and family activities.
- Tell them when they misbehave and explain how you feel about their behaviour; then have them propose other more acceptable ways of behaving.
- Help them to correct their errors and mistakes by showing or demonstrating what they should do. Don't nag!
- Give them reasonable chores and a regular family work responsibility whenever possible.
- Provide opportunities that will stimulate them in their development.
- Read enjoyable stories to them and with them. Encourage them to ask questions, discuss stories, tell the story, and to reread stories.
- Help their ability to concentrate by reducing distracting aspects of their environment as much as possible (provide them with a place to work, study and play).
- Don't expect them to progress at the same rate as other children. It is important that they progress at their own rates and be rewarded for doing so.
- Help them to develop self-esteem.
- Encourage them to cooperate socially by playing, helping, and serving others in the family and the community.

# The Management of Epilepsy: Basic Principles

## The role of the healthcare worker:

- *Use the information below to help identify children who may have epilepsy and ensure they are referred to a doctor.*
- *Give basic information to parents using what is written below.*
- *Provide support to the child and parents in other areas of difficulty the child may be experiencing, such as learning difficulties, depression and physical discomfort.*

A **seizure** (also called a fit or a convulsion) is a sudden (often short) period of 'disturbed' consciousness or total lack of consciousness. It is often accompanied by jerking movements.

In children under the age of six years, seizures may occur when the child has a fever and these are called **Febrile Convulsions**.

**Epilepsy** is a chronic condition caused by damage to the brain either from an injury or an abnormal structure of the brain, which results in the brain cells discharging abnormal electrical impulses. It is usually characterized by seizures that are not associated with fever or any other identified cause.

The common causes of epilepsy are:

1. Injury; which may have occurred before, during or after the child's birth. Often the cause of cerebral palsy may also result in epilepsy. That is many children with cerebral palsy may also have epilepsy.
2. Infection; especially those which affect the lining of the brain (meningitis) or infections such as malaria.
3. Genetic or inherited causes: which means some children have a family history of epilepsy
4. An imbalance in the chemicals in the body (for example very low blood sugar)
5. Unknown: up to one third of people with epilepsies will not have a clear cause

## Types of epilepsies

There are two main forms of seizure:

1. **Convulsive:** There is sudden muscle contraction affecting the whole body which may cause the child to fall down, jerk their bodies and lie very stiffly often followed by relaxation. This may alternate during an epileptic episode. The child may or may not pass urine or stools without meaning to. Sometimes it may only affect certain parts of the body (for example the arms).
2. **Non-convulsive:** These epilepsies on the other hand do not affect the muscles, but cause a change in the child's awareness (sudden staring or blinking), unusual behaviours, emotions or senses (for example unusual taste, smell, vision or hearing).

## Associated features

- Before a seizure, the child may occasionally experience an aura (or a sense) that the seizure is going to take place. This may happen when the child is experiencing unusual sensations such as flashes of light and an odd taste or smell. Seizures may occasionally be provoked by unusual triggers such as flashing lights.
- Some young children, in intense periods of crying, seem to 'get stuck' and are unable to take a breath. They stop breathing for a short instant and may become blue, resulting in a loss of consciousness. The moment the child loses consciousness they start breathing again. The breath-holding may occasionally trigger a seizure.

## Things to ask the parent or caregiver

Behaviour during the seizure can help a doctor understand what kind of problem the child has and what treatment to give them.

- Which arms and legs move; on one side only or both sides?
- How long did the episode last?
- Did the child pass urine or stool?
- Did the child recover immediately after the episode or were they confused?
- Was the child able to speak normally?
- Did the child remember what happened to them?

## What to do during a seizure

- Stay calm and call for help.
- Stay with the child until the seizure stops and they wake up.
- To prevent injury, remove anything dangerous from the surrounding area.
- Move the child, if possible, to a safe place but do not force them to move.
- Remove glasses so they do not break.
- If possible, gently roll their head and their upper body (if possible) to the side so that any fluids can drain out of the mouth. You may need to wait until they have stopped shaking before you do this.
- Loosen anything around the neck to make breathing easier. Loosen buttons or belts that are tight.
- Do not put anything in the child's mouth. If they have food in their mouth, do not attempt to take the food out because this may actually push it farther in.

## Safe sleeping

Make sure the child is unable to fall off the bed. Check the child during the night.

## What a doctor may do

A doctor will ask for a detailed history and examine the child. They may request certain tests to be carried out such as an X-ray or scan of the head, and a special test to see the electrical activity of the brain. The results will guide the doctor on whether the child has epilepsy or not and what treatments to recommend.

## Treatments for epilepsy

There are a number of medicines for epilepsy, some of which are better for certain kinds of seizures than other. All these medicines can have serious side effects and therefore must be used under direction of a doctor. Make sure the doctor describes how much and how often the medicine should be taken, since some medicines are taken once a day while others may be need to be taken twice a day.

Sometimes medicines for epilepsy can have side effects such as drowsiness, poor concentration, restlessness, irritability, allergic reactions and low blood counts.

### Common drugs that are prescribed to children are mentioned below:

	Child	
	Starting dose	Maintenance dose
<b>Carbamazepine</b>	5 mg/kg/day	10-30 mg/kg/day
<b>Phenobarbital</b>	2-3mg/kg/day	2-6mg/kg/day
<b>Phenytoin</b>	3-45mg/kg/day	3-8mg/kg/day (maximum 300mg daily)
<b>Sodium Valproate</b>	15-20mg/kg/day	15-30mg/kg/day

(From mh-GAP IG, WHO 2010).

