Malamulele
Onward

Carer-2-Carer Training Programme

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...Equipping parents of children with Cerebral Palsy to become facilitators of change.

Facilitator Manual 2020

Acknowledgements and Copyright

This manual was compiled by staff members of Malamulele Onward NPC to be used either by parents of children with CP who have attended the Carer-2-Carer Training Facilitator Course or therapists wanting to run workshops themselves. Twenty one trained parent facilitators were involved in helping to develop the material in this manual. Ten rural hospitals allowed these parents to pilot the workshops at their sites.

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The information in this manual may be shared with colleagues, families of children with CP and anyone interested in learning more about the condition.

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Malamulele Onward

Malamulele Onward (MO) is a non-profit organization committed to improving the quality of life of rural children with severe and moderate disabilities, mainly as a result of Cerebral Palsy (CP) as well as the life of their families and primary caregivers. The organization offers evidence-based and innovative solutions to the challenges of caring for a child with a severe disability whilst equipping and preparing families for a lifetime of caring.

The organization was established in 2006 and is based in Johannesburg where it has a Therapy and Training Centre. However, the organization's primary activities are in rural areas and it is currently operating at 21 sites in the Eastern Cape, Kwazulu Natal, Limpopo, Mpumalanga and Lesotho.

MO's aspirational goal is that all rural children with CP grow and learn in a supportive, caring and nurturing environment where they feel loved and included. We want children to remain painfree and comfortable as they grow older; we want them to remain at home with their families; and we want their families to feel equipped and able to take care of them. This can only be achieved if all people in the child's life are informed and work together for the child's best interests i.e. the child's primary caregivers and immediate family; neighbours; and the local healthcare providers.

To achieve our goal, Malamulele Onward has adopted the following strategies:

- Residential and on-site therapy and parent training for rural children with CP
- Re-engineering and restructuring of local hospital based CP Clinics
- Training and transfer of information and clinical skills to both professionals and lay people involved in caring for children with CP
- Development of parent-led services
- Establishing an evidence-base for therapy interventions and best practice

Carer-2-Carer Training Programme

The Malamulele Carer-2-Carer Training Programme (C2CTP) is an exciting initiative that Malamulele Onward (MO) began developing in 2012. Its main goal is for every parent of a child with CP to have an accurate understanding of their child's condition that is demonstrated through positive changes in both their and their child's quality of life and relationships with those around them. This programme forms an integral part of the MO vision for all children with CP to reach their full potential within a supportive environment. In order for parents to create a supportive environment for their children, they need to understand their children, feel competent as parents and feel supported within their community.

The C2CTP trains parents of children with CP to run workshops on CP for other parents, caregivers and lay people. This training programme does **not** replace the need for therapy or therapists, but is rather meant to support and complement existing services for children in public service hospitals. It acknowledges that current services in most public service hospitals are under large amounts of pressure due to insufficient numbers of therapists and consequently the basic needs of parents for information and support are not being met. The programme recognises parents of children with CP as an important resource to be mobilised and influential in helping other parents to not only understand CP, but to also accept and care for their child in a way that is sustainable. It also realises that the difference between "access to information" and "access to understanding" can create a significant barrier to creating a supportive environment for a child with CP. In order to combat this barrier the C2CTP provides parents with the opportunity to access information on CP that is presented in their own language, in a way that they can understand and by a person who is facing the same challenges with their own child.

How to use this manual

This manual has been designed to be used by a team comprised of one main facilitator (who is literate in their own language) and one co-facilitator (who does not need to be literate).

All text that is on a coloured/shaded background is text that is not said out aloud – it only exists to assist the facilitator. All text that is on white is to be said aloud to the group. Answers to questions (which all appear on white) must only be said after the group has finished answering and discussing the question. These answers are only there to make sure that all of the important points are covered and thus the facilitator must mention any that the group did not discuss. They do not exist for the facilitator to read out to the group in isolation.

There are 3 icons used in the manual:

Explain: This indicates that there is something that the facilitator needs to explain to the group.

Activity: This indicates that an activity needs to take place before continuing.

Question: This indicates a direct question that must be asked to the group.

These icons make it easier for facilitators to follow the manual. They can tell when there is an activity coming up, a concept to explain or a question to be asked. The icons also serve as a quick reference for the main facilitator.

The odd numbered pages (i.e. the pages on the right hand side) are the workshop guidelines for the facilitators to follow when running the workshops. The even numbered pages (i.e. the pages on the left hand side) have the activity instructions and the explanations that correlated with the workshop guidelines.

Ideally the facilitators should only use the guidelines when running a workshop, as the activities and explanations should be memorised and consolidated after the training and some practice. For example: they should be able to look at the picture of the activity on the odd numbered page and know exactly what instructions to give and how to run the activity. Likewise they should be able to see the explanation icon with text next to it such as “explain what aspiration is” and they should be able to explain it without having to look at the explanation itself.

The explanations and activity instructions exist in the manual for two reasons: firstly if the facilitator is preparing for a group and needs to practice their explanations, they can revise them. If they cannot read this more complicated text, then they can go to someone who can and that person can read it to them. This then puts the responsibility of revision and preparation on the facilitators. Secondly if a therapist wants to use the manual, they have access to all the explanations and activity instructions to run the workshops.

Instead of numbering the display material, each picture that needs to be put up for the group is shown in the manual. This way the facilitator can easily see which picture needs to go up at that time and when it comes to putting the pictures in the right order before the workshop, the facilitator can just page through the manual to see the correct order that the pictures will be needed in. All the pictures in the manual that represent display material are smaller than the pictures that are there to represent an activity.

Each section finishes with a main message so that there is repetition of all the points that are important for the parents to understand.

Preparing the workshop materials

Workshop materials the make up the fixed workshop kit:


2 Plastic cling sheets (if these are being used instead of large sheets of paper)


A marker (permanent or white-board depending on the surface used).


Pens (1 per pair of participants in the group)


Cut-out cups (1 per participant in the group) - Plastic or polystyrene cups can be cut-out as in the picture and used for the activities.


Teaspoons (1 per participant in the group) - Can be bought or parents can bring their own.


Large spoons (1 per pair of participants in the group) - Can be bought or parents can bring their own.


1 Pillow / folded blanket - This can usually be sourced from one's place of work or from home.

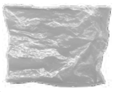

1 Ball (any size and colour) - Can be bought or can be made by taping up plastic packets into a ball.


1 Water bottle (500ml) - filled with water.


Blind folds (1 per pair of participants in the group) - Can use cut up dustbin bags, material, old stockings, etc.


Jackets / jerseys (1 per pair of participants in the group) - Usually there are enough between the participants without hvaing to have them as part of the kit.


Cloths (1 per pair of participants in the group) - These can be cloths or pieces of scrap material.



Ziplock sheets (1 per participant in the group) - Take a clear ziplock/plastic bag and smear it thinly with some vaseline, then fold it in half - when looking through it, objects should appear blurry.

3 Pieces of material (red, yellow and black in A3 size) - can also use towels or sheets of paper.

1 Shiny board - this can be made by covering a piece of cardboard with holographic paper, tin foil or the shiny sides of potato chips packets.

1 Cell phone or torch - this can be brought from home, or a torch can be bought as part of the kit.

1 Set of background pictures printed in A3 colour.

Picture packs - these must be printed from the ‘visual materials’ document in A4 colour (1 copy per pair of participants in the group). Each picture pack must be divided into 2 A4 envelopes (the pictures with a 1 are put into a envelope labelled 1 and the same is done for the pictures with a 2). The pictures should ideally be laminated in order for them to last.

2 sets of 5 bottle tops (all 5 must be the same colour and each set must be a different colour)

A set of 10 - 15 lids of different colours and sizes

Two bags each filled with 10 different objects that can be easily found (so 20 different objects in total)

A bench

Consumables that must be replenished for each workshop:

5 large sheets of paper (A1 size) - if plastic cling sheets or white boards are used that can be wiped clean, only 2 writing surfaces are required.

Some sheets of scrap paper

For Workshop 3 (getting active): some body lotion

For Workshop 4 (eating and drinking): Custard or any soft food with a similar texture such as yoghurt, porridge, etc

1

Introduction to CP

What is it and how does it affect my child?

Materials

For this workshop you will need:

A large sheet of paper

A marker

A cut out cup

Some small pieces of paper (1 per person)

ICE-BREAKER:

Write down each person's name on separate pieces of paper including yours. Put them all in a cup. Explain to the group that they are going to draw a name out of the cup without looking inside the cup. Then they must ask that person a question about themselves and the person must answer. Pass the cup around and once everyone has a name in their hand, start the group off by asking your question first. Then let each person have their turn. If someone draws their own name, they must swop it with the person next to them.

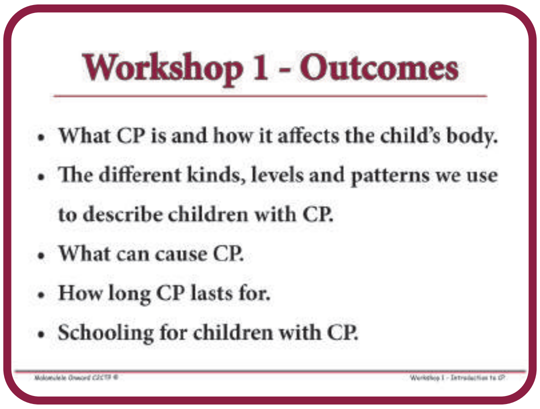
1 Welcome

Welcome everyone to the group and make sure that they are comfortable before you start.

Explain the ice-breaker and do it with the group.

2 Outcomes

Put up the outcomes and go through them with the group.



Workshop 1 - Outcomes

- What CP is and how it affects the child's body.
- The different kinds, levels and patterns we use to describe children with CP.
- What can cause CP.
- How long CP lasts for.
- Schooling for children with CP.

In this workshop we are going to get to know one another and develop a trusting relationship with each other as a group. We are all here to learn from each other and we all have something to teach the rest of the group because we all have experience with children with CP.

This is what we are going to talk about today:

- **What CP is and how it affects the child's body.**
- **The different kinds, levels and patterns we use to describe children with CP.**
- **What can cause CP.**
- **For how long does a child have CP.**
- **Schooling for children with CP.**

3 What we know about CP

You will need:

Today we are talking about CP, but I first want to find out from each of you what you know about CP.

? What do you know about CP?

Write down everyone's suggestions.

SHARING YOUR STORY:

When you share your story, answer the following questions:

- When did you know that something was not right?
- How did this make you feel?
- How did you come to learn that your child has CP?
- How did other people treat you when they saw you had a child with CP?
- What did you tell them?
- What helped you to cope?

4 Sharing our stories

Each of us has our own story about being a parent of a child with CP and about what we have experienced in our journey so far. If you are not a parent of a child with CP, you are here because there is a child with CP in your life and you understand a little about what it is like to care for a child with CP.

We are going to take some time now to share our stories with the group.

Check that everyone feels comfortable sharing their story with the group.

I will start.

Share your story about you and your child with the group.

? **Who would like to share their story next?**

Let each person share their story with the group.

CEREBRAL PALSY:

CP is short for cerebral palsy. The word 'cerebral' means having something to do with the brain. The word 'palsy' means a weakness or problem in the way a person moves or positions his or her body. All children with CP have damage to their brain and some children have more damage than others. This damage causes problems with the way that the child moves, gets around, eats, drinks and talks.

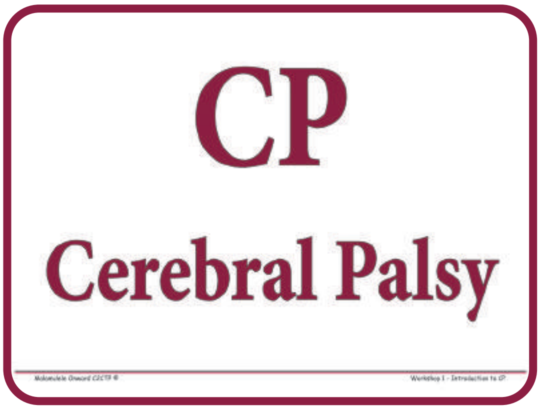
A child with CP has trouble controlling and moving the muscles of the body. Usually, the brain tells the rest of the body exactly what to do and when to do it. But CP affects the child's brain and what a child can or cannot do depends on which part of the brain is damaged. Depending on which part of the brain is damaged, a child might not be able to walk, talk, eat, or play the way that most children do.

Different parts of the brain can be damaged and that is why children with CP can be very different from each other.

5 What is CP?

Let us try to understand what CP means.

Put up the picture and explain what CP means.



CP

Cerebral Palsy

Malamulele Onward C2CTP ©

Workshop 1 - Introduction to CP

Check if there are any questions.

THE POWER STATION STORY:

If you have electricity in your house, the plug points and switches have wires that go all the way to the power station. This is how we get electricity. The power station sends the electricity to your house through the wires and poles. This electricity makes the appliances in your house work like the kettle, the stove, the lights, the TV, the cell phone charger and the fridge.

All of these different appliances are like the different parts of a child's body like the eyes, the mouth, the ears, the legs, the arms, and the hands. The power station is like the child's brain. Just as the electricity comes from the power station and makes your appliances work, so the messages from a child's brain travel through the body to make their body parts work.

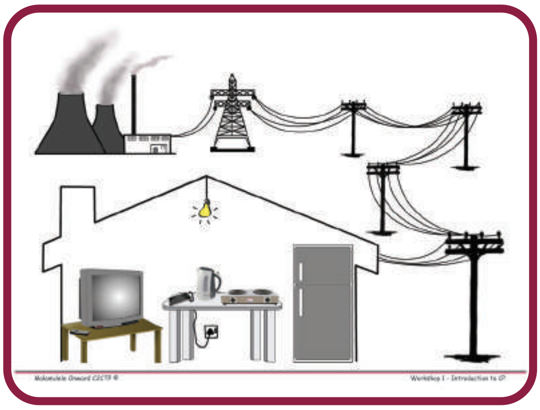
If there is a problem at the power station, there will be no power to make the appliances work. If there is no electricity from the power station, the poles and cables cannot supply electricity to the house. This is not because they are broken. Even if the appliances are new they will not work without electricity from the power station. The appliances are in working order, the poles and cables are in working order, but they cannot work if there is a problem at the power station.

Children with CP have a problem in their brain and this affects specific parts of their body. This does not mean that there is a problem with their body parts or the bones or the muscles. They are all working fine but there is a problem with the brain and so the different parts of the body do not understand the messages coming from the brain. Which parts of the body are affected depends on which part of the brain is damaged.

6 How CP affects the body

I am going to use a story to help you understand how CP affects the child's body.

Put up the picture and explain it to the group.



Check if there are any questions.

CHILDREN WITH CP ARE ALL DIFFERENT:

All children with CP have problems with moving, but they do not all have problems with things like seeing, hearing, talking, or learning. Every child has their own abilities and their own difficulties.

Some can walk, some can eat and drink easily, and some can sit on their own. Some children cannot lift their head, some cannot turn over, and some cannot see well. But each and every child with CP has some potential to change and become better at doing some things. How much they can improve depends on how much of the brain is damaged and how early the child starts therapy.

7 How do we know that a child has CP

?

How do we know that a child has CP?

The child has difficulty with:

- **moving**
- **seeing**
- **eating and drinking**
- **talking**
- **thinking and learning**
- **sitting, standing and walking**

Each child with CP is different - no two children are the same. So we cannot compare our children. Each child is unique and special.

Explain how children with CP are different.

We believe that every child with CP has the potential to change in some way, even though we cannot cure them.

Use the pictures to showw how different children with CP can be from each other.

MAIN MESSAGE

All children with CP have problems with moving.

Many children with CP have other problems as well.

Every child with CP has potential to change and improve.

Although we cannot cure CP, we can help each child to be the best that he/she can be.

WHAT DOES SPASTIC MEAN:

Some children with CP feel stiff all the time. It is very difficult for the child to move their arms and legs, because the muscles are very tight. The word we use to describe children who are stiff is spastic. The word spastic simply means that the muscles in the arms and legs are stiff all the time.

8 The different groups of CP

We have just said that all children with CP have problems with moving and that they are all different. We can describe children with CP in 3 different ways: (1) what group of CP they belong to, (2) how much they can move by themselves, and (3) which parts of the body are involved.

Let us start with the first part. Children with CP can fit into 3 main groups of CP.

The word we use to describe children with the first group of CP is 'spastic'.

Use the pictures to help the group understand what the word spastic means.

RECOGNISING CHILDREN THAT ARE SPASTIC:

We can recognise that a child is spastic by looking at them in different positions. No matter what position the child is put in, they look the same. If they are sitting, their arms and legs are in the same position. If they lie on their stomach, their arms and legs are in the same position. If they lie on their back, their arms and legs are in the same position.

Use the pictures to show the group how to recognise that a child is spastic.


1


2


3

WHAT DOES CHOREOATHETOID MEAN:

Some children with CP are moving all the time and it is difficult for them to keep still. It looks as if their arms and legs are scattered around them. When they try hard to do something, or when they become excited about something, then the movements become even more. They have a lot of difficulty controlling their movement and they look very disorganised. The word we use to describe children who are moving all the time, or moving too much is choreoathetoid.

RECOGNISING CHILDREN THAT ARE CHOREOATHETOID:

We can recognise that a child is a choreoathetoid by looking to see what happens when they try to move. Sometimes these movements can be very small and it is difficult to see in a picture, because you cannot see the child moving in a picture. These children will sometimes try to keep their arms and legs close to their body to stop the movement. When they reach for something, the movement may look almost "wild" because it is uncontrolled. The child may actually hit you with his arm when he is trying to reach for something. They did not mean to hit you, they just wcannot control the movements of their arms well.

The word we use to describe children in the next group of CP is 'choreoathetoid'.

Explain what the word choreoathetoid means and demonstrate for the group what a choreoathetoid child looks like.

Use the pictures to show the group how to recognise that a child is choreoathetoid.

WHAT DOES DYSTONIC MEAN:

Some children with CP push back a lot. Their bodies may feel relaxed, but whenever they try to move they suddenly become stiff. It is very hard for the child to relax when their body goes stiff. The more you try to stop them pushing, the more they will push. It is as if the child is too strong, and they push very hard. These children can be difficult to handle because sometimes they feel relaxed and sometimes they feel stiff. The word we use to describe these children is dystonic.

The word we use to describe children in the third group of CP is 'dystonic'.

Use the pictures to help the group understand what the word dystonic means.

RECOGNISING CHILDREN THAT ARE DYSTONIC:

We can recognise that a child is dystonic by waiting for them to look relaxed and then asking them to do something. As soon as they try to move, their body will become stiff. These children find it really hard to keep their heads in the middle. It can fall forward or they push their head back a lot. It is hard for them to bring their hands together in the middle. Often they will keep their arms stiff and out to the sides, away from their bodies. What is common about children who are dystonic is that their body may look twisted, or their legs get twisted and tangled up.

Use the pictures to show the group how to recognise that a child is dystonic.

It is not always easy to see whether a child is spastic or dystonic. Some children can be spastic and dystonic at the same time. When children belong to more than 1 group of CP we called them "mixed".

RECOGNISING CHILDREN THAT ARE ATAXIC:

Children with ataxic CP have trouble with their balance. Their movement is shaky, jerky and unsteady. Their movements are not smooth. Because the child has problems with their balance, they walk with their legs further apart than other children. Because of their unsteady movements and their problems with balance when they are walking, they can fall down easily. Sometimes when they are walking, they can look like a person who has had too much alcohol to drink. Like all children with CP, their problems with movement are because of the damage to the brain.

The word we use to describe children in the third group of CP is 'ataxic'.

Explain what ataxia means and demonstrate to the group what a child with ataxia looks like.

Use the picture to show the group how to recognise that a child is ataxic.

?

**What group do you think your child belongs to?
Why?**

Check if there are any questions.

MAIN MESSAGE

We have discussed 4 main groups of CP.

Some children are spastic and are stiff all the time.

Some children are choreoathetoids and move too much.

Some children are dystonic and suddenly become stiff when they try to do something or get excited.

Some children are ataxic and have shaky movements and problems with balance.

Some children are mixed because they belong to more than 1 group.

LEVEL 1 CHILDREN:

Level 1 children can walk inside and outside on their own and they can go up and down steps without holding onto anything. They can run and jump, but they may not be as fast as other children and their balance is not as good as children who do not have CP.

LEVEL 2 CHILDREN:

Level 2 children can walk inside and outside on their own, but outside can be difficult for them. They can walk up and down stairs if there is something for them to hold onto. Uneven ground and crowded places make it more difficult for them to move around. They cannot run or jump.

9 The different levels of CP

As we mentioned before, there are 3 ways in which we can describe children with CP. The second way is to describe the children according to how much they can move on their own. There are 5 levels and all children with CP can be described in terms of 1 of these levels.

Put up the picture and explain what a level 1 child can do.

Put up the picture and explain what a level 2 child can do.

LEVEL 3 CHILDREN:

Level 3 children can move around by themselves if they have equipment, like a wheelchair or a walker, and if the ground is level. They may be able to use a wheel chair on their own, but they need help over long distances. They are able to sit on their own.

LEVEL 4 CHILDREN:

Level 4 children use wheelchairs most of the time and need someone to push them. They can roll over by themselves and may be able to move around on the floor by themselves - for example by moving on their backs or their tummies or by rolling. They cannot sit by themselves but they can sit if you support them.

Put up the picture and explain what a level 3 child can do.

Put up the picture and explain what a level 4 child can do.

LEVEL 5 CHILDREN:

Level 5 children cannot move anywhere on their own. They cannot sit by themselves and they cannot roll over from their back to their tummy or from their tummy to their back. They may be able to roll a little from side to side. When you put the child on his tummy, he or she may be able to lift their head up a little, but not all level 5 children can lift their heads or roll from side to side. The main way to recognise a level 5 child is that he cannot change his position, he or she just stays wherever you put them.

CAN MY CHILD'S LEVEL CHANGE ?

When the child is very young (less than 2 years old) it may be difficult to decide what level he is. But once the child is two years old, it is easier to decide what level he is. With lots of help from parents and therapists, it may be possible for children to change their level and to move up one level, but this is not very common at all. Once you know which level your child is, he or she is always going to be in that level. A Level 5 child is not going to become a Level 3 or a Level 2 or a Level 1 child.

What may happen though is that your child can go DOWN a level, for example a Level 3 child who can walk using a walker may get stiffer as she or he gets older till eventually the child's legs are so stiff that they can no longer walk on their own.

This is why it is very important that we never stop helping our children. We want our children to be the best that they can be and we want them to stay like this for as long as possible and not get worse and stop doing the things they have learnt to do.

Put up the picture and explain what a level 5 child can do.

Level 4 and 5 children move very little on their own, and so it is very important to learn how to position them during the day because they cannot do it themselves.

?

What level do you think describes your child?
Why?

?

Can my child's level change?

Check if there are any questions.

MAIN MESSAGE

Children with CP can be described as being one of 5 levels.

These levels tell us how much a child can do.

Levels 1 to 3 are able to move on their own.

Children in levels 4 and 5 will need help to move or change positions because they cannot do it on their own.

3 WAYS THAT PARTS OF THE BODY CAN BE INVOLVED:

Most children with CP are affected throughout their whole body. This means that the arms as well as the legs have difficulty with movement. We call a child like this a 'quadraplegic'. For short we say 'quad'.

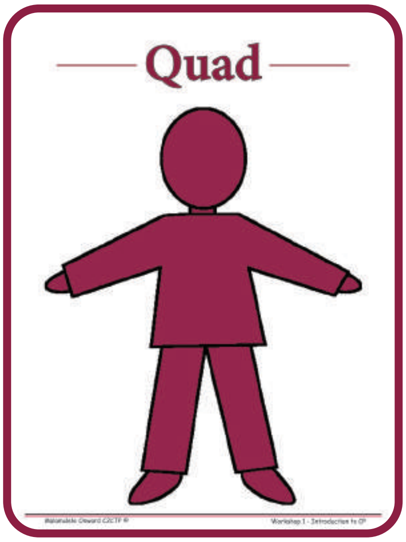
Some children's arms are not affected but their legs are. Usually these children can sit and use their hands, but have a lot of difficulty with walking. Sometime's the arms are affected a little, but the legs are much more affected than the arms. We call a child like this a 'diplegic'. For short we say 'di'.

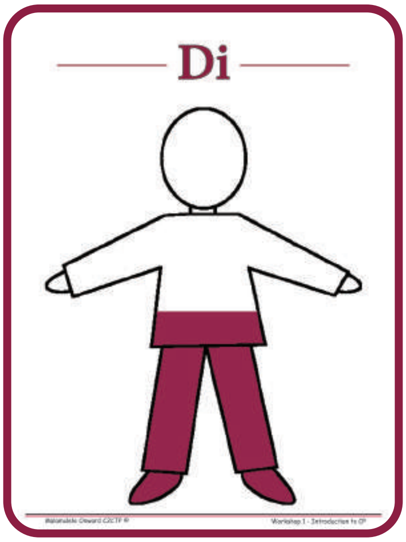
Some children are only affected on the one side of their body. This means that they have difficulty with moving the arm and leg on one side of their body. We call a child like this a 'hemiplegic'. For short we say 'hemi'.

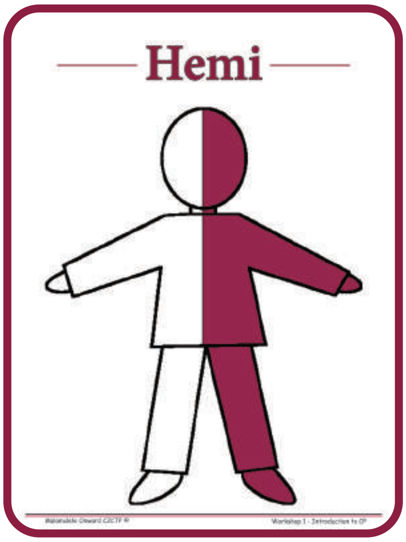
10 The parts of the body involved

The third way that we can describe children with CP is according to the parts of the body that are involved. There are 3 main ways in which parts of the child's body can be involved.

Put up the 3 pictures and explain the 3 ways that parts of the body can be involved.


Quad


Di


Hemi

Use the pictures to show what these children look like.

?

What parts of your child's body are involved?
Which word would you use to describe them?

Check if there are any questions.

MAIN MESSAGE

Children with CP can be described according to which parts of their body are involved.

We use the words 'quad', 'di' and 'hemi' to describe them.

11 Causes of CP

As a group together we are now going to try to understand as a group what can cause CP.

? **What do you think was the cause of your child's CP?**

Give everyone a chance to answer.

? **How do you know that what you just answered was the real cause?**
Did someone else tell you this?
Who told you what the cause was and how do they know the cause?

Use the questions to understand where the parents' ideas about the causes came from.

Most of the time the cause of a child's CP is not known, because it is difficult to tell exactly when the damage to the brain happened. Even though we do not often know the cause, or what happened or why it happened, we do know one thing: It is not a mother's fault that her child has CP.

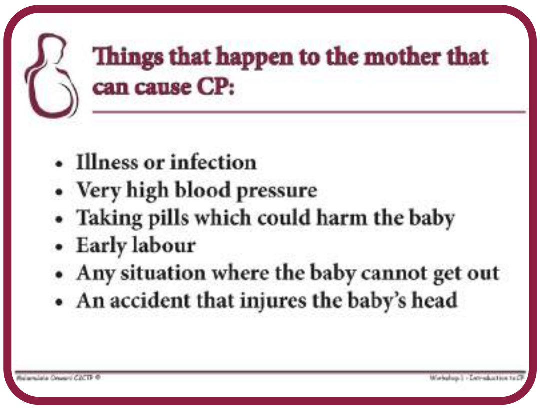
Sometimes there are things that happen that can make it more likely for a child to develop CP or to be at risk of having CP. Some of these things can happen to the mother while she is pregnant, some of them can happen while she is giving birth and some of them can happen to the baby after he or she has been born.

Let us first talk about what can happen to the mother either before or while giving birth.

THINGS THAT HAPPEN TO THE MOTHER THAT CAN CAUSE CP:

- If the mother has an illness or infection – the mother may pass the infection onto the baby while the baby is still growing inside her.
- If a mother has very high blood pressure, especially in the last month of pregnancy it may affect the baby.
- If the mother is taking pills which could harm the baby, especially pills that have not been prescribed by a doctor.
- If the mother goes into labour early.
- Any situation where the baby cannot get out. For example if the mother's pelvis is too small. If the baby cannot get out, the labour is long and difficult. If it is taking a long time for the baby to come out, the baby can get very tired and can get into difficulty and not get enough oxygen, or the heartbeat can become very weak.
- Sometimes there might have been a problem early on in the pregnancy and because of this the baby does not move well inside the mother. Then when it is time for the birth, the baby struggles and takes too long to be born.
- Being in an accident that causes injury to the baby's head, such as a car accident or if the mother is being beaten.

Put up the picture and explain each of the things that can happen to the mother that affect the baby.



Things that happen to the mother that can cause CP:

- Illness or infection
- Very high blood pressure
- Taking pills which could harm the baby
- Early labour
- Any situation where the baby cannot get out
- An accident that injures the baby's head

Check if there are any questions.

These are all things that can happen to the mother that can increase the chance of the baby having CP before or during the birth.

Now let us talk about things that can happen to the baby that put them at risk of having CP.

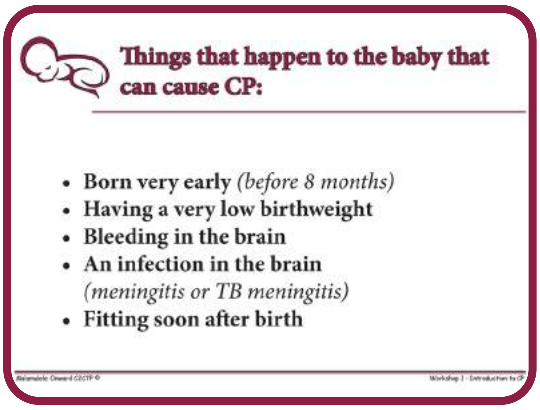
THINGS THAT HAPPEN TO THE BABY THAT CAN CAUSE CP:

- If the baby is born very early (before 8 months).
- If the baby's birth weight is very low (less than 1500g), the baby is at greater risk of developing problems in the brain
- If after birth, there is bleeding in the brain – this can especially happen in babies who are born too early before their due date.
- If after birth, the baby gets an infection in the brain like meningitis or TB meningitis.
- If the baby is fitting soon after he or she is born. Fitting in the first few days after a baby is born is usually a sign that the brain may have been damaged and did not get enough oxygen during the birth process.

THINGS THAT DO NOT CAUSE CP:

- Sex during pregnancy
- Emotional stress
- Angry ancestors
- Unfaithfulness in marriage
- Witchcraft
- Bad spirits
- Punishment from God
- Inherited from a family member

Put up the picture and explain each of the things that can happen to the baby after he/she is born.



Things that happen to the baby that can cause CP:

- Born very early *(before 8 months)*
- Having a very low birthweight
- Bleeding in the brain
- An infection in the brain *(meningitis or TB meningitis)*
- Fitting soon after birth

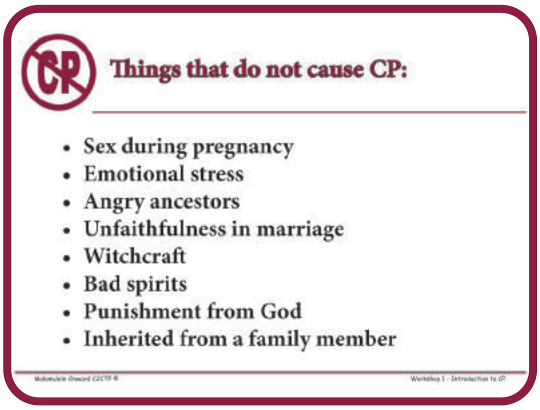
Check if there are any questions.

These are all things that can increase the baby's chance of developing CP.

But it is important to remember that just because these things increase the chance of CP, it does not mean that they will always cause CP.

Now that we have talked about what can cause CP, let us talk about the things that cannot cause CP.

Put up the picture and go through each of the points. Let the group discuss their feelings about what you have shared with them.



Things that do not cause CP:

- Sex during pregnancy
- Emotional stress
- Angry ancestors
- Unfaithfulness in marriage
- Witchcraft
- Bad spirits
- Punishment from God
- Inherited from a family member

Many parents feel like it is their fault that their child has CP and they go through life blaming themselves. This is often because the people around them blame them, because they think that these things can cause CP, but they are mistaken.

Remember:

CP is not a parent's fault.

It is something that no parent can control.

CP is not a disease or an illness that can be cured with medicine

Check if there are any questions.

MAIN MESSAGE

Most often the cause of a child's CP is unknown.

We only know of some risk factors that can increase a baby's chance of having CP.

Some of these happen to the mother and some happen to the baby.

It is not a parent's fault that their child has CP - It is out of their control.

WHY CHILDREN CANNOT DIE FROM CP:

CP does not kill children, but children with CP can die from the same causes that we can. If a child with CP dies, it is usually because they had an illness which made them very sick such as: TB, a chest infection, or pneumonia. If a child has epilepsy, and they are not taking medicine, the fits can become so severe that the child becomes unconscious. If the child does not get to a hospital very quickly, then it is possible that the child can die.

Children with CP grow to become teenagers and adults with CP. We often do not see many adults with CP in rural areas, because as they grow and become heavier, it becomes more difficult to transport them to the hospital.

12 CP is lifelong

Do you think that children can die from CP? Why?

After everyone has shared, explain why children cannot die from CP.

Use the pictures to show the group that children with CP can become teenagers and adults with CP.

WHY CP CANNOT BE CURED:

There is no cure for CP. Once there is damage to the brain, it cannot be fixed. Even the best doctors in the world cannot cure CP. It cannot be cured by an operation nor any medicines whether they are from a doctor or a traditional healer. Is also does not matter how much money you have. No amount of money can cure a child with CP. CP is lifelong. A child with CP will always have CP.

Therapists and doctors can help a child with CP to be the best that they can be, but they cannot take the CP away.

? Do you think that CP can be cured?

After everyone has shared, explain why CP cannot be cured.

Check if there are any questions.

MAIN MESSAGE

Children with CP will have CP for life.

They will become teenagers and then adults if they remain healthy.

There is no doctor, medicine, operation or machine that can repair brain damage.

GOING TO SCHOOL:

We said before that each child with CP is different and that what they are able to do depends on which parts of their brain are damaged. It is the same with learning. Some children with CP can learn the same as any other child and some children can only learn very simple things.

If a child with CP can learn like other children, then they need to go to a school that can help them learn even though they have problems with moving. Unfortunately there are very few of these schools and so it can be difficult to get some children accepted into them.

Some children with CP can learn at any school, but then they need someone with them all the time that can help them in class.

13 School and learning

? **Do you think that children with CP can go to school? Why?**

After everyone has shared, explain why some children can go to school and others cannot.

Ask your therapist for advice on how much your child can learn and whether or not they could go to school. They should be able to give you advice on what schools are available and how to apply for them.

Remember that all children with CP have potential to change and so all children with CP can learn something even if it is very small. We must never stop trying to teach them new things.

Check if there are any questions.

MAIN MESSAGE

Children with CP can go to school if they are able to learn.

How much they can learn depends on the parts of their brain that are damaged.

Ask your therapist for advice on schooling for your child.

14 End of the workshop

Break the group up into pairs.

I want you to discuss in your pairs what you have learnt today as there has been a lot of new information in this workshop.

Give everyone a few minutes to discuss.

I want you to answer 2 questions while in your pairs.

? **What will you tell your family after this workshop?**
How difficult will this be?

Give everyone a few more minutes to discuss their answers.

? **Now that the workshop has come to an end, does anyone have any questions before we close?**

Go through the parent handout with the group and check if there are any questions about it.

Close the workshop and make sure that everyone feels that their questions have been answered.

2

CP as a Way of Life

Looking after my child throughout the day.

Materials

For this workshop you will need:

A large sheet of paper

A marker

A pillow or folded blanket

1 Welcome

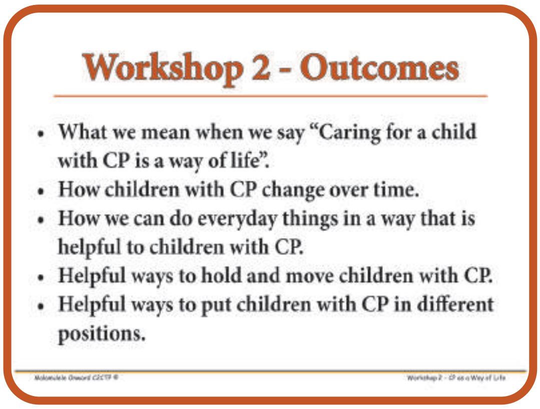
Welcome everyone to the group and make sure that they are comfortable before you start.

?

Before we start this workshop, what was one thing that you shared with your family about CP and how did they respond to your news?

2 Outcomes

Put up the outcomes and go through them with the group.



Workshop 2 - Outcomes

- What we mean when we say "Caring for a child with CP is a way of life".
- How children with CP change over time.
- How we can do everyday things in a way that is helpful to children with CP.
- Helpful ways to hold and move children with CP.
- Helpful ways to put children with CP in different positions.

In the last workshop we learnt that:

1. **CP is lifelong. A child will always have CP and it will not go away.**
2. **All children with CP have problems with movement.**
3. **Although we cannot cure CP, all children have the potential to change.**

Caring for a child with CP is a way of life and how children with CP change, depends on how they spend their time each day.

These are the things that we are going to talk about today:

- **What we mean when we say "Caring for a child with CP is a way of life".**
- **How children with CP change over time.**
- **Helpful ways to put children with CP in different positions.**
- **Helpful ways to care for children with CP.**
- **How we can do everyday things in a way that is helpful to children with CP.**

CARING FOR A CHILD WITH CP IS A WAY LIFE:

In this workshop we are going to talk about some helpful ideas for caring for children with CP, but these ideas are not exercises. They are not only for a particular time of day or to be done a certain number of times a day. These are ideas for every time we do anything with a child with CP. This is because a child with CP has difficulty with movement and this difficulty does not only happen some of the day, it is always affecting the child. So we have to always be working with the child in a way that is helpful so that the child's body does not become worse than it is.

This is why we say that caring for a child with CP is a way of life, because the ideas that we learn are things that we need to do all day, everyday - not only partiulcar times of the day or on certain days of the week. They are not exercises, they are a way to live our life with our child. Doing exercises each day can be helpful, but it is not enough to prevent the child from becoming worse.

3 CP as a way of life

Children with CP will become adults with CP and as they grow, they will change. They can either change in a good way or a bad way, depending on how they spend their day.

In this workshop, we will learn about how we can help children to change in a positive way and not become worse. In order to learn this, we first need to understand that CP is a way of life.

Explain what we mean when we say that "caring for a child with CP is a way of life".

THE STORY OF THE HUT:

Let us use the example of a hut to help us understand. If you have a beautiful hut, with a good roof and solid walls, it will be a comfortable place to live. If you just live in the hut and never do anything to keep it looking beautiful and strong, over time it will start looking worse. If you leave it for a very long time, it will become like the hut in the second picture.

If you live in the hut and want it to be a comfortable home for a long time, then you need to maintain it by patching the roof, repairing the walls and re-painting it. In the same way, a child with CP who is left in unhelpful positions or is not cared for in a helpful way, will become worse overtime. Children with CP (especially level 4 and 5) cannot do much for themselves and so we need to help them so that we can keep them from becoming worse over time.

We said before that all children with CP have potential to change and some children can change more than others depending on the damage to the brain. A hut also has potential for change and rather than just maintaining the hut, there are many things that we can do to improve it. The same is true for children with CP. They have the potential to change in a positive way, but they cannot change if we do not help them to change.

4 Change can be positive or negative

Children with CP change over time and this change can either be positive or negative. The less a child can move on their own, the more we need to do to yo help the child to move. This is because the less a child moves, the stiffer they will become and they will become stiff in the position that they are left in.

Use the pictures to explain the story of the hut.

In children who are level 4 or 5, it may be difficult to see a lot of positive change over time, especially as the child gets older - but the child can will become worse if we do not do something to prevent it.

In children who are level 1, 2 and 3, it is easier to see positive change over time, but there are still some parts of their bodies that can become worse if we do not help them.

5 What can go wrong over time

Let us look at an example of what can go wrong in children with CP over time.

Put up the pictures.

If you look at these pictures, you can see that this child can stand and can lie in a good position. His hands can open and he looks comfortable.

?

What do you think this child will look like in 10 years?
How will his body change?

Let the group answer and discuss their ideas.

WHAT THE CHILD LOOKS LIKE NOW:

Now the child we were looking at is a teenager. In these pictures, you can see that his body is no longer straight and the hips are twisted to one side. When the hips become twisted, the spine also becomes twisted and it cannot be made straight again. Even though he can still be put into a buggy, you can see that he cannot sit straight because his hips and spine are twisted. If you look at his knees and feet, you can see that he can no longer stand.

Put up the pictures and talk about what the child looks like now as a teenager.

These changes over time happen more quickly to children who are level 4 or 5, because they do not move on their own. The most important way to prevent a child from becoming worse like in these pictures, is to make sure that they are always in a good position and are not just left to lie on a bed. Remember that a child will become stiff in the position that they spend most of their time in. If they spend their time lying on a bed with their legs to the side, then they will become stiff in that position and their hips and spine will become twisted.

MAIN MESSAGE

Children with CP can change in a positive way or a negative way, depending on how they are cared for.

Children with CP will become stiff in the position that they spend most of their time in.

We can prevent children with CP from becoming worse over time.

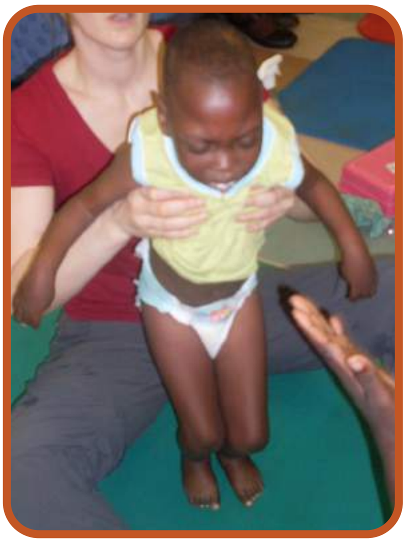
A LEVEL 4 OR 5 CHILD:

This is a level 5 child who is stiff and who needs a lot of help in order for him to not become worse. As you can see his mother has worked really hard to make sure that he does not get worse and he is still a healthy child who has not become any stiffer. He is able to still stand with his legs straight and his mother can move his body in all the ways that his body could move when he was younger. Even though there is not a big change, he is living a happy life with no pain. If you look at the first picture, you will see that his legs are lying to one side. This is how the teenager we just saw would have looked before he started becoming worse and this child would have become just as stiff if his mother did not work hard to prevent it.

6 What can go right over time

Now let us look at examples of what can go right for children with CP over time.

Put up the pictures and talk about a level 4 or 5 child.



A LEVEL 1 - 3 CHILD:

This is a level 3 child with mixed CP. If you look at her body and her feet when she was young, she does not look like she would be able to stand and walk with a walker. But you can see that she has learnt to sit and can walk in a walker. She also has become a happier child that what we see in the pictures where she was young.

Put up the pictures and talk about a level 1 - 3 child.

MAIN MESSAGE

Children can change in a good way over time.

This change is small in children who are level 4 or 5, but we can prevent them from becoming worse.

This change is easier to see in children who are level 1-3, but this change cannot happen if we do not care for the child in a way that is helpful during the day.

7 Why a good position is so important

We spend some of the day either moving, holding or carrying our children, but most of their day is spent in different positions. The way that children with CP are positioned is important, especially for level 4 and 5 children, because they cannot move on their own.

If a child is left in one position for a long time, they will become worse like the hut over time. Let us talk about how we can position children with CP in a way that is helpful and prevents them from becoming worse over time.

Put up the pictures.

WHY THESE POSITIONS CAN BE A PROBLEM FOR A CHILD WITH CP:

When we put a child with CP down to rest, we will often see that the legs lean to one side. In some children, the legs lean all the way to the one side and in some children the one leg only turns inwards a little. But in all the pictures, the children's knees are facing a different way to their body.

Lying like this causes the hips to come out in children with CP and when this happens we say that the hip is 'dislocated'. Even if the one leg is only turning in a little, the hip will become dislocated If we leave the child lying in this position.

When the knees are not facing the same way as the body, the hips become twisted, the spine also becomes twisted, and the hips come out. Once this happens, the child is in a lot of pain and we cannot change what has happened.

Many children with CP look like the children in these pictures when we put them down to rest.

?

What do you like about the way the children are lying?
And what do you think is a problem with the way that the children are lying?

Explain what the problem is with the way that these children are lying.

THE DEVELOPMENT OF THE HIP JOINT:

This is a picture of what the hip joint looks like in a child that does not have CP. You can see that the hip bone has a deep hollow that the leg bone fits into securely. The shape of the hip bone helps to keep the leg bone in the right place. Children are not born with a hip joint that looks like this. After the child is born the hip joint develops through the baby crawling, standing and walking. Crawling and walking are very important for the hollow in the hip bone to become deep like the one we see in the picture.

THE HIP JOINT IN A CHILD WITH CP:

This is a picture of what the hip joint looks like in a child with CP. Children that are level 4 and 5 never crawl or walk and so their hip joint remains very shallow and so it is easier for the leg bone to come out or dislocate because it does not fit securely.

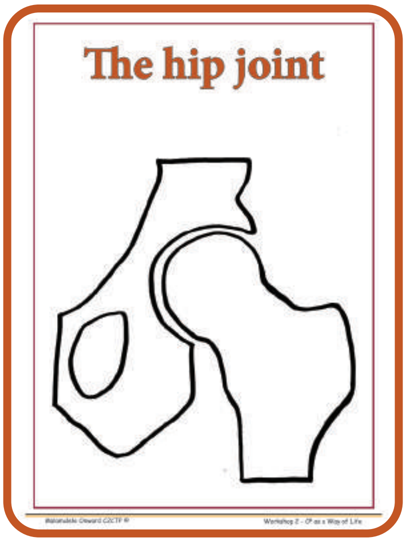
Children with CP who can walk, even if they need help, will develop a more secure fit between their hip bone and leg bone and so it is less likely that their leg bone will come out. BUT it is important that these children practise walking and if they cannot do it on their own, then we need to help them.

8

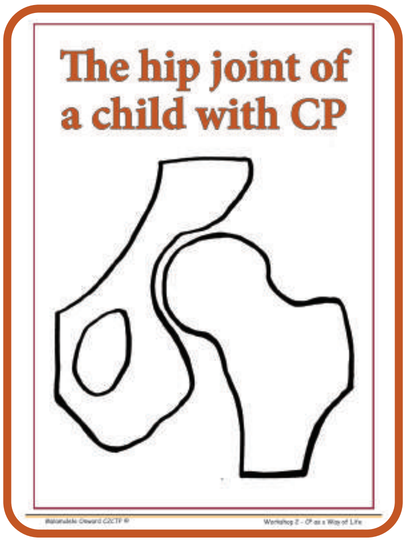
Why and how the hips can become dislocated

Let us talk about why a child's hips can become dislocated over time.

Put up the picture and explain how the hip joint usually develops in a child.



Put up the picture and explain how the hip joint can develop in a child with CP.



Children who are level 4 and 5 have a high risk of their hips dislocating.

The main problem with the hip dislocating is that it is very painful and once the hip has come out, it cannot go back in. This means that a child with a dislocated hip will always be in pain and they will need to take medicine for the pain for the rest of their life. We are teaching parents this information because we want to prevent children from being in pain. For some children we cannot stop it from happening at some stage, but we can stop it from happening when they are young. Through the way that we care for our children during the day, we can give them many more pain free years.

ACTIVITY:

- Ask for someone to be a volunteer.
- Use your volunteer to demostrate how we support a child's top leg when they are lying on their side.
- Show them that by putting a pillow or folded blanket between the legs, we help keep the hips and knees straight.
- If we do not support the top leg, it pulls on the hip which can cause the hip to come out.

9

Positions that are helpful for a child with CP

Whenever we put a child with CP down to rest, we need to make sure that the knees are facing the same way as the body. This is not only important for when they are lying on their back, but for any position that they lie in. When a child lies on their side, we need to remember to support their top leg so that it does not pull on the hip.

You will need:

Just like we used a pillow/blanket to support the child's top leg, we need to use what we have at home to try and keep them in a good position. We can use pillows, rolled up towels, blankets and anything in the house that can help. But how we do it for one child, is not the same way we need to do it for other children. Each child is different and so we need to figure out how to help them stay in a good position.

Let us look at some ideas for helping children with CP to stay in a good position.

Put up the pictures and talk about what has been used for each child.

All these children are lying in different positions and the pillows and blankets have been used in different ways to support the children.

?

When do we put a child in a lying position?
Do they lie down all day? Do they only lie down when they are sleeping?

- **When they are sleeping.**
- **When they are resting.**
- **If they are going to play in that position.**

Children with CP should only be lying down when they are resting, sleeping or playing. It is not helpful for the child to be lying down all day, nor is it helpful for the child to be sitting all day. Remember that we said that children with CP will become stiff in the position that they are left in over time. So if a child is lying all the time, their body will become stiff and stay in that position. If the child is sitting all the time, their body will become stiff and stay in that position. Children with CP need to use different positions during the day just like other children.

These new things that we have learnt about positioning a child are not only important when the child is lying, but it is also important when the child is sitting and standing. If the knees face a different way to the body when the child is sitting or standing, it will also cause the hips to come out.

Check if there are any questions.

MAIN MESSAGE

When we leave a child in a position, we need to make sure that the knees are facing the same way as the body.

If we do not position them well, their hips will dislocate over time.

If they are lying on their side, we need to support the top leg.

This is important for all positions, not only when the child is lying down.

10 Standing

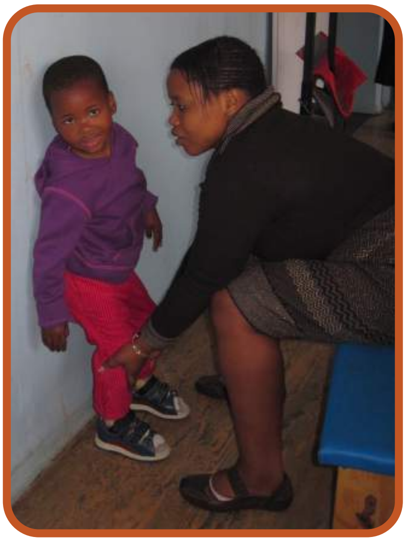
Let us understand a little about standing.

? **How can we help a child with CP to stand?**

- Support the child between our legs
- Hold the child's hands
- Lean the child against a wall or your body
- Put the child in a standing frame
- Support the child against a table or chair

Put up the pictures as the group mentions each idea and use the pictures to suggest any ideas that the group did not think of.






STANDING IN A WAY THAT IS HELPFUL:

- Make sure that both feet are on the floor and that they are straight. The legs should not pull up so that the feet are not on the floor.
- Make sure that the child's body is straight and that they are not falling to one side.
- Make sure that the child's hips are facing forward and the knees and feet are straight and facing the same way as the body.

Why do you think it is important for a child with CP to stand?

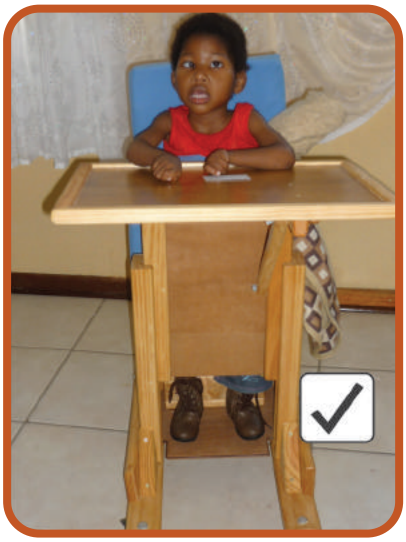
- To stretch the legs
- For the legs to learn to take weight
- To make the hips stronger
- To increase blood flow and make the heart stronger
- To help with constipation
- To help with vomiting

Just like the other positions, when we help a child with CP to stand, we need to make sure that they are standing in a way that is helpful and will not cause harm to them over time.

How do you think we can make sure that a child is standing in a way that is helpful?

Let the group answer and discuss their ideas.

Put up the pictures as you explain how we can make sure that a child is standing in a way that is helpful.



?

When do you think standing can be harmful for a child?

- **If the child has a floppy neck or a heavy head that they cannot hold up.**
- **If the child's feet cannot go flat on the floor.**
- **If the child cries or looks like they are in pain when standing.**

Check if there are any questions.

MAIN MESSAGE

There are many different ways that we can help children with CP to stand.

It is important for children with CP to stand, as long as they are standing in a way that is helpful.

Never make a child stand if it causes them any pain.

CARING FOR A CHILD WITH CP:

Here are some helpful points to remember when caring for a child with CP:

1. Move the child slowly and give them time
Children with CP need to be moved slowly. If we move them too fast, they will become stiffer and more difficult to move. If a child is calm, we need to move them very slowly so that they stay soft in their body. If they become stiff, we need to stop moving them and give them time to relax again.

2. Do not force the child's body to move
Moving the child's arms, legs and body must be easy, we must not force the child's body to move in ways that it cannot. Any time that we force the body to move, it will be painful for the child and we do not want to cause pain.

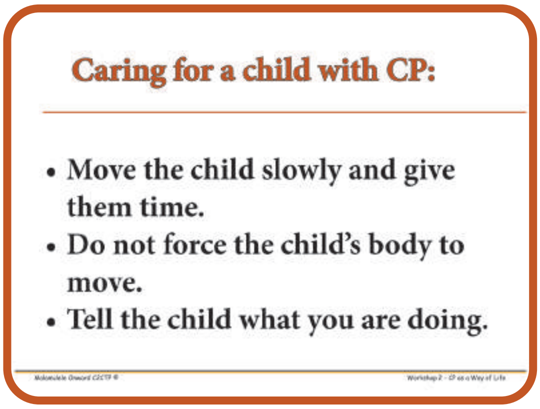
3. Tell the child what you are doing
If we just start moving the child without talking to them, they do not know what you are doing and they can become worried about what is happening. This will make them stiffer in their bodies and more difficult to move.

11 Caring for a child with CP

Now that we know how to best position a child with CP, let us learn about helpful ways to care for a child with CP.

Everyday there are times when we either move, hold or carry our child. When we do these things, there are ways that we can do them that can make the child worse and there are ways that we can do them that can be helpful for the child.

Put up the picture and explain the points.



Caring for a child with CP:

- Move the child slowly and give them time.
- Do not force the child's body to move.
- Tell the child what you are doing.

Caring for a child with CP can be difficult because they are either stiff or they are pushing back and we need to learn how we can care for a child with CP in a way that prevents the child from becoming worse.

Some children are stiff all the time like children that are spastic and some children either push back or move too much like children that are dystonic or choreoathetoid. The way that we care for a child who is stiff is different to how we care for a child that pushes back or moves too much.

MOVING AND TWISTING:

One of the helpful ways to loosen a child who is stiff is to move and twist them. Children who are stiff have difficulty with moving and so we need to help them to move in the ways that they cannot. Children who are more severely affected do not move their bodies in all the ways that other children can, because they cannot. If a child is severely affected we need to move their body for them. Children who are mildly affected do not move their bodies in all the ways that other children can, because it is difficult for them. If a child is mildly affected we can encourage them to move their own bodies even if it is difficult.

Twisting a child's body from side to side is also helpful as this is one of the ways that other children move. Once again if the child is severely affected we need to do it for them, but if the child is miildly affected, we can encourage the child to do it on their own.

12 Caring for a child who is stiff

If a child is stiff, we need to loosen their body.

?

What do you think we can do to loosen a child who is stiff?

Let the group answer and discuss their ideas.

Put up the pictures and explain how moving and twisting can loosen a child who is stiff.


Moving


Moving


Twisting


Twisting

MASSAGING AND STRETCHING:

Another helpful way to loosen a child that is stiff is to massage and stretch them. If children who are stiff do not move enough, their muscles can become very tight and can become shorter. We can help make the muscles softer by massaging them and stretching them.

Put up the pictures and explain how massaging and stretching can loosen a child that is stiff.


Massaging


Massaging


Stretching


Stretching

Check if there are any questions.

MAIN MESSAGE

If a child is stiff, we need to loosen their body.

Moving, twisting, massaging and stretching are all ways that we can loosen the child's body.

If there are some ways that the child can move on their own, we need to encourage them to do it.

ACTIVITY:

- Do the activity in pairs.
- One person is the caregiver and the other is the child.
- The child sits on a chair and pushes back. The caregiver must put their hand behind the child and stop them from pushing back by pushing also.
- Then ask the caregiver to stop pushing.

13 Caring for a child who pushes back or moves too much

If a child is pushing back or moving too much, we need to calm the body and help the child to become soft and there are some helpful ways to do this.

What happens if you push against the person who is pushing back?

- **They keep on pushing back.**
- **Their body goes stiff.**

What happens if you stop pushing against the person who is pushing back?

- **They stop pushing and they relax.**

The same thing happens with children who push back. If we push against them, they will keep on pushing back, but if we stop pushing they stop pushing back and relax.

DO NO T FIGHT THE CHILD:

Children who push back are very difficult to control. If they push back, we need to let them go back without letting them fall, and when they stop pushing we can bring them back to the position they were in. It does not help to push against the child’s back as they will just become stiffer. If we let them go back, they soon relax and then are eaiser to bring back to where they were.

So the first way we can help a child become soft is to not fight the child.

Put up all the pictures in a row and explain what we mean when we say: "do not fight the child".

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SUPPORT THE BODY:

When we hold a child who is pushing back and moving too much we often want to hold their arms because this is the part that is moving the most. This however does not make the child feel safe because their body is still moving and they can still fall. If they do not feel safe, they will not become calm and soft.

If we support the child at their body, their body stays in one place, which means that they cannot fall and they will feel safe. If they feel safe, it will be easier for them to become calm and their body and arms will become softer.

Children who push back and move too much often do not feel safe because they are not in control of their body and this makes it difficult for them to relax. We need to support their body to help them feel safe.

Put up the pictures and explain how we should support a child's body if they push back or move too much.

CARING FOR A CHILD THAT PUSHES BACK OR MOVES TOO MUCH:

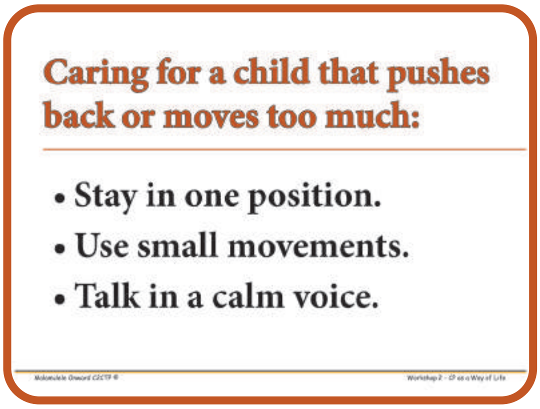
Here are some helpful points to remember when caring for a child that pushes back or moves too much:

1. Stay in one position
In order for the child to feel safe and in control of their body, we need to make sure that we stay in one position. If we move around and keep changing positions, the child will not feel safe and stay soft.

2. Use small movements
If we move the child that pushes back in a big way, they will become stiff. We need to move the child in small ways, so that they feel safe.

3. Talk in a calm voice
If we talk with an excited voice, the child will become excited and loose control of their body. We need to talk in a calm voice so that they can here us clearly, but do not get excited by it.

Put up the picture and explain the points.



Caring for a child that pushes back or moves too much:

- Stay in one position.
- Use small movements.
- Talk in a calm voice.

We have spoken about the ways the can hold or move children with CP that are helpful to them, but these are not exercises that we do at a particular time each day. They are a way of life and something that we can use whenever we are moving, holding and carryin our children.

For example, it will be easier to dress a stiff child if we do some twisting and loosening before we dress them. It will be easier to dress a child that pushes back if we help calm their body and move slowly.

Check if there are any questions.

MAIN MESSAGE

If a child pushes back or moves too much, we need to calm their body and help them to become soft.

We must not fight the child when they push back.

We support the body to make the child feel safe.

14 The things that we do everyday

You will need:

?

I want you to think of a typical day with your child. What are all the things that you do with your child during a typical day?

Write down everyone's suggestions.

DRESSING A CHILD IN SITTING:

Dressing can be a fun activity for the child. If a child is lying down to be dressed, they cannot see what is happening and they cannot help. By helping them to sit they can see their body, they are getting to move and they can help even if it is only a little.

① - ③ Before we undress the child, we can prepare the child by doing some moving like lifting the arms, twisting the body and reaching forward.

④ - ⑥ Then when we are taking the clothes of, we can help the child to use their hands to help to take the clothes off.

We can encourage the child when they are able to help a little and this helps to make dressing more fun for the child. Look at how well the mother is supporting this child and making him feel safe while she is helping him to undress.

15 Dressing and undressing

Let us talk about one of the activities that we do everyday with our child. Let us talk about dressing.

?

In what position do you dress your child? Do you dress them lying down or do you help them to sit?

Put up the pictures one by one and explain why it is helpful to let the child sit when dressing them.

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⑦ It is important to encourage the child when they are able to help a little and this helps to make dressing more fun for the child.

⑧ - ⑨ Even when taking socks and pants off, the child can help. Look at how well the mother is supporting this child and making him feel safe while she is helping him to undress.

? What do you think about dressing and undressing a child like in these pictures?
Do you like this way of dressing?
Do you think this is how you could do it with your child at home?

Let the group answer and discuss their ideas.

MAIN MESSAGE

Lying down is for resting, sleeping and playing - not for dressing.

Dressing can be fun and more interesting for the child if we dress and undress them while sitting.

It is important to remember what we have learnt about how we hold and move our child when we are doing everyday activities.

We as parents can make all the activities that we do with the child fun and interesting through the way that we hold and move them.

16 End of the workshop

? **Now that the workshop has come to an end, does anyone have any questions before we close?**

? **After learning about CP as a way of life, what will you do differently when you go home?**

Go through the parent handout with the group and check if there are any questions about it.

Close the workshop and make sure that everyone feels that their questions have been answered.

3

Getting Active

Getting my child's body ready to move throughout the day.

Materials

For this workshop you will need:

Some body lotion

A bench

1 Welcome

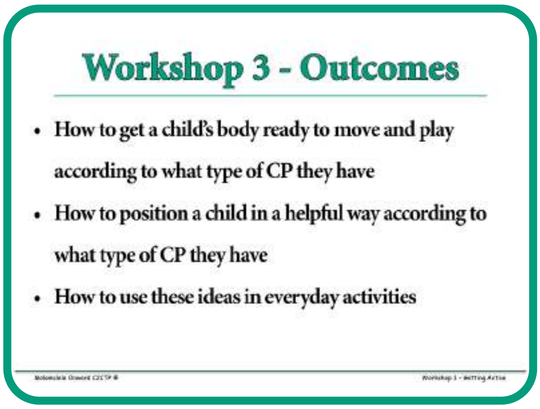
Welcome everyone to the group and make sure that they are comfortable before you start.

?

Before we start this workshop, what is one thing that you remember from the last workshop you attended?

2 Outcomes

Put up the outcomes and go through them with the group.



Workshop 3 - Outcomes

- How to get a child's body ready to move and play according to what type of CP they have
- How to position a child in a helpful way according to what type of CP they have
- How to use these ideas in everyday activities

In workshop 2 we learnt that we need to understand our child's body, and what the child's body is doing all the time.

In today's workshop, we are going to learn how we help the child's body get ready to move. Just like soccer players do a warm-up before a game starts, so we have to do some warm-up for the child's body.

We are also going to learn the how to position our children in helpful ways depending on what kind of CP the child has and what the body is always doing.

Understanding our children better and how to help their bodies will make it easier for us to interact with them and how to make everyday living simpler.

These are the things that we are going to talk about today:

- **How to get a child's body ready to move and play according to what type of CP they have.**
- **How to position a child in a helpful way according to what type of CP they have.**
- **How to use these ideas in everyday activities.**

3 Understanding the child's body

Every child with CP is different. If we want to help the child to do things for himself and if we want to make it easier for us to do every day things for the child, we need to understand our child's body, and what the child's body is doing all the time.

- **Is the child's body always stiff (spastic)?**
- **Is the child's body sometimes loose and sometimes floppy or sometimes pushing back (dystonic)?**
- **Is the child's body always moving too much and always looks disorganised (choreoathetoid)?**
- **Is the child only using one side of their body (hemiplegic)?**
- **Are the child's legs stiffer and more difficult to use than his arms (diplegic)?**

4 Helpful positions for being active

In workshop 2 we learnt about putting our children in a good position when they are going to stay in that position for a while.

? Can you remember the golden rule for making sure that a child is resting in a good position?

- **The knees must face the same way as the stomach**

? What about when children are active and moving?

When children are active, some positions can be helpful and make it easier for them to do things, while some positions make it more difficult.

For example: If a child is drawing a picture on a piece of paper but they are lying on their back, it is going to be very difficult. If that child sits on a chair at a table rather, it will be easier for the child to draw.

It is the same for children with CP. Depending on how CP affects their body, some positions may make it easier for them to play and be active, but because children with CP are all different, what works for one child may not work for another child.

We are now going to look at helping children who are stiff.

ACTIVITY:

- Ask for someone to be a volunteer.
- Use your volunteer to demonstrate how to massage a child.
- Start with the body.
- Then the arms and hands.
- Then the legs and feet.

5 Children who are stiff (spastic)

Remember we said in Workshop 2 that if children are stiff, we need to make them loose.

?

Can you remember the four things we can do to help a child who is stiff become looser?

- **Twist**
- **Move**
- **Massage**
- **Stretch**

Let us start with massage. Massage is one way of helping stiff muscles become soft. If possible, the child should be able to massage their own stiff arms and legs. If they are unable to, then you need to help them.

Remember, we only massage if the child's body is stiff. We only massage those parts of the body which are stiff.

You will need:

Put up the pictures to show and explain examples of massage.

ACTIVITY:

- Ask the group to sit on their chairs with their backs facing the wall.
- Then ask them to try to touch the wall behind them.
- Once everyone has tried it, ask them to now try to touch the wall but while keeping their legs still.

6 Moving, twisting and stretching

To be able to move, twist and stretch the child, one part of the child's body must be supported and kept still, while the other part is moved.

? **How did that feel?**
Did you feel how body stretched more when you kept your legs still?

Put up the pictures to show how to twist a child.

ACTIVITY:

- Divide everyone into 3 groups.
- Group 1 must think about a child with stiff legs and show the others how they would stretch a child's legs while he is (i) lying, (ii) sitting and (iii) standing.
- Group 2 must think about a child with stiff arms or 1 stiff arm and show the others how they would stretch a child's arms and hands while he is (i) lying, (ii) sitting and (iii) standing.
- Group 3 must think of a child with a stiff body and show the others how they would stretch the child's whole body while he is (i) lying, (ii) sitting and (iii) standing.
- Give each group a few minutes to discuss their ideas before they show the others.

IDEAS FOR STRETCHING STIFF LEGS:

- The child can use a towel to pull their body towards their feet while keeping their legs straight.
- This kind of stretch can also be used for a child who has stiff arms in order to stretch both their arms and legs at the same time.

Let us now think of ideas for how we can help our children to stretch, twist and move.

Put up the pictures to show some more ideas and explain what is happening in each picture.

IDEAS FOR STRETCHING STIFF LEGS:

- The child can lie flat on the floor on his stomach and stretch each leg back as far as he can.
- The child can lie on her back with her feet on a box. Gravity will help her as she pushes her knees down to straighten her legs.
- The child can lie on her back with her legs against the wall.
- Two children can play by putting their feet together and straightening their legs. One can straighten his legs while the other bends his legs, or each child can have one leg straight and one leg bent and then change sides.
- Children can stand and then bend over to touch their toes while keeping their legs straight.
- A child can kneel on all fours and then lift their bottom into the air, while trying to push their heels to the floor.

IDEAS FOR STRETCHING STIFF ARMS:

- The child can use one arm to stretch the other one forward.
- The child can clasp their hands together and stretch their arms out over a table.
- The child can reach both arms up above their head.
- The child can put their hand up against the wall.
- The child can lie on a straight arm either on a table,
- or on the floor.
- The child can put their stiff hand on their knee and then push down on it with the other hand.
- The child can sit on his hands, keeping his elbow straight
- The child can rest her head on her hands.

IDEAS FOR STRETCHING, MOVING AND TWISTING THE WHOLE BODY:

- The child can lie on his stomach and look up at something.
- Children can sit on the floor with their feet together and legs straight, while passing a ball or balloon to each other. As they reach forward they stretch the back of their body.
- Children can sit back-to-back and pass a ball/balloon to each other.
- Children can sit to the side while playing with a ball.
- Children can fold their body forward over their knees and stretch their arms out.
- When sitting on a bench and keeping their arms folded, children can twist and move their legs from side of the bench to the other side

? **How can you use these ideas of stretching, twisting and moving in everyday activities such as dressing, undressing and bathing?**

Let the group share some ideas and then put up the pictures and discuss what is happening in each picture.

Check if there are any questions.

MAIN MESSAGE

If a child’s body is stiff, we need to make them loose.

We can make a child’s body loose by massaging, twisting, moving and stretching.

We only use massage if the child’s body is stiff. We only massage those parts of the body which are stiff.

If possible, the child should be able to massage their own stiff arms and legs. They should also twist, stretch and move their own bodies if they can. If they are unable to, then you need to help them.

We can help the child to move, twist and stretch during everyday activities like dressing, undressing and bathing.

LAYING THE CHILD ON THEIR STOMACH:

Laying the child on their stomach is a helpful position because: it helps to stretch the hips and as the child reaches, it helps to stretch the sides of their body.

When the child is lying on his stomach, help him to rest on his elbows. Then help him to lean on one elbow and use the other hand to reach for toys. Do this to both sides.

SITTING TO REACH AND TWIST:

Let the child sit on a bench or a crate while you sit behind him. Then help him to reach away from his body to play. The child can reach up, forward and twist to the side while the bottom half of his body stays still, just like we all did earlier.

If the child can do it on his own, we need to encourage him to twist and reach.

7 Helpful positions for children who are spastic (stiff)

Let us look at some positions that are helpful for a child who is stiff:

Put up the pictures and explain why it is helpful for a child who is stiff to lie on their stomach.

Put up the pictures and explain why it is helpful for a child who is stiff to reach and twist while sitting.

STANDING TO REACH AND TWIST:

The child can stand in a standing frame or between your legs with a table in front. Once again the child's body is supported and stays still, while the child reaches his arms away from the body and uses his hands to explore.

If the child can hold their body up then we only need to support the bottom half from the hips down. The child can stand between your legs or in a standing frame but only the hips and legs stay still while the child uses his body and reaches.

Put up the pictures and explain why it is helpful for a child who is stiff to reach and twist while standing.

Take the pictures off the wall before starting the next section

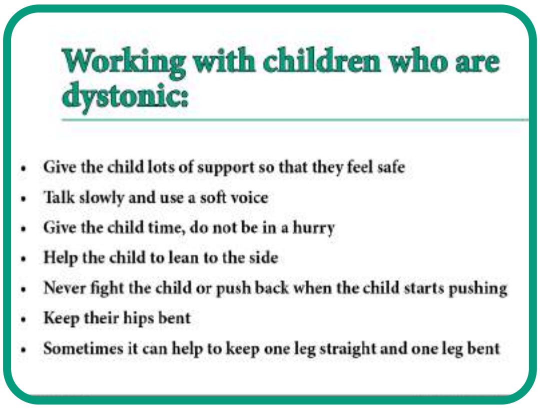
8

Children who are sometimes loose, sometimes stiff or sometimes push back (dystonic)

In workshop 2, we learnt that for children who are loose and then become stiff or who push back, we need to help their bodies to relax and let go. If we give the child lots of support, they feel safe and then it is easier for them to let go.

We want the child to be active in their bodies without their bodies pushing back or becoming stiff for example, when they stretch out to touch a toy, their whole body becomes stiff.

Put up the pictures and then talk through the ideas for working with children who are dystonic.



Working with children who are dystonic:

- Give the child lots of support so that they feel safe
- Talk slowly and use a soft voice
- Give the child time, do not be in a hurry
- Help the child to lean to the side
- Never fight the child or push back when the child starts pushing
- Keep their hips bent
- Sometimes it can help to keep one leg straight and one leg bent

ACTIVITY:

- Divide everyone into pairs.
- Ask the group to think about how they can use these ideas about handling a dystonic child in everyday activities such as dressing, undressing and bathing
- Give the pairs some time to practice.
- Then let each pair demonstrate their ideas for the group.

Check if there are any questions.

MAIN MESSAGE

If a child's body is sometimes loose, sometimes stiff and sometimes pushes back, we need to help their bodies relax and let go.

This does not mean that the child is not active. We want the body to be active without pushing back.

We need to give the child lots of support, talk and move slowly, help the child lean to the side, keep the hips bent and give the child time.

We must never fight the child's body.

9 Helpful positions for children who are dystonic

In Workshop 2 we learnt that for children who are loose and then become stiff or who push back, we need to help their bodies to relax and to help them feel safe. We need to help them be active in their bodies without their bodies pushing back.

If the activity is too exciting and the child becomes stiff – it will be too difficult for the child to participate. If the child gets stiff or loses control of their body when they use their hands, then we should rather do activities where they use their eyes for looking or ears for hearing, like reading a book or singing songs. If we do want the child to use his or her hands, we we need to give them lots of help and support.

Although we have learnt that when children are in a position for a long time, the knees must face the same way as the stomach, it is not always the same for when children are active. For children who are sometimes loose and sometimes stiff, it usually helps to make their stomach face away from their knees when we want them to be active and play. This position helps them to relax better and they do not get so stiff when they want to use their hands or they get excited.

Put up the pictures and show the group where the knees are facing away from the stomach.

LYING WITH THE HIPS AND KNEES BENT:

Laying the child on their back can be a helpful position but only if the hips and knees are bent, otherwise it is easy for the child to push back. When the child is lying on their back, the whole body is supported underneath. This is a nice position for looking games.

For many children who are sometimes loose and sometimes stiff, it is difficult for them to bring their hands together. If they lie on their side, it makes it easier for their hands to come together to play, because the bottom hand is supported.

Let us look at some more positions that are helpful for children who are sometimes loose, sometimes stiff and who sometimes push back:

Put up the pictures and explain why it is helpful for a child who pushes back to lie with their hips and knees bent. Show the group that in the first picture there is another example of where the knees are facing away from the body.

HELPFUL WAYS FOR A DYSTONIC CHILD TO SIT:

One way that is helpful for dystonic children to sit is for them to sit to one side, either on the floor or next to someone on a bench. The hips must be bent and the child should lean on one arm and then use the other arm to play.

If the child is sitting and facing straight, then it is important for the hips to be bent just like when the child is lying on his back.

If the child becomes too stiff when he tries to use his hands, then just let him look at a book and use his eyes to tell you when to turn the page. Again it is important that his hips are bent and you are supporting his body.

Put up the pictures and explain how to help a dystonic child to sit and play. Again, show the group that in some of the pictures, the knees are facing away from the body.

HELPING A DYSTONIC CHILD TO STAND:

It is important for children to stand, but many children who push back need lots of support to stand. The child can stand in a standing frame or between your legs with a table in front. The body must have lots of support so that the child feels safe to move their arms away from their body and so that it is easier for them to explore with their hands. Remember that children who push back need you to support their body to make them feel safe.

Put up the pictures and explain how to help a dystonic child to stand.

Take the pictures off the wall before starting the next section

Check if there are any questions.

MAIN MESSAGE

Children who are dystonic need lots of support when we put them in different positions.

For dystonic children, it is helpful to make the knees face a different way to the body.

Keeping the knees and hips bent can also be helpful for the dystonic child.

ACTIVITY:

- Ask everyone to keep both sides of their bottom in their chair and to reach as far to the left as possible.
- Once they are all reaching, ask them to reach just a little further.

10 Children who move too much (choreoathetoid)

Let us now talk about children who move too much.

When I asked you to reach your arm out to the side, you were able to do it because you kept your bottom half of your body still and you used your stomach muscles to stop you from falling over. We call this stability.

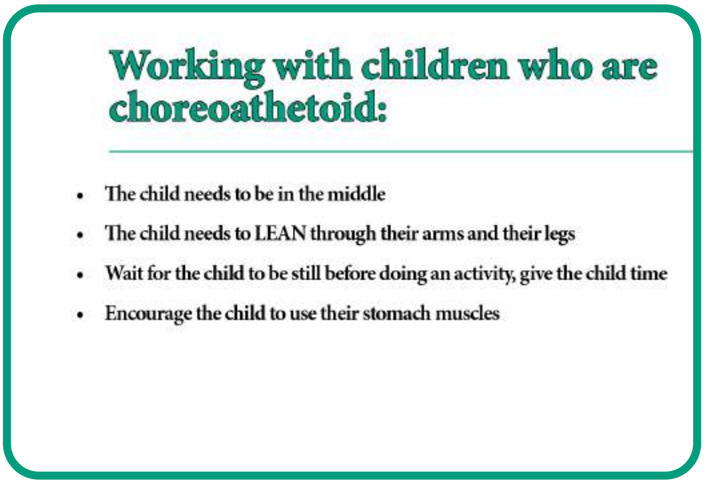
That is because one part of your body (your bottom and your legs) is stable so that another part (your body and arm) can move. Children who move too much do not have this stability. This is because their body is always moving too much and they cannot keep one part still. It is difficult for them to keep one part still while the other part moves. Their bodies are also often floppy and it is difficult for them to use their stomach muscles.

So let us talk about how we can help the child with choreoathetosis get ready to be active.

ACTIVITY:

- Divide everyone into pairs.
- Ask the group to think about how they can use these ideas about handling a choreoathetoid child in everyday activities such as dressing, undressing and bathing?
- Give the pairs some time to practice.
- Then let each pair demonstrate their ideas for the group.

Put up the pictures and talk through the ideas for working with children who have choreoathetosis.



Working with children who are choreoathetoid:

- The child needs to be in the middle
- The child needs to LEAN through their arms and their legs
- Wait for the child to be still before doing an activity, give the child time
- Encourage the child to use their stomach muscles

Put up the pictures and discuss how these activities are helpful for a child who moves too much.

Check if there are any questions.

MAIN MESSAGE

If the child moves to much, we need to keep them in the middle.

The child needs to LEAN through their arms and their legs and use their tummy muscles.

Wait for the child to be still before doing an activity, give the child time.

LYING ON THE SIDE:

Lying the child on their side can be a helpful position to make it easier for the child to use their hands in the middle of their body, just like we discussed for the child who is dystonic. In this position they also need less arm support to use their hands.

PUSHING THROUGH ONE ARM WHILE THE OTHER ARM MOVES:

One way that is helpful for these children to sit is over a bench with their legs over each side. Then one arm can be pushing while the other arm is playing. Anytime that a child who moves too much is sitting, they should push through one arm to help keep their body still, while the other arm moves.

11 Helpful positions for children who are choreoathetoid

Children who move too much need to learn how to use their stomach muscles and one of the ways we can help them to do this is by pushing through their arms.

Let us look at some positions that are helpful for these children who are always moving too much:

Put up the picture and explain why laying the child on their side is helpful for children who move too much.

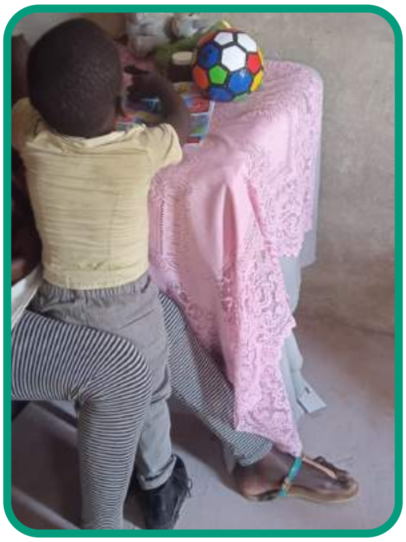
Put up the pictures and explain how to help the child push with one arm while the other arm moves.

STANDING FOR A CHILD WHO MOVES TOO MUCH:

The child can stand in a standing frame or between your legs with a table in front. They can push through both arms or they can push through one arm while the other arm is playing. The table can be at an angle to make it easier for the child to push against.

If the child can walk, pushing a bench or chair will help them to push through their arms and use their stomach muscles.

Put up the pictures and explain how to help a child who moves too much to stand and push through his arms.



So can you see now how we can use a child's position to make it easier for them to play and be active. These positions also make sure that the child is playing in a way that is helpful. If the child is in a helpful position, the time he spends being active will be helpful for his body, just like therapy. This is because the child is doing activities in a way that helps him to use and control his body better.

Check if there are any questions.

MAIN MESSAGE

Pushing through the arms helps choreoathetoid children to use their stomach muscles.

It is also helpful for choreoathetoid children to be in the middle.

IDEAS FOR EVERYDAY ACTIVITIES:

The most important way to make it easier for children to do everyday activities by themselves is to understand what position makes it easier for them and to then find a way for them to do the activity in that position. For example, sitting on a bench with a wall behind their back can make it easier for some children to take a shirt off, as if they just sit on a bench, they may lose their balance and fall off. Some children will find it easier to sit on the floor with their legs crossed.

It is always helpful for the child to sit on a firm surface. Trying to dress on a soft bed will make it more difficult for the child. Children may need to use different positions depending on what item of clothing they are putting on or taking off. For example, some children will find it easier to sit on a bench and bend down to take their shoe off, other children will find it easier if they rest their foot on their other knee.

For children who are hemiplegic it is often easier for them to dress the hemi arm and leg first before they dress the other arm and leg. We can also make it easier for children to dress by using clothes that make it easier. For example shoes with velcro are easier to take off than shoes with laces. Shirts made from material that can stretch easily are easier than tight cotton shirts. Pants with elastic are easier than pants with zips and buttons.

12 Children who are level 1, 2 or 3

Children who are level 1, 2 or 3 should be encouraged to do more things for themselves and one of those things is learning how to dress and undress.

Put up the pictures and explain some ideas for helping children to dress and undress themselves.

When children dress and undress themselves, it is important for them to fold their clothes up neatly!

Put up the pictures to show examples.

Check if there are any questions.

MAIN MESSAGE

All children with CP can learn and so we need to make sure that they are learning to do more things by themselves.

It is helpful to start with everyday activities such as dressing, undressing and bathing.

REMEMBER: we must help the child to be in a good position

13 End of the workshop

? **Now that the workshop has come to an end, does anyone have any questions before we close?**

? **After learning about how to help your child's body get ready to move and do activities, what will you do differently when you go home?**

Go through the parent handout with the group and check if there are any questions about it.

Close the workshop and make sure that everyone feels that their questions have been answered.

4

Eating and Drinking

Making meal times safe
and comfortable for my child.

Materials

For this workshop you will need:

A cut out cup (1 per person)

A teaspoon (1 per person)

A large spoon (1 per pair)

Custard (or any soft food like yoghurt or porridge)

Some water

1 Welcome

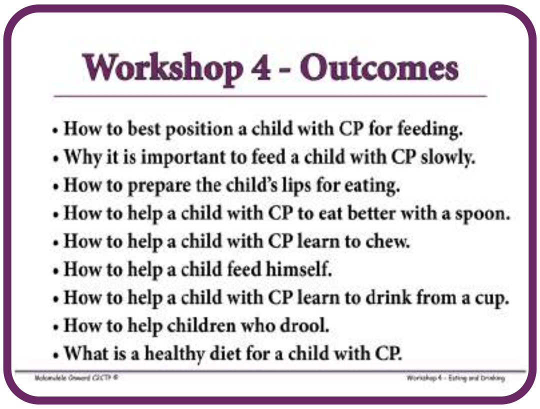
Welcome everyone to the group and make sure that they are comfortable before you start.

? **Before we start this workshop, what was one thing that you learnt from the last workshop on "CP as a way of life" and how have you used it at home?**

During this workshop we are going to do some activities that involve eating. Please only eat the food when we are doing the activities. If you eat in between the activities, we will run out of food.

2 Outcomes

Put up the outcomes and go through them with the group.



Workshop 4 - Outcomes

- How to best position a child with CP for feeding.
- Why it is important to feed a child with CP slowly.
- How to prepare the child's lips for eating.
- How to help a child with CP to eat better with a spoon.
- How to help a child with CP learn to chew.
- How to help a child feed himself.
- How to help a child with CP learn to drink from a cup.
- How to help children who drool.
- What is a healthy diet for a child with CP.

Many children with CP have difficulty with eating and drinking and we as parents can help them eat and drink more safely and comfortably through the way that we go about feeding them.

This is what we are going to talk about today:

- **How to best position a child with CP for feeding.**
- **Why it is important to feed a child with CP slowly.**
- **How to prepare the child's lips for eating.**
- **How to help a child with CP to eat better with a spoon.**
- **How to help a child with CP learn to chew.**
- **How to help a child feed himself.**
- **How to help a child with CP learn to drink from a cup.**
- **How to help children who drool.**
- **What is a healthy diet for a child with CP.**

Divide the group into pairs and tell them that they will stay in the same pairs for all the activities in this workshop. Then give each pair 2 full cups of custard, 1 big spoon and 2 teaspoons to keep for the activities.

ACTIVITY:

- Do the activity in pairs.
- One person is the caregiver and the other is the child.
- The child sits with their head back as in the picture.
- The caregiver then feeds the child a few spoons of custard.
- Then the pairs swop so that each person has a turn to be the child.

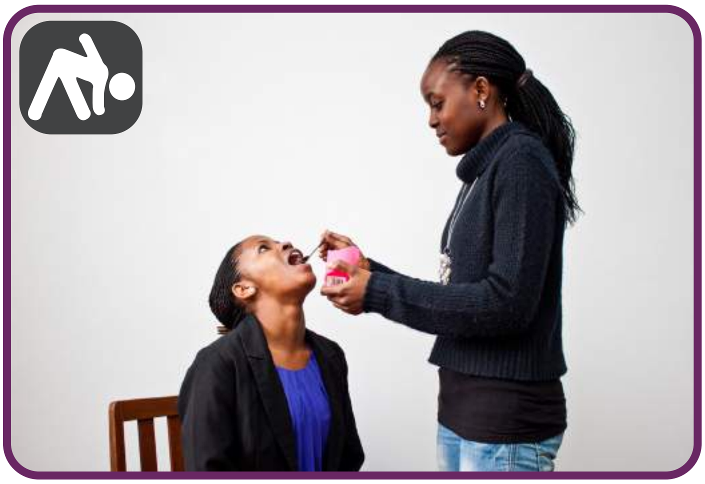
ASPIRATION:

In our bodies we have two pipes: one goes to our lungs and is for the air that we breathe. The other one goes to our stomach and is for our food. These pipes are very close together and in between them is a flap. When we eat, the flap closes the pipe to our lungs so that the food goes to our stomach. When we breathe in, the flap closes the pipe to our stomach so that the air goes to our lungs.

This only happens if we are sitting in a good upright position. If our head is tilted back, it is difficult for the flap to close properly and small pieces of food can go down the air pipe and into the lungs. If this happens to a child with CP, their breathing can become difficult, they can develop chest infections, they can become very sick and can even die. from it.

3 A good position

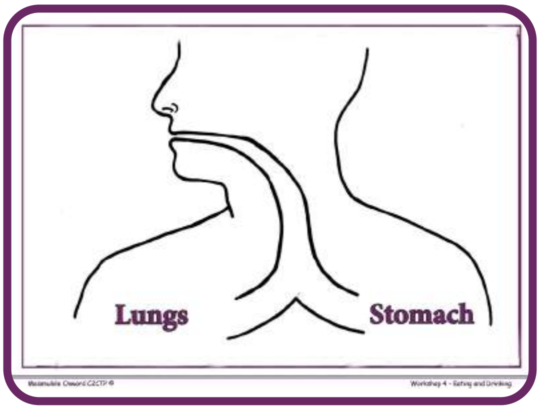
You will need:



? How did it feel to be fed in this position?

? Do you think this is a safe position to eat in?
Why?

Put up the picture.



It is not safe for anyone to eat while their head is back and it is because of something called ‘aspiration’.

Use the picture to explain what aspiration is and check if there are any questions.

ACTIVITY:

- Sit on a chair in the middle of the group in a poor position.
- Ask the the group how they would change your position to make it better.
- As each person makes a suggestion, ask them to come and correct your position.

Put up the 3 pictures of children eating in good positions and point to the examples as the group gives suggestions.

?

So from this activity, how do you think we should position a child with CP well for eating and drinking?

- **The child must be sitting upright.**
- **Their chin must be close to their chest.**
- **Their arms and shoulders should be forward.**
- **Their hips should be bent.**
- **Their feet should be supported.**
- **They should feel comfortable.**

FEEDING IN A CHAIR:

Wherever possible children with CP should be fed in a chair instead of a person's lap, because as they grow they will become too big and heavy for the person to support them in a good position. It will also be difficult for an older child to start using a chair for feeding if they are only used to eating whilst sitting on someone's lap.

However, sometimes it is not possible to put the child in a chair. For example: if there is not a safe chair in the house, or if the child is away from home. That is alright, as long as the child eats in a chair whenever there is one available, so that they grow up feeling used to it.

Put up the pictures and explain why feeding a child in a chair can be helpful.

? **How do you think you as the caregiver should sit when feeding your child in a chair?**

- **It is important that you are comfortable.**
- **You should sit in front of the child so that they can look at you.**

? **What if you do not have a chair for your child?**

Put up the picture as an example while the group discusses their ideas.

AFTER FEEDING:

After feeding the child, it is helpful to put them in an upright position, not lying down. They can be standing or sitting, as long as there is nothing tight across their stomach. Children should spend at least 30 minutes in an upright position after meals.

It is helpful to put a child in an upright position, because the food can move through the stomach quicker. This can be very helpful for children who vomit after feeding.

When you are feeding your child, you should be able to bring the food from below the child's eyes so that they do not tilt their head back.

Use the pictures to show this.

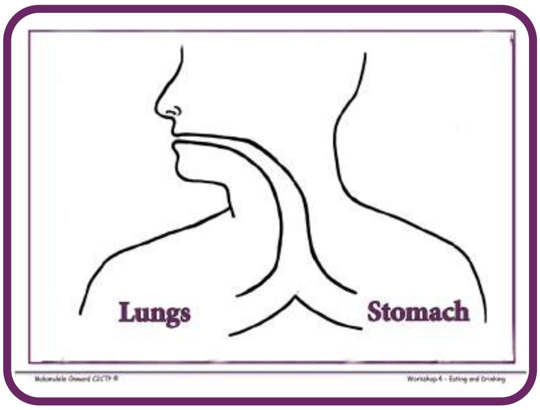
? When you are finished feeding your child, what position do you usually put them in?

Use the pictures to explain why a child should be in an upright position after feeding.

WHEN TO GIVE THE CHILD WATER:

It is difficult for children with CP to clear their mouths after eating and so there is still some food that has not gone to the stomach. If we give them water straight after a meal and some accidentally goes to the lungs, the water will wash the food into the lung and this will cause an infection. If we wait for 30 minutes after the child has eaten, it gives them time to clear their mouth of bits of food. Then because the mouth is clear, if we give them water and some accidentally goes into the lungs, it will just be water, so the lungs will not get infected.

Use the picture to explain why children with CP should only be given water 30 minutes after a meal.



If the child often vomits after a meal, this may mean that he or she has reflux. You need to consult a doctor.

MAIN MESSAGE

A good position is important for a child with CP to be able to eat and drink safely and comfortably.

A child cannot eat and drink safely if their head is tilted back.

It is important that you are also comfortable when feeding your child.

Bring the food from below the child's eyes and in front of the child so that their head does not tilt back.

Make sure that the child stays in an upright position for at least 30 minutes after meals.

Only give the child water to drink 30 minutes after a meal.

ACTIVITY:

- Do the activity in pairs.
- One person is the caregiver and the other is the child.
- Take the caregivers away from the group so that the children cannot hear what you are telling them.
- Tell the caregivers that they must feed the child very quickly with the big spoon.
- The caregiver then feeds the child a few big spoons of custard very quickly.

4 Feeding slowly and using the right size spoon

You will need:

? What did you not like about the feeding?

? How would you change it?

- Feed the child slowly.
- Give the child enough time to swallow after each spoon of food.
- Feed small amounts at a time.
- Use a spoon the fits the child's mouth.
- Use a shallow spoon, not a deep one.

MAIN MESSAGE

Children with CP need to be fed slowly.

Use a shallow spoon that fits the child's mouth.

Feed small amounts at a time.

PREPARING THE CHEEKS AND LIPS FOR EATING:

1. Push your cheeks together to get an OOO sound. Blow kisses too!
2. Use your fingers from the nose downward to pull your top lip down.
3. Use your hands to wipe down your face from your forehead to your top lip.

5 Preparing the lips for eating

Just like we massage and stretch a stiff child's body to make them loose, if a child has stiff cheeks and lips, we can use massage and stretch to loosen the muscles in their face.

Put up the pictures and explain how a child who is more able and active child can prepare their own cheeks and lips for eating.

1

2

3

These loosening activities can be done everyday before mealtimes.

ACTIVITY:

Tell the group that you want each person to eat a spoon of custard and they must think about what they do with their tongue and lips while they eat the custard.

6 Eating with a spoon

Let us learn about how we can help a child with CP to eat with a spoon more easily.

You will need:

When everyone is finished, put up the 3 pictures and ask the question.

1


2


3


SUPPORTING THE JAW:

- Support is given with one hand as in the pictures.
- The support is very light - we are not pressing hard.
- We do not make the child's jaw move up and down.
- We just stop the mouth from opening too wide.
- Jaw support is light and is only used to help a child whose mouth opens too wide.

? What do you do with your tongue and lips when you eat a spoon of custard?

1. We open our lips and place the food on our tongue
2. We close our lips to take the food off the spoon
3. Then we swallow with our lips closed

? Why do you think a child with CP can have problems with being fed with a spoon?

- They cannot close their lips to remove the food.
- They cannot close their mouth to swallow.
- Their tongue pushes the food out of their mouth.
- Their mouth opens too wide.

So let us learn how we can help a child who opens their mouth too wide.

Put up the pictures and explain to the group how they can help support the child's jaw when feeding.

FEEDING WITH A SPOON:

① Before you begin, the child must be in a good position for feeding. Support the child's jaw lightly.

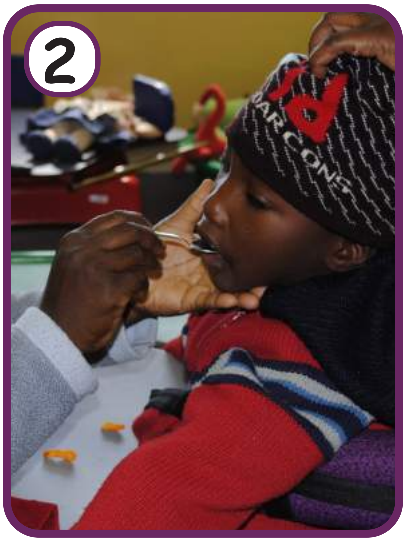
② Then gently press the spoon down on the tongue wait for the child to try and use their lips to take the food off the spoon.

③ If the child does not respond, you can help bring the lip down gently.

Go to each person in the group and let them feel what it should feel like.

Now let us see how we can feed a child with CP with a spoon:

Put up the pictures one at a time and explain each one before you continue.



WAITING FOR A CHILD TO USE THEIR LIPS:

It is very important that we give the child the opportunity to use their lips to take the food off the spoon. If we just feed them and do not give them an opportunity to move their lips, over time they will not be able to move them any more and feeding will be more difficult and less safe for the child.

If it is difficult for the child to use their lips, you do not have to do this for the whole meal as it would take a long time. Rather feed the child a few spoons and then finish the meal through finger-feeding or cup-drinking, which we will talk about later in this workshop.

Explain why it is important to wait for the child to use their lips to take the food off the spoon.

Put up the picture.

When we are feeding it is very important not to scrape the spoon on the child's teeth to get the food into their mouth.

Why do you think we should not do that?

- **It causes their teeth and gums to move forward.**
- **It causes their head to tilt back.**
- **The child does not learn how to use their lips.**

Ask your therapist to help you with this as it is very difficult to do in the beginning and it takes lots of practice.

As we said earlier, it will be easier for the child to get the food off the spoon if it is a shallow spoon and not a deep spoon.

Use the picture to show the group an example of a deep and a shallow spoon.

If your child tends to bite down hard on the spoon, it is best to use a soft plastic spoon like the one in the picture as this will not hurt them when they bite hard.

Check if there are any questions.

MAIN MESSAGE

If the cheeks and lips are stiff, we can use massage and stretch to loosen them before meals.

When we support a child's jaw it must be light support.

We support the jaw to stop the mouth from opening too wide, we do not open and close the child's mouth.

Help the child to use their lips when eating with a spoon and give them enough time to try.

A shallow spoon makes it easier for the child to remove the food with their lips.

Do not scrape the food onto the teeth.

Ask your therapist to help you practice.

7 Helping a child to chew

Now that we have learnt about feeding a child with CP with a spoon, let us learn about how we can help them to chew.

Ask the following questions and discuss the answers.

? **Why do you think it is important for children to learn how to chew?**

- **So that they can eat more types of food and be healthier.**
- **Eating harder foods helps the teeth and gums stay in better condition.**
- **If a child only eats soft foods, they do not learn to chew.**
- **We use the same muscles for chewing that we use for talking.**

? **Pretend to chew. What do you do with your tongue, jaw and lips?**

- **The tongue moves in all directions.**
- **The jaw moves side to side and around.**
- **The lips stay closed.**

? **Why do children with CP have difficulties with chewing?**

- **It is difficult for them to close their lips, so food may fall out of their mouth.**
- **The tongue and jaw only moves forwards and backwards and pushes the food out of the mouth.**
- **Their mouth opens too wide.**

At the end of the discussion, check if there are any questions.

HELPING A CHILD TO CHEW:

First place the food in between the child's back teeth with your fingers. Be careful not to put your fingers between the teeth, as they may bite you. If the child's mouth opens wide, then support the jaw lightly. Do not move their jaw for them, we need to encourage them to move their jaw on their own.

Put the food in on one side and then on the other side.

When we are teaching a child to chew, the types of food need to be soft and dissolve easily so that if a piece breaks off, it will not cause the child to choke. Later when the child can chew, we can use harder fruits and vegetables as well as meat.

? What kinds of soft foods do you think we could use to help a child with CP learn to chew?

- Cooked potato, carrot or other vegetables, cut into sticks.
- Soft chips or biscuit.
- Soft pieces of fruit like pears, cooked apples, or bananas.

Now let us look at how we can help a child to chew.

Put up the pictures and explain how to help a child to chew.

GIVE THE CHILD A CHANCE TO PRACTICE CHEWING:

It is very important for us to give the child chances to practice chewing. Otherwise, they never learn how to chew and they will not able to eat the same foods as the rest of the family.

It is important for the child with CP to practice chewing, but we do not have to feed them like this for the whole meal, as it may take a long time. Rather we can do it for a few minutes before every meal so that they have many opportunities to chew and can learn to eat more solid foods.

Explain why it is important to wait for a child to chew.

As with spoon feeding, ask your therapist to help you with this as it is very difficult to do in the beginning and it takes lots of practice.

Check if there are any questions.

MAIN MESSAGE

It is important for a child to learn how to chew.

When teaching the child to chew, always use soft foods that can dissolve easily if a piece breaks off, so that the child does not choke.

We support the jaw to stop the mouth from opening too wide, we do not open and close the child's mouth.

Be patient and give the child time to chew.

Give the child something to try to chew at every meal.

Ask your therapist to help you practice.

MAKING IT EASIER FOR CHILDREN TO FEED THEMSELVES:

First, the child's position is very important. They need to be able to sit upright and comfortably and have enough support. It is also helpful to have a table in front of them so that they can lean on it to rest their arms and just use their hands to eat. Their feet should be able to rest firmly on the ground. Sometimes the child may need more support, for example support at the sides. It is important that the child has as much support as possible to make it easier for them to feed themselves.

We can also make it easier by changing the objects used at mealtimes such as the plate, spoon, cup, etc. A non-slip mat under the plate can stop it from moving around. We can make the handle of the spoon bigger so that it is easier for the child to hold. Wrapping a piece of foam or a strip of cloth around the handle of the spoon can make it thicker so that is easier for the child to hold.

We can also bend the handle of the spoon. In this way, it is easier for the child to get the spoon to their mouth.

Another way we can help children to feed themselves is to help them to hold the spoon by putting our hands over their hands.

Self-feeding is difficult for many children and it should only be practiced for a short while if it is very difficult, not the whole meal. Let the child practice for a short while near the end of the meal so that the child is not hungry or miserable.

As with everything we do each day with the child, we want to help the child to do more things for himself, even if it takes time. The more the child has the chance to practice , the easier it will be for them to do things by themselves.

8 Helping a child to feed himself

If a child is able to help feed himself, even just a little bit, we need to make it possible for him to practice. Let's think of ideas for how we can make it easier for a child to feed himself.

Put up the pictures and share some ideas for how we can make it easier for children to feed themselves.

THICKER LIQUIDS CAN BE HELPFUL:

Children with eating and drinking difficulties, usually take a long time to swallow. Using a thicker liquid that pours slowly can be helpful, as it allows that child more time to swallow. This means that the child is less likely to choke and has the opportunity to learn to drink from a cup better.

9

Drinking from a cup

Now that we have learnt about feeding a child with a CP, let us learn about how we can help them to drink from a cup more easily.

If I pour a cup of custard and a cup of water, which one will pour quicker?

- **Water**

If a child takes a long time to swallow, will it be easier to swallow something that flows quickly or slowly?

- **Slowly**

Explain why thicker liquids are more helpful for a child that takes a long time to swallow.

Can you think of some examples of thick liquids that we can use?

- **Yoghurt mixed with milk or water.**
- **Custard mixed with milk or water.**
- **Mageu.**
- **Soft porridge.**
- **Thick soup without any lumps.**
- **Fruit and vegetables mashed into a smooth consistency.**

When you make a thick liquid, make sure that it is not so thick that it does not run when you tilt the cup. It should run slowly when you tilt the cup.

DRINKING FROM A CUP:

① Before you begin, the child must be in a good position for drinking without their head tilting back.

② Place the edge of the cup on the child's bottom lip and tilt it just until there is some liquid touching the lips. Do not just tip the cup into the child's mouth and expect him/her to be able to swallow it.

It is important to rather be patient and wait for the child to move their lips or to start sipping from the cup. When their lip feels that there is something to drink it sends a message to the brain, but this message can take a long time.

③ When the child does start to move their lips, do not tilt the cup anymore. Rather let the child drink what was touching their lip and then move the cup away until they have swallowed what is in their mouth already. Then bring the cup back to their lips.

Show the group what a cut out cup looks like.

Why do you think that it is helpful to use a cup that has been cut out?

- **There is space for the child's nose, so you can tilt the cup without the child tilting their head back.**
- **You can see into the cup, which means you can control how much liquid is pouring into the child's mouth.**

Now let us see how we can help a child with CP drink with a cup:

Put up the pictures one at a time and explain each one before you continue.

Why do you think it is important to wait for the child to move their lips, instead of just tipping the liquid into their mouth?

- **If children are not given the opportunity to use their lips and mouth, they will lose their ability to use them and drinking will become more difficult and less safe.**

ACTIVITY:

- Do the activity in pairs.
- One person is the caregiver and the other is the child.
- The caregiver must mix a little water with the custard left in the cup and then help the child to drink.
- Tell the children that they must pretend that they are a child with drinking difficulties - they must wait a few seconds with the liquid against their lips and use small movements to let the liquid in.
- Then the pairs swop so that each person has a turn to be the child.

Now let us practice this in our pairs.

You will need:

As with feeding, ask your therapist to help you with this as it can be difficult to do in the beginning and it takes lots of practice.

Check if there are any questions.

MAIN MESSAGE

Using thicker liquids can make it easier and safer for a child to drink

A cut out cup helps a child to drink without tilting their head back.

It is important for children to use their lips to drink.

Allow the child to drink small amounts at a time.

Ask your therapist to help you practice.

HELPING CHILDREN WHO DROOL:

1. Use your finger from the chin upward to help the bottom lip to close, if the child can do it himself then let him do it like the picture shows.
2. Put something thin between the child's closed lips. They must try keep it there without biting it with their teeth.
3. Ask the child to try and blow kisses with their lips. If they do not know how, then show them and let them copy you.
4. Get the child to drink through a straw or thin piece of pipe. They can also blow bubbles through the straw.

10 Helping children who drool

Children with CP have the same problems with controlling their mouth as their body. Some children's mouths are stiff and cannot close, other children's mouth move too much, or the muscles around the mouth may be floppy and so the mouth hangs open. If the mouth is open all the time, the child is likely to drool. As children learn to chew and to eat and drink better, so will the drooling become less as they will develop better control of their lips, learn to close their mouths and to swallow.

If a child drools, we need to help them to drool less and we can do this in a fun way.

Put up the pictures and share some ideas to help children who drool.

1


2


3


4


HELPING CHILDREN WHO DROOL:

5. Smear honey or something similar on the side of the mouth or the sides of the bottom lip.
6. The child must lick the honey off with sideways tongue movements.

At the end of meals we will either wipe the child's face or give them the cloth to wipe it themselves. Either way it is important to think about how we wipe the child's mouth. If we just wipe it, we cause the child to drool more, because we are wiping away the saliva, instead of the child swallowing it like we do. The more we wipe, the more the child will drool.

Instead, we should wipe from the side of the face towards the lips, so that we only wipe what is on the child's face. By wiping from the side towards the lips, we can help close the child's lips so that they can swallow their saliva.

MAIN MESSAGE

Many children with CP have problems with drooling.

We can help children to drool less by using activities where they have to use their mouth in different ways.

Wipe towards the child's lips, not across them.

11 Healthy eating

It is important for children with CP to be healthy and we are now going to look at some helpful ideas about healthy eating.

Firstly, children should be fed small meals 5-6 times a day, not 3 large meals.

?

Why do you think that this is helpful for the child?

- **Children have smaller stomachs and therefore they get full quickly and they get hungry quickly.**

For children with CP to be healthy we need to make every meal count and we can do this by making sure that we give them at least one food from each food group every day. One way of doing this is to split the plate three ways so that each third of the child's plate has a different colour or type of food on it.

Put up the picture to show an example.

THE THREE FOOD GROUPS:

There are three main groups of food that are important for a healthy diet:

In group 1 we have the 'energy foods' so that children can play and learn. These are foods such as: bread, maize, rice, oil, margarine, root vegetables, bananas. Give one of these foods at each meal.

In group 2 we have the 'body building foods' so that children can grow. These are foods such as: milk, peanut butter, fish, chicken, beans, cheese, yoghurt, eggs. Give a few of these once or twice a day, and at least one of these at each meal.

In group 3 we have the 'protective foods' to fight off germs. These are fresh fruits and vegetables. Give at least one fruit, one green vegetable and one orange vegetable every day.

Put up the picture and use it to explain the three food groups.

The three food groups:

Energy foods:

Body-building foods:

Protectve foods:

It is also important that children with CP drink enough water during the day. By helping your child to move everyday, giving them fresh fruit and vegetables, and plenty of water, they should experience less problems with constipation.

The next helpful idea is that junk foods should only be given on special occasions or as treats every now and then because they are not important for the child's health.

Can you think of some examples of junk food?

Once everyone has given suggestions, put up the picture and mention any that were not said.

Junk foods:

CHANGING A CHILD’S DIET:

One of the biggest mistakes parents make when they are given advice about their child’s diet, is that they suddenly change what they feed the child. This causes the child to become upset because suddenly they are not eating the food that they are used to and if the amount of food is suddenly less, the child will feel hungry.

We need to make changes to the child’s diet slowly so that the child has time to get used to the new diet.

ANOTHER EXAMPLE:

If a child is used to only drinking cooldrink and we want them to drink water, we cannot suddenly start giving them water only and no cooldrink. We need to change it slowly. We can change the diet slowly by first mixing the cooldrink with some water to make it less sweet. Then each week we can add more water to the cooldrink until it has very little cooldrink in it.

Explain why it is important to change a child's diet slowly.

? **So if a child is used to having 4 spoons of sugar in their pap, how would you change their diet slowly so that they do not have any sugar in their pap?**

- **First start giving them 3 spoons of sugar, then 1 week later give them 2 spoons of sugar, then the next week give them 1 spoon of sugar, then the next week half a spoon of sugar, then no sugar.**

Share another example with the group.

Check if there are any questions.

MAIN MESSAGE

Children should eat 5-6 meals a day.

It is important for children with CP to eat a balanced diet with food from all three food groups.

They should drink plenty of water.

They should only eat junk food on special occasions.

We need to make changes to a child's diet slowly.

BRUSHING A CHILD’S TEETH:

- Just like with any other activity, the child must be in a good position with enough support for you to brush their teeth. Use the child’s buggy if they have one.
- It is easiest if you have a table in front of the child with a cup of water and a bowl to spit in.
- Use only a small amount of toothpaste (the size of a pea), otherwise it will cause the child to drool more. It is also helpful to use a plain tasting toothpaste, rather than one with a strong flavour.
- Just like when you help a child to eat and you give the child support at the jaw, so to must you support the jaw when brushing the child’s teeth.
- If the child tends to bite the toothbrush, bring the toothbrush onto the child’s teeth from the side, rather than from the front.
- Talk to the child throughout the toothbrushing experience.

10 Brushing your child's teeth

?

Do you brush your child's teeth every day?
Do you have any concerns when brushing your child's teeth?

- **Do not brush because the child bites down hard on the toothbrush**
- **The child's gums bleed**
- **Worried about the child swallowing the toothpaste**

Let us look at some helpful ideas for brushing your child's teeth.

Explain some ideas for brushing a child's teeth.

Children with CP are more likely to experience rotten teeth, because it is difficult for them to clear their mouths after eating. Thus it is important to brush their teeth at least twice a day to prevent rotten teeth, as this will cause pain.

12 End of the workshop

? **Now that the workshop has come to an end, does anyone have any questions before we close?**

? **After learning about eating and drinking what will you do differently when you go home?**

Go through the parent handout with the group and check if there are any questions about it.

Close the workshop and make sure that everyone feels that their questions have been answered.

5

Communication

My child and I understanding each other.

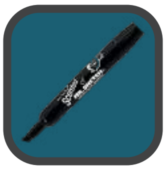
THE ANSWER PAGE:

Names:	**Describe:**
Actions:	

Materials

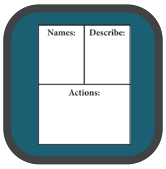
For this workshop you will need:

A large sheet of paper

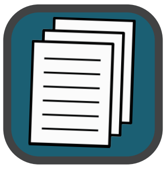


A marker

A ball



A large sheet of paper with the answer page drawn onto it x 2



Sheets of paper (1 per pair)

Pens (1 per pair)

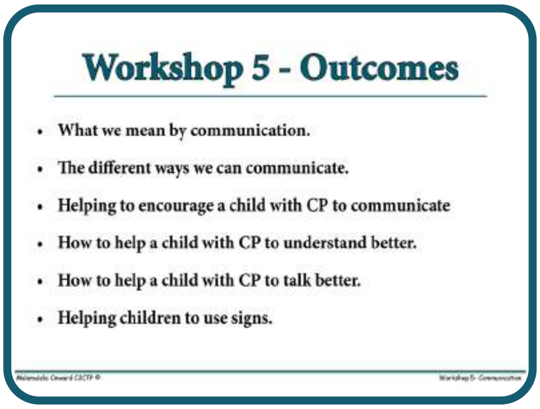
1 Welcome

Welcome everyone to the group and make sure that they are comfortable before you start.

? **Before we start this workshop, what was one thing that you learnt from the last workshop on “Eating and drinking” and how have you used it at home?**

2 Outcomes

Put up the outcomes and go through them with the group.



Workshop 5 - Outcomes

- What we mean by communication.
- The different ways we can communicate.
- Helping to encourage a child with CP to communicate
- How to help a child with CP to understand better.
- How to help a child with CP to talk better.
- Helping children to use signs.

Many children with CP cannot talk, but they are still able to communicate and we can learn how to give them opportunities to communicate so that we can understand them better.

These are the things that we are going to talk about today:

- **What we mean by communication.**
- **The different ways we can communicate.**
- **How to encourage a child with CP to communicate**
- **How to help a child with CP to understand better.**
- **How to help a child with CP to talk better.**
- **Helping children to use signs.**

Divide the group into pairs and tell them that they will stay in the same pairs for all the activities in this workshop. Then give each pair: a pen and some paper.

3 What is communication

Put up the picture.

? What is each person in the picture doing?

- One person is talking.
- The other person is listening and understanding.

Put up the picture.

? What is happening in this picture?

- The teacher is talking and giving information.
- The group is listening, understanding and learning.

MAIN MESSAGE

Communication is what we use to get messages to each other and there are two parts to communication: talking and understanding.

Remember that even if your child cannot talk, they can still listen and understand.

ACTIVITY:

- Do the activity in pairs.
- One person will be giving the message and the other person will be receiving the message.
- Tell the pairs that the person giving the message needs to tell their partner who they live with at home, BUT they are not allowed to talk or write.
- The other person can talk to try and understand what their partner is saying.

4 Different ways we can communicate

You will need:

What were all the different ways you used to communicate?

- **Eye contact**
- **Voice or sounds**
- **Hand signals or signs**
- **Facial expressions**
- **Pointing with hands**
- **Nodding or shaking head**
- **Body language**

Write down everyone’s suggestions.

Think about your child. How much can your child understand and how do they communicate with you?

Give everyone time to share and add their suggestions to the sheet of paper.

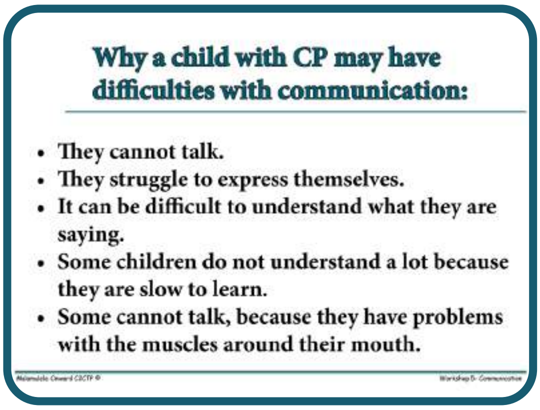
WHY A CHILD WITH CP MAY HAVE DIFFICULTIES WITH COMMUNICATION:

- They may be unable to talk at all.
- They may struggle to express themselves even when using their hands or eyes.
- The child may be able to talk, but it may be difficult to understand what they are saying.
- Some children do not understand a lot because they are slow to learn and they may not know how to talk.
- Other children are able to understand well, but they cannot talk because they have problems with the muscles around their mouth.

5 Why a child with CP may have difficulties with communication

? **Why do you think that a child with CP may have difficulties when trying to communicate? - Remember that communication involves talking and understanding.**

Wait for everyone to share. Then put up the picture and explain the answers.



Why a child with CP may have difficulties with communication:

- They cannot talk.
- They struggle to express themselves.
- It can be difficult to understand what they are saying.
- Some children do not understand a lot because they are slow to learn.
- Some cannot talk, because they have problems with the muscles around their mouth.

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Workshop 5- Communication

MAIN MESSAGE

All children with CP can communicate and they all use different ways to do it, even if they cannot talk.

For example, some children can only use their eyes to show someone what they want.

TWO IMPORTANT SKILLS FOR COMMUNICATION TO HAPPEN:

Joint Attention:
In the beginning, babies can interact with a person or with an object. Joint attention is when the baby and another person both look at the same object together. If your baby wants something she will try to get you to look at it. She can either use her eyes and look at you and then at the object and then back at you to show that she wants it. She can get your attention and point at it. A child may walk up to you and take your hand to lead you to the object. All these forms of communication are getting joint attention.

Remembering that something is still there:
When babies are young, if we take their bottle and put it under a blanket, they will not look for it. This is because if they cannot see it, they cannot remember that it is there. This is why peek-a-boo is a fun game. When babies are older, if we put their bottle under a blanket, they can remember that the bottle is still there and they will look for it.

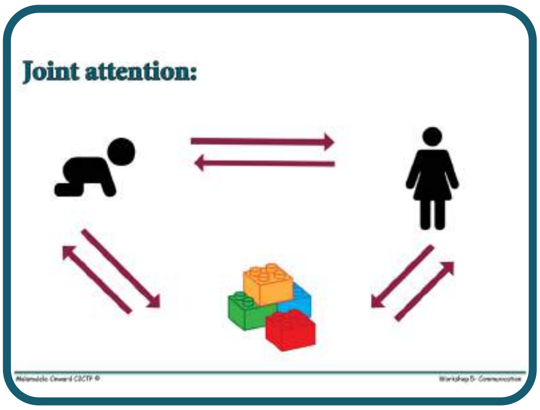
6

How to encourage a child with CP to communicate

Children with CP communicate in different ways and can experience different challenges in communication. Therefore, we need to learn how to communicate with them so that we can develop their communication and help them to learn.

The most important place to start is to believe that the child can communicate and that they are trying to communicate, we just must learn how to listen and understand what they are telling us. For example, when a baby first cries, she is communicating, but we do not understand what she is trying to tell us. But if we spend time listening and trying to understand what the baby is telling us, we begin to learn what her different cries mean and we start to develop her communication. We must do the same for children with CP, because often they are communicating, we just do not understand what they are telling us. Let us look at some ideas for encouraging the child to communicate.

Put up the picture and explain the two skills that children need in order to communicate



We need joint attention with another person if we want to communicate with them. For example if I want to ask someone to pass me the ball, I need to be able to look at the ball with them. I also need to remember that the ball is there, even if I cannot see it. Otherwise I will not ask for it.

HELPING CHILDREN TO DEVELOP JOINT ATTENTION:

In the beginning, babies first communicate through crying, but they do not interact with a person, they just cry. We can then make the communication interactive by saying "Oh, are you telling me that you are hungry?" and then we see if we are right by offering the child a bottle.

As babies grow up, they start looking at things. If a baby/child looks at something, for example he is sitting in his buggy and he looks at the TV, you can say: "I see that you are looking at the TV". Then turn the TV on. At this stage we do not know if the child actually wanted the TV on, but we are teaching him that looking at the TV means that he wants it on.

Once the child knows this, we can expect him to use looking to communicate that he wants the TV on. If another time he decides to cry and you know that he is crying because he wants the TV on, do not turn it on. Show him that all he needs to do is look at it, and then only ever turn the TV on when the child looks at it.

Sometimes you may not see that he is looking at it, so he may make a sound or cry to get your attention, then he will look at the TV to show that he wants it on and you will then turn it on. This is joint attention because you are both interacting with each other and the TV.

Let us look at how we help children to develop joint attention through how we respond to their communication.

Explain and demonstrate the ideas for helping children to develop joint attention.

USING THE O-W-L PRINCIPLES:

When children with CP have difficulties with communication, we usually always start the communication by talking to them and then encouraging them to communicate back to us. The O-W-L prinicples help us to encourage the child to communicate, without us been the first one to start the conversation. Instead we encourage the child to start the conversation.

The O-W-L principles tell us to OBSERVE, WATCH, LISTEN. If we watch the child, wait for them to try and communicate and listen for what they are trying to say we can do the following to encourage communication:

- Wait and let the child take the lead or start the communication when he is playing
- Then follow the child's lead by joining in his game, keeping attention on the same activity (remember joint attention)
- Copy the child's sounds, actions and words
- Comment on the child's actions and objects when he is playing or doing any other daily actvities like dressing or eating
- If the child attempts to communicate (like looking at the TV and then at you), say what is happening "I see that you are looking at the TV, would you like me to turn it on?" - by doing this we help the child understand what his communication means
- Encourage the child to take turns with you to keep the communication going
- Wait and give the child opportunities to start communicating with you, instead of you always starting the communication

Put up the pictures and explain the O-W-L principles of encouraging communication.

O - W - L principles

- Wait and let the child lead
- Join in his game - joint attention
- Copy the child
- Comment on what the child does
- Respond when the child tries to communicate
- Take turns
- Wait and give the child opportunities to start the communication

Check if there are any questions.

MAIN MESSAGE

Believe that the child can communicate

Children need joint attention to communicate

Children need to remember that an object exists before they can ask for it

We can help a child develop joint attention through how we respond to their communication

We need to encourage children to start the communication

ACTIVITY:

- Hold up the ball and ask the question.

7 How we can help children with CP to understand better

We are now going to learn about helping children to understand words better and then we will learn about helping them to talk better.

Let us begin by talking about how children learn to understand words.

You will need:

? I want you to think about a child who does not have CP and how they learn what different things are called. For example, how do they learn that this is a ball?

- From us talking to them and telling them that it is a ball.
- From us using the word in sentences like “Take the ball” or “Hit the ball”.

When we talk to a child during different activities, we want them to learn many new words. We do not want them to only talk about the names of things. We can also describe them and talk about the actions that we can do with them.

If we can speak, then we use words to communicate. But if we cannot speak, like in the first activity, we use other ways to communicate. For children with CP who cannot talk, it is difficult to learn new words just from hearing them. This means that if we want children to learn to understand new words more easily, we need to use words and the other ways of communicating.

For example, if I ask the child if he wants some juice, I can point to the juice when I ask - remember joint attention. Or I can show a sign like I am drinking out a cup when I ask. Or I can use my facial expression when I ask. I can even show the child a picture of some juice to ask if they want any. The more ways we use to communicate the word, the easier it is for the child to start remembering and understanding the word. We can also say that words have more meaning when we use our body or other objects when we say tham.

Demonstrate this for the group using the following words: brown, big, scary.

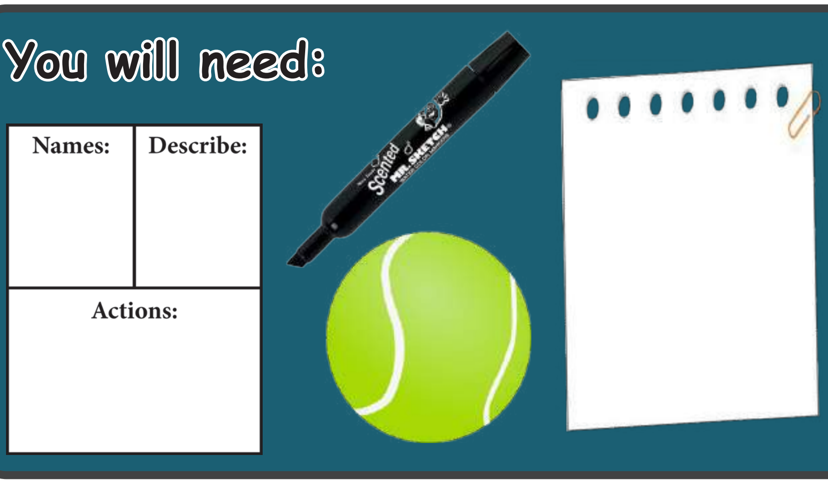
ACTIVITY:

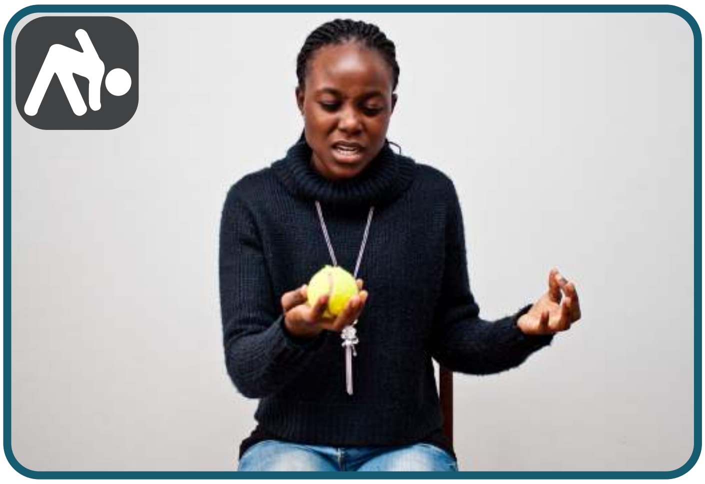
- Put up the answer page on the wall for everyone to follow.
- Tell the group that you are going to ask them a question about the ball. When they answer, they cannot only say the word. They can say it but they must also use their body, facial expression, actions or pictures too.
- Throw the ball to someone in the group and ask them the first question and write the answers on the page.
- Then ask that person to throw the ball to someone else and ask that person to answer the second question.
- Write the answers on the page and repeat this exercise until you have asked all the questions.

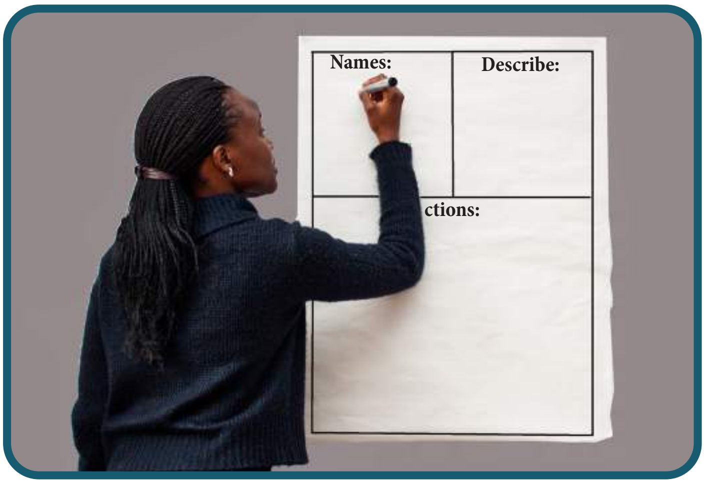
8 What can we talk about

Let us look at a ball and try to answer some questions about it.

You will need:







?

We first want the child to know what the object is. So what is it called?

- A ball

?

Then we want to describe it. Let us start with what does it look like?

- Round, yellow, bright

? What does the ball feel like?

- Hard, furry, rough

If we are talking about a type of food, we can also talk about what it tastes like and what it smells like.

? After we have described the object, we can talk about the actions. What actions can you do with a ball?

- Bounce, catch, throw, roll, hit

Check if there are any questions.

MAIN MESSAGE

Children are learning all the time from words that they hear, so it is important for us to talk to them.

Children learn to understand words before they learn to say them, so even if they cannot talk, we can still help them to understand words.

There are many things that we can talk about. We do not only have to talk about what things are called.

We must use words and all the other ways to communicate to help the child understand better.

While playing with a ball, a child can learn many different words.

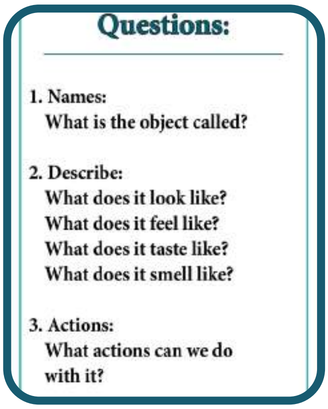
ACTIVITY:

- Put up the answer page on the wall for everyone to follow.
- Tell the group that you want them to think about bath time and that as a group they are going to use the questions to help them think of as many words as possible.
- Ask each question one at a time and write the ideas on the answer page.
- Write all the ideas on the page before you move onto the next question.

9 Talking about everyday activities

In the same way that caring for a child with CP is a way of life, so is talking to them. We can talk to our child during the activities that we do with them everyday. Let us do an example of what we can talk about during bath time.

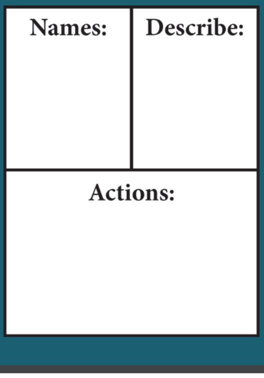
Put up the questions that we asked in the last activity.



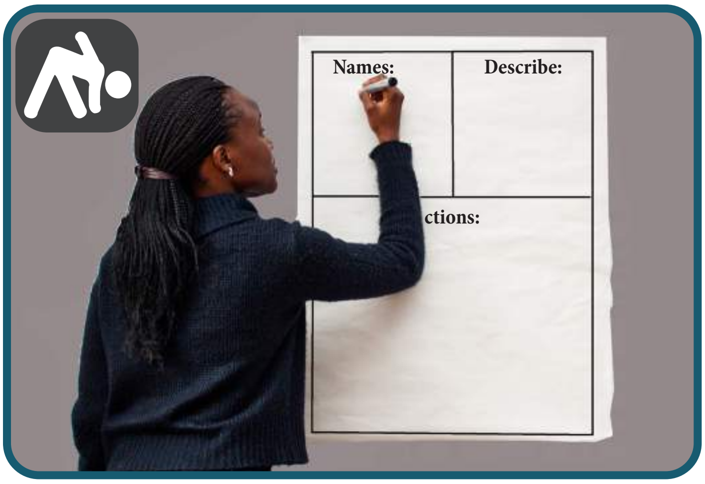
Questions:

1. Names:
   What is the object called?
2. Describe:
   What does it look like?
   What does it feel like?
   What does it taste like?
   What does it smell like?
3. Actions:
   What actions can we do with it?

You will need:



Names:	Describe:
Actions:	



Keep the questions up on the wall for the next activity.

We want the child to learn many things during many everyday activities, not just bath time. So let us think about some of the other activities that we do during the day.

ACTIVITY:

- Do the activity in pairs.
- Explain that each pair will be given an activity to think about.
- They must then use the questions on the wall to help them think of all the things that they can talk to their child about, during that activity.
- One group must talk about 'feeding', another group must talk about 'dressing' and the third group must talk about 'playing a game'.
- They can write down their answers to help them remember.
- Give them ten minutes to think about their activity.
- Then bring the group together again and ask each pair to share their ideas.
- As each pair shares, ask the rest of the group if they have anything to add.

CHILDREN WHO CANNOT SEE OR HEAR WELL:

Learning to communicate is more difficult for a child with CP who cannot see or hear well. If a child cannot see or hear well, we need to let them feel everything, because their hands have to act as their eyes and their ears. If a child cannot see well, we can help them understand and learn by using their other senses like hewaring, touch, taste and smell.

For example:

- During bath time, let the child smell and touch the soap and tell them what it is. Let them feel the water before you put them in the bath.
- During feeding, let them touch the spoon and smell the food.

You will need:

Before we finish this section, let us think about children who cannot see or hear well and how we can help them to understand better.

Explain how to help children who cannot see or hear well to understand better.

Check if there are any questions.

MAIN MESSAGE

There are many different things to talk to our children about during the everyday activities that we do with them.

If we talk about these things each day, the child will slowly learn to understand these words.

If a child cannot see or hear well, we need to use their other senses to help them learn.

GIVING CHILDREN A CHANCE TO TALK:

1. Know your child well and look for how they are trying to communicate

Are they just saying words or just using their voice? Can they use their eyes or hands for pointing? Can they show you "yes" or "no"?

2. Call their name - get joint attention

When you are talking to your child, first encourage them to look at you by calling their name and touching them. You can also use their vision to get their attention like flashing a light or showing them something thats easy for them to see.

3. Ask them questions

Give your child an opportunity to say something by asking them questions. For the child who is talking - ask questions to help them think.

For the child who is not talking, ask yes/no questions.

4. Let children choose

Give the child opportunities to choose between things such as what shirt they will wear that day.

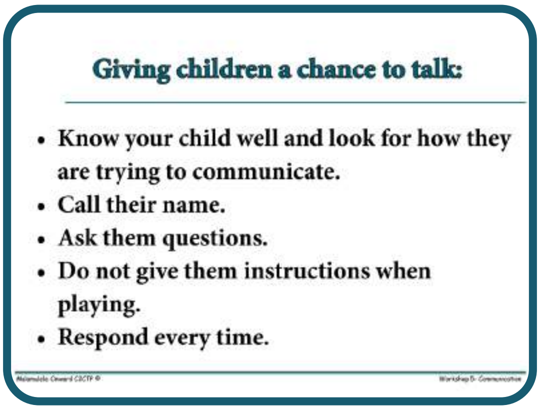
5. Respond every time

Respond every time the child tries to tell you something to show them that you are interested in what they have to say. For example: "Oh you are looking at the banana, you want it."

10 How we can improve a child’s talking

All children with CP want to communicate with people around them. It is our responsibility to give them a chance or reason to talk to us. Even though they may not be able to speak, they can still talk to us through their hands, eyes, sounds and bodies Let us talk about how we can do this.

Put up the picture and go through each of the points with the group.



Giving children a chance to talk:

- Know your child well and look for how they are trying to communicate.
- Call their name.
- Ask them questions.
- Do not give them instructions when playing.
- Respond every time.

We are now going to learn how to ask questions to give a child with CP the opportunity to choose. There are many ways times in the day that we can give children a chance to choose. They can choose which shirt or pants to wear that day, they can choose what toy to hold while you are changing their nappy, they can choose what object to play with or which song they want you to sing. Lets use eating as an example.

GIVING CHILDREN OPPORTUNITIES TO CHOOSE:

For a child who can talk, it is easy. We just ask: "What would you like to eat?"

For a child who cannot talk, we can give them the choice between two foods. If they can point, it is easy for us to see which one they want. If they cannot point, then we have to watch carefully to see if they either use their eyes to point or move their body towards the food they want.

For a child who can show YES/NO, we can ask: "Do you want carrots? Do you want meat?" Then we have to watch carefully to see their answer. They can either nod/shake their head, move their body or show it on their face.

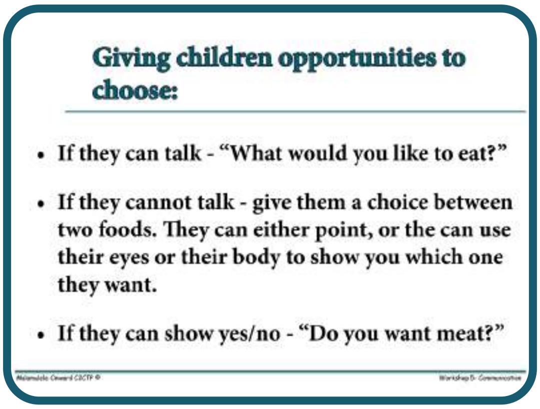
These are all ways that we can give the child a chance to talk.

HOW TO PRESENT A CHOICE:

When we give a child a choice we need to be patient. If we just hold two toys infront of the child and they look at one, we are not sure that they have noticed both toys. So we need to first show them the one toy, then the other toy, and then we show both toys so that the child knows what each option is.

We need to make sure that we hold the toys far enough apart so that we can easily see which toy the child is looking or pointing at. If the child looks only at one toy, then take the other one away and check that the toy you have is really what the child is wanting.

Put up the picture and explain how to give children opportunities to choose.



Giving children opportunities to choose:

- If they can talk - "What would you like to eat?"
- If they cannot talk - give them a choice between two foods. They can either point, or the can use their eyes or their body to show you which one they want.
- If they can show yes/no - "Do you want meat?"

Put up the picture and explain how to present a choice to a child with communication difficulties.

ACTIVITY:

- Now choose someone from the group to pretend to be a child who uses their eyes to communicate.
- Demonstrate to the group how you should present a choice to the child.

Check if there are any questions.

MAIN MESSAGE

It is important to give a child the chance to say something, even if they cannot talk, because if we do not give them a chance to talk, they will stop trying to communicate.

Children use different ways to tell us what they want, but we need to watch carefully to see what they are trying to say.

Always get the child's attention before you ask them a question.

Make sure the child has seen both options before they make a choice

Be patient and give the child time

HELPING CHILDREN LEARN TO POINT:

Pointing is just a simple sign. If a child is able to point, it opens up a world of possibilities in communication. It allows the child to choose between many things either through pictures, photographs, words or the actual objects. As children learn to understand more words or pictures, the more choice they begin to have.

If children learn to point at the object they want, they can then learn the pictures of those objects as it is easier to have pictures that objects when giving a child a choice. If we can then help the child to learn the words, we can give them more choice because we can just write the words when we need them, instead of finding pictures.

To practice making choices, you can cut pictures of out a magazine and stick them in a book. Find pictures that will help your child to communicate with you. For example, one page could be colours of your child's clothing. Then when you want to ask what colour shirt they want to wear, you open the book and let them point to the colour and whatever colour they point to, that is the shirt they wear that day. This helps them to learn that the can make a choice and it will help them understand the different choices, in this case, different colours.

11 Teaching a child to use signs

The same way that we help children understand by using many different kinds of communication like hand signs, body movement, facial expression, pictures and sound, so we can help a child express themselves better by teaching them different ways to communicate.

Two ways that we can do this is to teach them to point or practise pointing and to teach them some signs.

Put up the pictures and explain how we can help children communicate through pointing.

HELPING CHILDREN LEARN TO USE SIGNS:

1. Understand what signs the child can make
Because children with CP have problems with movement, we cannot just teach them sign language, as they may not be able to do the signs. We must first understand what the child can do with their hands and body and then think of what signs are possible to use.

2. Start with an asking sign
For children who have never used signs before, it is helpful to start with an asking sign. Let’s use the example of the sign for “more” so that the child can ask for something. Using signs to ask for something that the child wants is more motivating for the child.

3. Keep using the same sign over and over until the child understands
Whenever you are doing something the child likes or feeding her for example, stop what you are doing and use the sign to ask if she wants more, so that she learns what the sign means. If she cannot use the “more” sign, find a different sign for her to use for “more”. Keep using it all the time just like we repeat words to help a child understand.

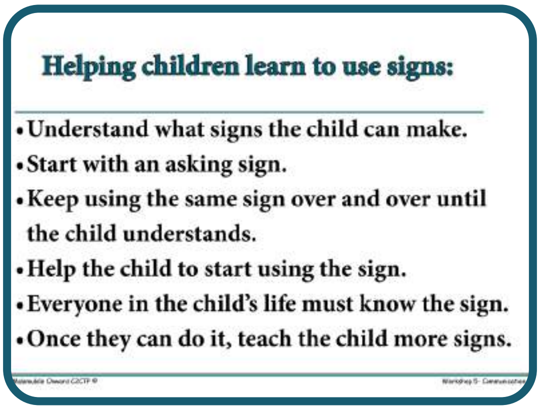
4. Help the child to start using the sign
If it is easy for the child, they may start using the sign once they understand. We can help the child learn to use the sign, by asking if they want more and then putting our hands of theirs to help them make the sign before we give them more. Once they understand start waiting for them to make the sign before you give more.

5. Everyone in the child’s life must know the sign
It is important that everyone communicating with the child uses the same sign and knows how to help the child learn to use the sign. This will help the child to understand and use the sign in all situations.

6. Once they can do it, teach them more signs

Children can also learn to communicate by pointing to something to indicate that it needs attention. For example, a child can be taught to point at their nappy when they are wet. This is a better way to communicate than crying for example. It also allows the child to start the communication as when we give a choice, we are the one's starting the communication. Another way to help a child start conversations is to teach them to use signs.

Put up the pictures and explain how we can help children communicate through signs.



Helping children learn to use signs:

- Understand what signs the child can make.
- Start with an asking sign.
- Keep using the same sign over and over until the child understands.
- Help the child to start using the sign.
- Everyone in the child's life must know the sign.
- Once they can do it, teach the child more signs.

Check if there are any questions.

MAIN MESSAGE

Pointing helps children to make many more choices.

Children can learn to use signs to communicate if they cannot say words.

For to learn signs, we must use the same sign over and over and with everyone in the child's life

ACTIVITY:

- Do the activity in pairs.
- Each pair is going to do a role play where they use good communication during the same activity that they discussed earlier in the workshop.
- Remind each pair of which activity they discussed (feeding, dressing, playing with a ball).
- They can decide who is going to be the child and who will be the caregiver.
- Give each pair one of the following instructions:
  1. Your child cannot talk, but they can point and make signs.
  2. Your child cannot talk, but they can use their eyes.
  3. Your child cannot talk, but they can show "yes" and "no".
- Give the pairs ten minutes to prepare what they are going to do for their role play .
- As each pair does their role play for the group, encourage the rest of the groups to observe and comment. Then move onto the next group to present their ideas.

12 Practicing our communication

Now let us bring everything together and practice all the ways to help a child with understanding and talking. We are now going to practice good communication in our pairs.

? **Does everyone feel more confident about how to communicate with a child with CP?**

Check if there are any questions.

MAIN MESSAGE

Remember that ALL children with CP can communicate, we just have to work out how they are trying to do it.

It is important to give children the opportunity to make choices.

We can help children with CP to communicate better through what we do during everyday activities.

13 End of the workshop

? **Now that the workshop has come to an end, does anyone have any questions before we close?**

? **After learning about communication what will you do differently when you go home?**

Go through the parent handout with the group and check if there are any questions about it.

Close the workshop and make sure that everyone feels that their questions have been answered.

6

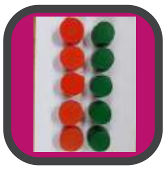
Play

Unlocking my child’s potential

Materials

For this workshop you will need:


4 strips cut from a refuse bag


2 sets of 5 bottle tops (all 5 must be the same colour and each set must be a different colour)


A set of 10 - 15 lids of different colours and sizes


Two bags each filled with 10 different objects that can be easily found (so 20 different objects in total)


A few large sheets of paper


A marker

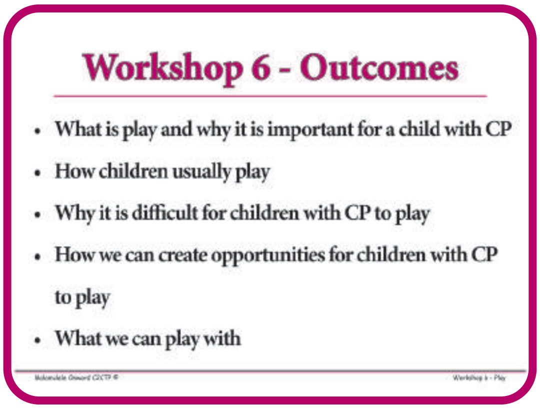

A ball

1 Welcome

Welcome everyone to the group and make sure that they are comfortable before you start.

2 Outcomes

Put up the outcomes and go through them with the group.



Workshop 6 - Outcomes

- What is play and why it is important for a child with CP
- How children usually play
- Why it is difficult for children with CP to play
- How we can create opportunities for children with CP to play
- What we can play with

In this workshop we are going to talk about ‘play’. Play is an important part of life for all children. But playing can be difficult for children with CP. If we want to think of CP as a way of life, we need to know how we can make it easier for children with CP to play.

This is what we are going to talk about today:

- What is play and why it is important for a child with CP
- How children usually play
- Why it is difficult for children with CP to play
- How we can make it easier for all children with CP to play
- What we can play with

ACTIVITY:

- Divide the group into two teams and give each team a set of lids
- Lay down the strips to make a grid with 9 squares as you can see in the picture

- Explain the game: The aim of the game is to get 3 of your plastic lids in a row. The rows can go down, across, or diagonally (demonstrate these options on the grid). The teams have to stand on the opposite end of the room from where the grid is. One person from each team has to run to the grid at the same time and put down their lid in the square they choose. Then they have to run back to the team as quickly as they can and once they touch their next team mate, that person can run out and place their lid in a block and so on. So this is a game of speed and the quicker you are, the quicker you will get your lids onto the blocks.

There are two rules:

1. You must touch the next team member before they can leave the group.
2. You are not allowed to move the other team's lids – once there is a lid in a block it must stay there.

- If the other team has 2 lids in a row, you may block them by placing your lid in the third block if it is empty. Then the other team will have to think of another row to make.
- The first team with 3 lids in a row wins.
- Play the game 2 or 3 times so that everyone gets a chance to play.

3 What is play and why is it important?

In this workshop we are going to learn about play, but first I want to ask you a question:

? **We all know that children like to play and we used to play when we were children. What about now? Can we still play even though we are not children?**

You will need:

? **Now tell me, during this activity, did you feel like you were playing? What did it feel like to play this game?**

Each person must describe how they felt while playing the game. Write down the answers on a sheet of paper.

Possible answers:

- **It felt challenging**
- **It was fun**
- **It made me laugh**
- **It was fun to watch the others**
- **We took turns**
- **I wanted to win**

THREE IMPORTANT THINGS FOR PLAY:

1. *The activity must be fun and enjoyable. If you are not having fun and enjoying yourself, will you feel like you are playing? No*

2. *The activity must be something that you want to do. If you do not want to do it and somebody forces you to do it, will you enjoy it? No*

3. *You must be active. If we all played the game, but you had to sit, keep quiet and just watch, would you feel like you are playing? No*

So we can see that anyone can play and have fun, but there are three important things for play to take place:

Put up the picture and explain the three important things for play.

Three important things for play:

- The activity must be fun and enjoyable
- The activity must be something that you want to do
- You must be actively involved

Do you play with your child?
How do you play with your child with CP?
What do you do?
What games do you play?

Let each person talk about how they play with their child with CP.

How do you play with your other children?

Let each person talk about how they play with their other children.

WHY PLAY IS IMPORTANT:

Play is like a child's job and children usually spend most of their time playing. In other words play is way of life for all children and they play throughout the day. So for children with CP it is should be the same. Play should be a part of everyday life just like it is for other children.

But there is one main reason why play is important. Did you know that when children are playing, they are learning?

? **Do you think that playing with your child is important or is it just a waste of your time?**

Explain why play is important.

Now I want everyone to close their eyes and think back to when you were a child. Try to remember your favourite game that you used to play and how it made you feel.

Give the group a few minutes to think about their game.

Then I want you to think about all the things that you learnt through playing that game.

Give the group time to think and then let each person explain the game or activity they are thinking about and what they learnt through playing.

ACTIVITY:

Put your set of lids on a table in front of the group and for each lesson, ask the group to think of ideas of how they can use the lids to play with a child and teach them that lesson. Once the group has no more ideas, share your example. Then move on to the next lesson.

- New skills – You can help the child learn the different colours of the lids, you can build towers so he practices using his hands, you can teach him to match the colours and build a tower in each colour.
- How to take turns – You can build a worm with the lids, where the child puts down one lid and then you add the next lid and then the child adds the next lid and so on. Or build a few towers with the lids and take turns knocking them down.
- How to follow rules – You could tell the child that you are going to play a game where you each are going to pick up 2 lids at a time and put them in a container or the rule could be that the child has to organise the colours before he can build a tower.
- How to make things – You and the child can use the lids to make a picture or you can build something with the lids like a house.
- How to fit things together – You can play a game where the child has to fit the smaller lids into the bigger lids or see how many lids they can get to fit into each other.
- How to solve problems – You can play a game where you and the child have to move one lid across the table as quickly as you can without using your hands. The child will have to try other ways to move the lid and work out which way is the quickest. The problem is that the child can't use their hands, so they have to solve the problem by finding another way.
- How to communicate – You can give the child a choice between which colour lids he wants to play with or you can ask the child to name the colours as he picks them up, or you can use the lids to tell a story. Remember to talk to the child during the activity. Tell him what you are doing, describe the bottle tops and talk about the actions.

4 Learning through playing

Put up the picture.

This is a picture of a mother and child playing with some plastic lids that are different colours and sizes. We are going to try and think of ways that we can use these lids to help a child to learn through playing. Let's look at the different lessons that a child can learn through playing.

Put up the picture and do the activity.

Lessons that a child can learn through play:

- New skills
- How to take turns
- How to follow rules
- How to make things
- How to fit things together
- How to problem-solve
- How to communicate

You will need:

So can you see that through playing simple games, children can learn many new things.

Through play, children learn important skills and they learn to understand the world around them. Through playing with different things, they learn what they can do with those things. For example a child will pick up a spoon and hit a pot with it and they will learn how to make a noise. A child may pour water from one cup into another and they will learn that if they do not do it slowly and look at what their hands are doing, they will make a mess.

Through playing mothers get to know their children and learn how to communicate with them. A simple game that makes a child laugh means that a mother can have fun with her child and her child can show her that he is enjoying himself.

Check if there are any questions.

MAIN MESSAGE

All children need to play - it is their job.

Play must be fun.

Play helps children understand the world around them.

Children learn new things through playing.

Anyone can play.

YOUNG CHILDREN USE THEIR SENSES TO EXPLORE:

Seeing, touching, hearing, smelling and tasting. These are the five senses that children use to explore, especially when they are young. Young children usually put everything in their mouth and like to suck or chew on things. They also explore their body with their hands and learn what their hands can do such as: banging; pulling; pushing; tearing; turning; shaking; etc.

They enjoy hearing sounds such as music and singing. When they start crawling, they move around to explore and like to climb in and out of things as well as over and under things.

5 How children play

Children use many different kinds of activities when they play and these activities usually change as the child becomes older. We all use our senses to explore and understand the world around us and it is the same for children when they play.

?

Can you name the five senses that we use?

- **We use our eyes to see, our ears to hear, our nose to smell, our mouths to taste, and our hands to touch.**

Put up the pictures as you explain how children uses their senses to play.

HOW OLDER CHILDREN PLAY:

As children become older they learn to control the objects around them to make new things.

Children start experimenting with these objects and begin to learn what works and what doesn’t work. For example if a child is mixing sand and water, they will learn that the more sand you put in, the thicker it will become. They will learn that if you put too much sand in, it will not pour out of the cup.

Many children like to build things. For example: they can build a tower out of pieces of wood; or they can use sticks to build a road for a toy car.

They like to use objects together. For example: a child can use a plank and a brick to make a ramp to roll a stone down; or they collect stones and put them all into a container.

They pretend objects are something else. For example they can climb into a crate and pretend it is a car; or a bucket can become a drum; or a small box can be a cell phone.

They also like to match things and begin learning to draw. For example if they have some colourful lids, they will put the ones that are the same colour together, or they will put stones together according to their size.

As children start playing with other children, they learn how to share, how to not fight with other children and how to take-turns while playing.

Put up the pictures as you explain how children play when they become older.

HOW CHILDREN PLAY WHEN THEY ARE READY FOR SCHOOL:

When children become old enough to start school, they can begin playing games with rules such as soccer, or games that involve following one person as the leader.

Children also enjoy testing their skills against each other. For example they will try to race each other, or they may try to climb the highest tree.

They also learn school tasks such as cutting, drawing, reading, writing, counting, etc.

So you can see that as children become older, the way that they play changes.

Put up the pictures as you explain how children play when they are ready for school.

Children with CP, especially those who Level 4 and 5 who have problems with moving around, will not be able to play in all these different ways. Also children who have problems with learning (even if they can move around) will also not be able to play in all these different ways.

Some children, even though they are older, still put things in their mouth. This may be because they cannot use their hands well; or because they have a learning problem and still play like a very young child. Some children may be able to put blocks in to a container, but they cannot match the blocks according to colours. This may be due to a problem with learning or a problem with vision.

Leave all these pictures on the wall until the end of the next section.

6 Why it may be difficult for children with CP to play

All children can play, even if they have problems with moving, or seeing, or learning or using their hands. We need to make it easier for children to play. If it is too difficult to play, the child may give up and stop trying.

Let's look at what makes it difficult for children to play.

? Why do you think that it may be more difficult for level 4 and 5 children to play?

- They can't move much on their own
- It is difficult to change their position
- They can't sit on their own
- It is difficult for them to move their arms or reach for objects
- It is difficult for them to hold objects
- They can't ask for a toy
- They may have vision or hearing problems
- They may be slow to respond
- They're not interested
- They may have a learning (intellectual) problem

Share any of these ideas that the group does not mention.

? What about children who are levels 1, 2, or 3? They can move around on their own. Why do you think that it may be difficult for level 1, 2 and 3 children to play?

- They may do things very slowly
- They may not be able to keep up with other children to play games
- Children who are hemi where the one hand is affected may find games that use two hands more difficult
- Children who are di where the legs are affected may not be able to play running games
- Their communication may be slow or difficult for someone to understand
- Other children may not want to play with them because they are different
- They may have a learning (intellectual) problem

Share any of these ideas that the group does not mention.

All children with CP are different and so the way that they play will be different. It is important that you learn about how your child is able to play so that you can make it easier for them to play in different ways. Just as you need to understand how your child communicates, you need to understand how your child plays. This is because CP is a way of life and playing is a part of life for all children.

? **Now look at the pictures again and think about all the ways that your child plays and share these with the group.**

Give each person time to share how their child plays.

It is more difficult for children with CP to play, but this does not mean that play is impossible. ALL children with CP need us to help make it easier for them play. Play is part of every child's life.

By making it easier for children with CP to play throughout the day we are helping them to learn new skills and understand more about the things around them. Being able to play also allows children with CP to have fun just like any other children and be a part of the family.

For children with CP, it takes more effort to move their bodies, but because play is fun, play can motivate them to move more and become better at doing some things.

Check if there are any questions.

MAIN MESSAGE

Children use many different activities to play.

As children become older, the ways that they play are different.

It is important for you to understand how your child plays so that you can help him/her to have fun and learn new things.

All children with CP can play - some just need more help than others.

We can make it easier for children with CP to play.

IDEAS FOR HELPING CHILDREN WITH CP TO PLAY:

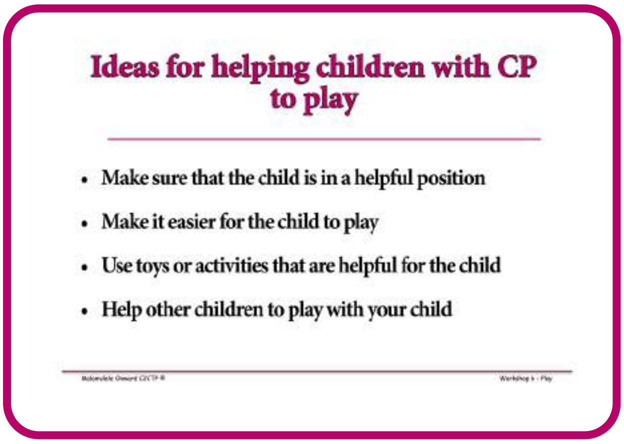
There are four important ways that we can help children with CP to play:

1. *Make sure that the child is in a helpful position*
2. *Make it easier for the child to play*
3. *Use toys or activities that are helpful for the child*
4. *Help other children to play with the child*

7 How can we help children with CP to play?

Once you understand how your child can play, it is important for you to help your child to play in a way that is helpful and becomes a way of life.

Put up the picture and read through the points. Leave this page up on the wall until you are finished with these sections.



Ideas for helping children with CP to play

- Make sure that the child is in a helpful position
- Make it easier for the child to play
- Use toys or activities that are helpful for the child
- Help other children to play with your child

Every child is different and so how we help a child to play will be different for each child. A position that is helpful for my child may not be helpful for your child, or a toy that is helpful for a young child may not be helpful for an older child.

Remember from workshop 6 that we learnt how to get our child's body ready to move and play and that there are some positions which are more helpful for them. When we are playing with the child, we must first make sure that the body is ready to play and that the child is in a position that is helpful.

Can you remember what you learnt from Workshop 6 and which positions worked best for your child and why?

Ask each member of the group to describe one helpful position for her child which will make play easier.

ACTIVITY:

Play the same noughts and crosses game that you played at the beginning of the workshop except this time you are going to make it hard for everyone by doing the following:

- Give the group orders – tell the group that this time each team will take turns; they won't be playing at the same time. Rather each team will get a turn to put a lid on the grid
- Also tell them that they have to hop on one leg the whole time. If they put their foot down before they make it back to their team, then they have to do it again.
- Only give the one team 3 lids so that only 3 people get a turn.
- Give the group with the most lids 2 turns in a row.
- Be impatient with the group.
- Do not smile and do not act in a fun way - just tell the group what to do.
- When a team wins, do not be excited, just move on to another round.
- In the middle of the second round, just walk over and pack a way the strips on the ground without saying anything.
- Then tell everyone to sit back in their seats.

8 Making it easier for children with CP to play

Let us learn about what else we can do to make it easier for our child with CP to play.

You will need:

Put up a blank sheet of paper on the wall and draw a straight line down

? **How was this experience of playing the game different for you compared to when we played it earlier? (eg it was not fun because we were given orders)**

Write down the answers on the left hand side of the page.

? **What could I have done differently to make the experience better for you?**

Write down the answers on the right hand side of the page.

MAKING IT EASIER FOR CHILDREN WITH CP TO PLAY:

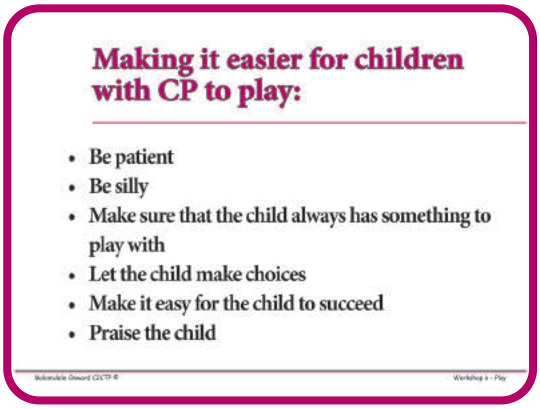
- ***Be patient:*** *Children with CP may need more time to respond than other child and so we need to be patient and give them lots of time. Some children take a very long time to respond and so we have to wait a very long time for them. If a child is trying to respond and we are too impatient, the game is not fun for the child and can be very frustrating.*

- ***Be silly:*** *Play must be fun and we can make it fun through the way we express ourselves. When we play with a child we should be silly and use fun facial expressions and actions. This helps the child to understand what it means to play and that play is something fun to do.*

- ***Play at the child's level:*** *When we play with children, we need to try and play at the same level as them. If they are playing on the floor, she should be on the floor. If they are sitting, we should try to sit at the same level. We always want to be able to see them face to face.*

- ***Let the child make choices:*** *Let the child lead the play by letting them choose. If you are going to give them a toy, rather let them choose which toy they want. You can also let them choose what to do with the toy or who they want to play with. This will also help them practice their communication.*

Put up the picture and go through the points with the group. As you explain each idea, use a picture as an example.



Making it easier for children with CP to play:

- Be patient
- Be silly
- Make sure that the child always has something to play with
- Let the child make choices
- Make it easy for the child to succeed
- Praise the child

Malamulele Onward C2CTP © Workshop 6 - Play

MAKING IT EASIER FOR CHILDREN WITH CP TO PLAY:

- ***Make sure that the child always has something to play with:*** *We can make it easier for children to play if we make sure that there is something for them to play with. For example: If a child is sitting in a chair for a while, make sure that there is something for him to play with that he can reach easily. If he knocks the toy off the table, you can tie it to the table so that it can't fall off. If the child is lying on their back, you can hang some toys above them so that they are easy to see and touch.*

- ***Show the child how to play with objects/toys:*** *We have seen that children often play by copying adults. We can make it easier for children to play by showing them how to play with toys.*

- ***Make it easy for the child to succeed:*** *When children play it is important that they are successful at what they are trying to do, otherwise they become bored or frustrated and will stop trying. For example: if you hold a toy for the child to reach and then when they are reaching, you keep on moving the toy further away to try and make them reach more, it may become too difficult for the child. However, if the child reaches and you let them be successful, it will motivate them to try harder and more often.*

- ***Praise the child:*** *If a child responds, reaches or succeeds at doing something, we must praise them as this will also motivate them to try more. Praising the child is also a way that we can make a game more fun and playful.*

Give the child things to play with

Show the child how

Make it easy to succeed

Praise the child

These are all ways that we can make it easier for our children with CP to play no matter how difficult it may be for them.

When we are playing with the child we can also use what we learnt about communication in the communication workshop.

First we need to get the child's attention. We can call his name or touch him to get his attention. We can also use play to help a child to understand more by talking about we are doing. We can name the objects, describe them and talk about what we are doing with them. We can talk about everything the child is doing.

Check if there are any questions.

MAIN MESSAGE

There are many things we can do to make it easier for our children with CP to play.

We need to be patient, playful and let the child make choices.

We need to make it easy for the child to succeed and to praise the child when they do.

We need to give the child things to play with and show them how to play.

We can use play to help the child's communication.

It is important that the child has fun and enjoys playing.

9 Using toys or activities that are helpful for a child with CP

We have just said that we need to make it possible for the child to succeed when they play.

? **What do you think we as parents can do to make sure the child is successful when they play?**

Let the group discuss their ideas.

If we want a child to succeed:

- **We must first understand what our child can do**
- **And we must then understand how they play**

Then when we play with them we must use activities that they CAN do and toys that they CAN play with. For example: If my child can only move his arm away from his body a little bit, we could play a game of knocking down a tower of blocks, because it only takes a small movement to make the tower fall down.

If he can only move his arm a little bit, I will build the tower very close to him so that he is able to succeed and knock it down. If I build it too far away from him, he will try but won't succeed and after trying a few times, he will stop trying and give up.

Use the picture to show the group what you are saying.

Once a child is able to play by doing activities that he CAN do, we can help the child learn to do more by making the activity a little more difficult.

For example: If my child can knock down the blocks easily when the tower is close to him, then I can move the tower just a little bit further away from him. Then he can still succeed but now he has to try a little harder to knock them down and this will help him learn to move his arm more. But he must still be able to do it, if I want him to keep on trying.

So if we want the child to succeed when playing, it is important that we use activities that the child CAN do and use toys that the child CAN play with.

THE CHILD'S AGE

Another way to make sure that we are using activities and toys that are helpful is to think about the child's age and to try and use activities and toys that the child should be playing with at that age.

? If my child is 6 years old and he likes sounds, would it be helpful for me to use a baby's rattle to play with him?
Why?

Let everyone answer the question.

? What could I use instead of a rattle?

- A cellphone
- Sing a song
- Playing a drum

? If my child is 10 years old and we are doing a looking activity with a book, would it be helpful if I use a book that was made for 2 year old children?
Why?

Even if some children cannot do much on their own, they should not be treated like babies if they are not babies. Remember when we dress them, we do it in sitting not lying down because only babies are dressed lying down. It is the same for when we play with children, we need to play in a way that takes account of their age.

Put up the pictures one at a time and for each picture ask the questions on the next page.

?

Do you think the activity and toys in the picture are helpful for the child?
Why?

Is the child playing?
Why?

Let the group discuss their answers for each picture and use the pictures to show examples of what you have been explaining.

It is also important to remember that we need to choose the right time for playing with our child. A child who is cross or who is tired will not want to play. We also need to give the child breaks.

So does everyone now know how we can create opportunities for play by making sure that the activity or toy is helpful for the child.

Check if there are any questions.

MAIN MESSAGE

We need to understand what our child is able to do and how they are able to play

We need to use activities that our child can succeed at doing

Children with CP should play activities or use toys that are right for their age

10 Helping other children to play with your child

Let us now talk about helping other children to play with our child.

Usually adults do not have much time in their day to play because they have too many other responsibilities that take up their time. We as adults have also forgotten how to play like a child and so the way that we play can be different.

Children usually spend most of their time playing with other children, not adults. If CP is a way of life, then children with CP should be playing with other children. Adults cannot spend most of their day playing with their child with CP and so it is important that other children are helping the child to play as well.

? Can you think of any other reasons why it is helpful for a child with CP to play with other children?

- Children feel safer playing with other children compared to adults
- They learn to take turns when there are other children
- Children are not scared to be silly
- Children can help motivate each other to play
- If a child with CP cannot use their hands, another child can help them
- They learn to communicate with other children

ACTIVITY:

Divide the group into smaller groups of three and explain that each group will do a role play. In the role play, one person is the parent, one is the child with CP and one is another child. The person who is the child with CP must act like their own child with CP. So if their child is a dystonic child, then they must act like a dystonic child.

Give them a few minutes to prepare a role play where they show the group how a parent can help another child to play with the child with CP.

After everyone has completed their role play, ask the group to share the ideas that they learned from the role plays and write down these lessons.

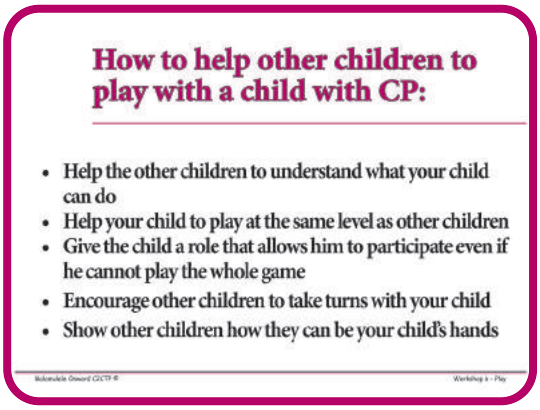
HOW TO HELP OTHER CHILDREN TO PLAY WITH A CHILD WITH CP:

- ***Help the other children understand what your child can do***
  Just as we need to understand our children with CP well to help them to play, we can help other children understand them too. This will make it easier for other children to include your child when they are playing.

- ***Show other children how they can be your child's hands***
  Some children cannot use their hands to play activities and so we can show other children to be their hands for them. For example if the game is matching coloured lids, the child with CP can use his eyes to choose the one that is the same colour and then the other child can pick that one up and put it next to the right colour. This allows the child with CP to still play the game even though he cannot use his hands. Remember to show the other children how important it is for them to talk to your child and explain what they are going, and also to give your child time.

You will need:

Put up the list of ideas on how to help other children play with a child with CP and discuss them one by one.



How to help other children to play with a child with CP:

- Help the other children to understand what your child can do
- Help your child to play at the same level as other children
- Give the child a role that allows him to participate even if he cannot play the whole game
- Encourage other children to take turns with your child
- Show other children how they can be your child's hands

HOW TO HELP OTHER CHILDREN TO PLAY WITH A CHILD WITH CP:

- ***Give the child a role that allows them to take part even if they cannot play the game***

  Question: Who do you think needs to be involved to make a soccer match happen?

  - *Soccer players, goalie, coach, referee, cheerleaders, water bringer*

  To play a game of soccer, you do not only need soccer players. If your child cannot physically play soccer, he can still be included in the game. He can be the cheer leader, or the referee.

  For example:
  In a soccer game, when the ball goes out or a goal is scored, the players have to start playing again. If the only thing your child can do is show a sign for "go" or say "go", then make it a rule that each time the players can only start once your child has shown them to "go". That way your child is still a part of the game and he is able to help lead it.

- ***Encourage other children to take turns with your child***
  If other children are playing a game, you can encourage them to give your child a turn. Or you can help another child to play a game with your child where they each take turns. By allowing each child to take turns, it allows your child to play in a way that they are able to and allows the other child to still use his abilities even if he can do more than your child. For example the game could be throwing a ball. When your child has his turn, he may just have to push the ball if he can't throw. Then when it is the other child's turn, he can try and throw the ball into a bucket, because he may become bored if all he does is push the ball. So each child can play according to their own abilities by taking turns.

HOW TO HELP OTHER CHILDREN TO PLAY WITH A CHILD WITH CP:

- ***Help your child to play at the same level as other children***
  If your child is lying on the bed and the other children are sitting around a table, it will be very difficult for your child to play with them. It would be more helpful to find a way to help your child sit with the other children. If your child is standing in a standing frame and is higher than the other children, the other children can stand on crates to be able to play at the same level. When other children play with your child, it is important that they can look at each other easily and that your child is not separated from the group.

Put up these pictureswwW when you talk about helping a child with CP to play at the same level as other children.

Check if there are any questions.

MAIN MESSAGE

It is important for children with CP to spend time playing with other children.

Other children can motivate a child with CP to play better than most adults.

As adults, we need to help children with CP to be included in activities with other children.

Playing with other children is fun.

ACTIVITY:

Each person in the group must choose one object from each of the two bags. Tell the group that they must think of ideas of how they would play with their two objects.

Give them some time to think of ideas. Then ask each person to demonstrate their ideas for the group. As each person shares their ideas, invite the rest of the group to demonstrate any more ideas that they have for those two objects.

TOYS MADE FROM WASTE MATERIALS:

- ***A tactile board***
  To make a tactile board, all you have to do is take a piece of cardboard and then stick different things to it. Use things that feel different to each other. Some things should be rough, some smooth, some soft and some hard.

- ***A picture book***
  Cut out a few pieces of cardboard all the same size. These are for your pages. Put them all together and on the left side, make 2 holes through all the pieces of cardboard. You can then thread some string through the holes and tie the pages together to make a book. Then you can collect pictures of things your child likes and stick them in the book.

11 What can we play with?

Children do not need toys that are bought from the shop to play. There are many things that are around us every day that can be used to make play fun and exciting. We just have to be creative.

You will need:

Now that we have been creative with our ideas, let us look at some toys that are easy to make for children with CP.

Use the pictures to show the group some ideas of easy toys that can be made from waste materials. Explain how each one is made.

TOYS MADE FROM WASTE MATERIALS:

- ***A posting box***
  Collect some bottle tops or other objects for posting. Then find a box and cut some shapes out of the lid. The shapes need to match the objects that you have for posting. You can then add colours to the box if you want to.

- ***A shaker***
  Find a container that has a lid. Then find some smaller objects to put inside. You can use seeds, stones, lids, pieces of wood, etc.

- ***A mobile***
  Cut off the bottom part of a 2L Coke bottle and make a small hole in the bottom. Turn it upside down. Thread some string through the hole and tie a knot so that the bottom of the bottle stays attached.

  Then make little holes at the edges of the plastic and thread more pieces of string so that they hang down. You can then attach small objects to the pieces of string. Examples of things you can attach are: sweet wrappers, bottle tops, cut out shapes and pictures, toilet roll inners cut into circles, etc.

?

Earlier we each shared about the ways that our children with CP can play. Keeping that in mind, which of these toys do you think would be the best for your child? Explain why.

Check if there are any questions.

MAIN MESSAGE

Anything can become a toy.

You do not need to buy toys in order to play, you just need to be creative.

Many toys can easily be made from materials that are around all the time.

We need to use toys that are suitable for the way that our child can play.

ACTIVITY:

Get everyone to stand in a circle and ask them to think about different activities that we can use to get children to use both their hands. Give them a few minutes to think of some ideas. Explain to the group that you are going to throw the ball to someone, when they catch it they must share one of their ideas. Then they throw the ball to someone else and that person shares their idea. Keep playing until no one has any more ideas to share. These ideas should not be about what you can do with a ball. Using the ball and throwing it to someone in the circle is just a fun way of getting everyone in the group to take part and share their ideas. Everybody needs to think about different activities children can do using both hands.

ACTIVITIES FOR USING BOTH HANDS:

- *Pulling material through a slit in the lid of a closed container*
- *Posting things through the lid of a container*
- *Putting bangles on and off*

12 Helping children with CP to use both hands

Children usually use both hands to play and explore the objects around them. We also use both our hands to do things. When children with CP are only using one hand (eg children with a hemiplegia), we need to help them to learn to use both hands. We can do this in play activities and every day activities around the house.

You will need:

Use the pictures to show the group some more ideas for helping children to use both their hands.

ACTIVITIES FOR USING BOTH HANDS:

- *Holding a stick/pole with both hands and using it to hit a ball/balloon*
- *Opening containers to get something out*
- *Using pegs to attach every day things to a string (like hanging washing on the washline)*
- *Holding the edges of a towel and rolling a ball/balloon on top (without letting it roll off)*
- *Watering the garden with a watering can*
- *Pushing a wheelbarrow*
- *Using a water pump*
- *Eating yoghurt with a spoon*
- *Washing hands/clothes in a basin*

9 End of the workshop

? **Now that the workshop has come to an end, does anyone have any questions before we close?**

? **After learning about playing with your child what will you do differently when you go home?**

Go through the parent handout with the group and check if there are any questions about it.

Close the workshop and make sure that everyone feels that their questions have been answered.

7

CVI
Cerebral Visual Impairment

Understanding where and what my child can see.

Materials

For this workshop you will need:

A blindfold cut out of a black dustbin bag (1 per pair)

A jacket/jersey - any top that can open in the front (1 per pair)

A cloth (1 per pair)

A clear ziplock bag smeared with vaseline and then folded in half (1 per person)

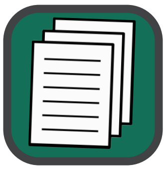
Set of black and white pictures (1 per pair)

Set of red and yellow pictures (1 per pair)

1 set of background pictures

A board covered in shiny paper or tin foil (1 per pair)

A cell phone



Sheets of paper (1 per pair)

Pens (1 per pair)

1 Welcome

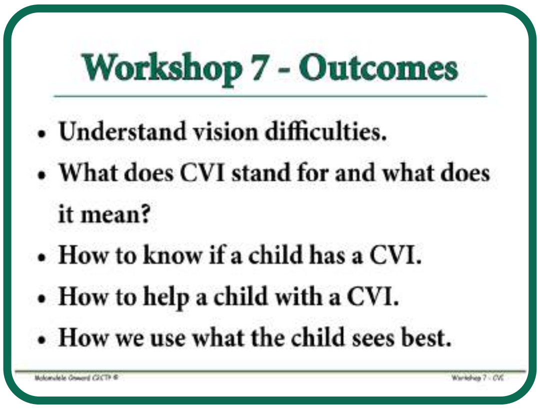
Welcome everyone to the group and make sure that they are comfortable before you start.

?

Before we start this workshop, what was one thing that you learnt from the last workshop on “Communication” and how have you used it at home?

2 Outcomes

Put up the outcomes and go through them with the group.



Workshop 7 - Outcomes

- Understand vision difficulties.
- What does CVI stand for and what does it mean?
- How to know if a child has a CVI.
- How to help a child with a CVI.
- How we use what the child sees best.

Many children with CP also have problems with vision. There are many reasons why a child with CP has problems with vision. Today we are going to talk about just one of these reasons. We are going to talk about the problem called 'CVI'.

These are the things that we are going to talk about today:

- **Understand vision difficulties.**
- **What does CVI stand for and what does it mean?**
- **How to know if a child has a CVI.**
- **How to help a child with a CVI.**
- **How we use what the child sees best.**

Divide the group into pairs and tell them that they will stay in the same pairs for all the activities in this workshop. Then give each pair: a pen, some paper, a blindfold, a shiny board and a cloth. Then give each person: a picture pack and a plastic sheet. Tell them that their partner must not see what is in their picture pack.

ACTIVITY:

- Do the activity in pairs.
- One person is the caregiver and the other is the child.
- The child must wear the dustbin bag blind fold and sit on a chair.
- Take the caregivers away from the group so that the children cannot hear what you are telling them.
- Tell the caregivers that they must quickly take the jacket off the child and then wipe their face without saying anything.
- After the activity, the child can take the blindfold off.

3 What it feels like to not see

You will need:

What did it feel like to have your jacket taken off and your face wiped while you could not see?

How could the caregiver do this differently?

- Talk to the child and explain what you are doing.
- Take your time and do it slowly.
- Let the child feel the jacket.
- Be gentle, not rough.

Choose one pair to demonstrate for the group how to do it differently.

Some children can only see a little, but are not blind and it is just as frightening for them if someone does things to them without helping them to understand what is happening. If you have a child that can see, but not well, you still need to explain what you are doing and let them touch and smell the things that are around them.

MAIN MESSAGE

If we have a child who is blind or cannot see well, we must work slowly and talk to them about what we are doing.

This will help them to understand what is happening and they will feel less frightened.

WHAT WE DO WHEN WE THINK THAT A CHILD CANNOT SEE WELL:

When a child with CP cannot see well, we often think that the problem is with the eyes, but there can be many reasons why a child has problems with seeing. If a child cannot see well, we first send them to the doctor for an eye test. If the doctor says that there is a problem with the eyes, then he can give the child glasses to help them see better.

If he says that the eyes are fine, then we know that the problem is coming from the brain. The eyes can see but the brain cannot understand what the eyes are looking at.

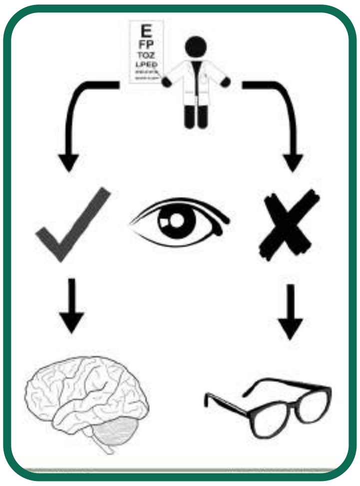
4 Difficulties with vision

Although some children with CP have no problems with their vision, some children with CP do. Let us look at the main vision problems children with CP can have.

? How can you tell if a child does not see well?

- They cannot look at something
- They do not notice the things aorund them
- Their eyes are not facing the same way
- They walk into things
- They hold things very close to their face when they want to look at them
- They always stare at one place

Put up the picture and use it to explain what we do if we think that a child cannot see well.



There are three main problems that child with CP can have with their vision:

1. There is a problem with the eyes stopping them from seeing clearly
2. The eyse are looking in different directions (squint)
3. There is a problem in the brain. The eyes can see but the brain cannot understand what the eyes are seeing.

CHILDREN WHO CANNOT SEE CLEARLY:

If there is a problem with a child's eyes and they cannot see clearly, this can usually be helped with having spectacles/glasses made for the child. The problem happens because the light coming into the eye is not shining on the right part, so the spectacles/glasses help make the light shine on the right part of the eye so that the child can see clearly. If a child has this problem and they do not get spectacles/glasses, their eyes will slowly become worse.

CHILDREN WHOSE EYES LOOK IN DIFFERENT DIRECTIONS:

Just like a child's body, the eyes are controlled by muscles. And just like a child with CP has problems with how their body moves, so can children also have problems with how their eyes move. To see clearly, our eyes need to work together and focus on the same thing. But if there are problems with how the eyes move, they will not work together. If the eyes do not work together and they look in different directions, the child sees two different things. This is confusing for the brain, and in some children the brain chooses to only understand one eye and it ignores the other eye.

When the eyes do not work together, it is called "strabismus" or sometimes "lazy eye" or "squint".

Put up the picture and explain how we can help a child who cannot see clearly.

Put up the picture and explain why some children's eyes look in different directions.

WHAT DOES CVI MEAN ?

For some children, when the brain was damaged at birth, the part of the brain for vision was also damaged. These children have a problem with seeing because of the damage to the brain, not because the eyes are damaged.Their eyes can still be fine.

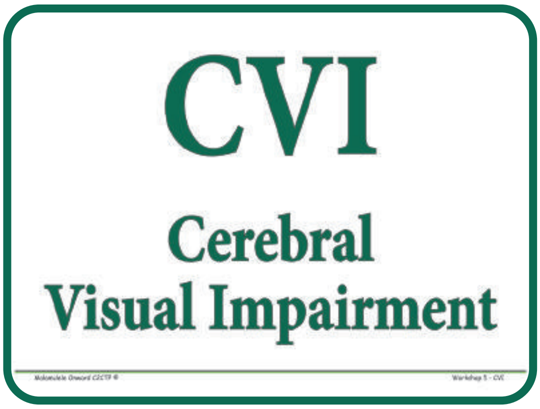
We call this Cerebral Visual Impairment and we say CVI for short. Sometimes it has been called "cortical blindness" even though the child is not actually blind. The eyes are working, but the brain is damaged and cannot understand what the eyes are seeing.

HOW DAMAGE TO THE BRAIN AFFECTS THE BODY:

Remember that in the first workshop we talked about how a power station supplies electricity to the appliances in the house. Even though there is nothing wrong with the appliances, they will not work if there is a problem at the power station.

So just like the appliances, the child's eyes are working fine, but the problem in the brain stops the eyes from being able to see well.

Put up the picture and explain what CVI means.



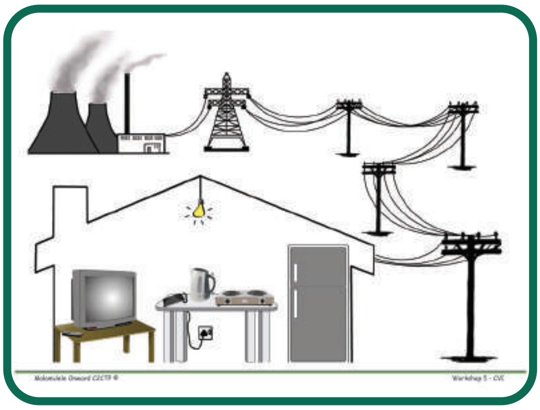
CVI

Cerebral
Visual Impairment

Malamulele Onward C2CTP ©

Workshop 5 - CVI

Use the picture of the powerstation to remind the group of how damage to the brain affects the body.



MAIN MESSAGE

Children with CP can have problems with their eyes or a problem with their brain affecting their vision

When the eyes are working, but the brain cannot understand what the eyes are seeing, we call it a CVI.

SIGNS OF CVI:

- The child takes a long time to look at something.
- The child looks at an object, but then looks away when reaching for it.
- The child just stares in one direction.
- The child will look at an object for a moment and then look away, as if they cannot focus on it.
- The child looks towards the light, so their eyes look up and to the side.
- The child cannot follow objects with his/her eyes.
- Some days the child seems to see better than others.
- The child can see things better when we hold them to the side rather than in front of the child.
- Some children can see an object better when it is moving.

5 How do we know if a child has a CVI?

Let us look at the different signs that tell us that a child might have a CVI...

Use the pictures to go through the different signs of CVI and acknowledge the ones that have been mentioned.

? Have you noticed your children showing any of these signs?

If a child has a CVI, it does not mean that they show all of these signs. Remember that all children with CP are different and like CP, CVI can be severe or mild.

Understanding CVI can be very difficult, so you need to ask your therapist to help you to understand what your child can see.

Check if there are any questions.

MAIN MESSAGE

There are many signs that can tell us that a child has CVI.

Children with CVI are all different and so some of them can see more than others.

Ask your therapist to help you understand what your child can see.

WORKING WITH A CHILD WITH A CVI:

There are five main points to remember when working with a child with a CVI:

1. The child must be positioned well
When a child has a CVI, it is more difficult for them to use their eyes if they are in a poor position or if they are moving too much. If we want to help a child with a CVI to look at things, we need to give them as much support as possible so that it is easier for them to use their eyes.

2. Make sure that it is quiet
When we want a child with CVI to use their eyes, it is important that the room is quiet and that there are no noises to distract them. For most children with a CVI, it is easier to use their ears for listening than to use their eyes for looking. So, if it is noisy, they will listen to the sounds instead of looking at what you are showing them, because it is easier.

3. Give the child breaks
Just like learning to sit or stand at a table is tiring for children with CP, so too is looking for children with a CVI. When we help children with a CVI to see, we need to give them breaks as their eyes become tired.

4. Be patient
This is the most important thing to remember about a child who has a CVI. We must be patient and wait for the child to look. Some children with a CVI can take a long time to respond. It takes a lot of patience.

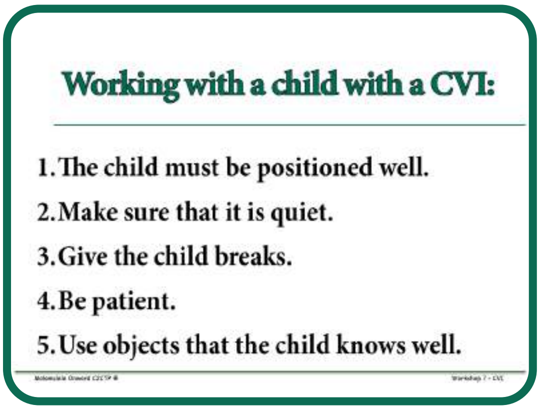
5. Use objects that they child knows well
It is easier for a children with a CVI to see objects that they are familiar with. The more we show them the same objects, the easier it becomes for children with a CVI to see them.

6 Helping children who have a CVI

Although children with a CVI cannot see well, there are many things that we can do to help them see better.

There are five important points to remember when working with a child with a CVI.

Put up the picture and explain the important points to remember.



Working with a child with a CVI:

1. The child must be positioned well.
2. Make sure that it is quiet.
3. Give the child breaks.
4. Be patient.
5. Use objects that the child knows well.

Check if there are any questions.

Before we can help a child with a CVI to see better, we need to understand where we must hold objects for them to see best and what objects are easier for them to see.

Let us do some activities to help us understand what things are easier for a child with a CVI to see.

ACTIVITY:

- Do the activity in pairs.
- One person must sit on their chair and hold up the plastic sheet in front of them as in the picture.
- The other person must stand three big steps away from the person that is seated and hold up the black and white picture from their pack.
- The person standing must move closer and closer until the other person can say what the picture is.
- Then the person standing must hold the picture close to the person's face and ask if they can see it well.
- The pairs can then swop positions and the person now standing will use the picture from their pack which is different to the one that has already been used.

7 Where must we hold objects

Now let us first learn about where we should hold objects for the child to see.

You will need:

?

Did everyone need the picture to come closer to see what it is?
Was it easier to see the picture when it was very close?

When we show an object to a child with CVI, it is important to remember that we need to hold it close enough for the child to see it, but we do not want to hold it right in front of their face. Often it is easier for a child to see objects when they are held to the side of the child's eyes.

Check if there are any questions.

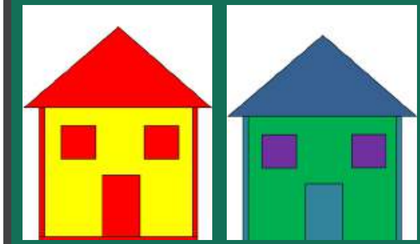
ACTIVITY:

- Do the activity in pairs.
- One person must sit on their chair and hold up the plastic sheet in front of them as in the picture.
- The other person must stand three big steps away from the person that is seated and hold up the two colour pictures from their pack next to each other.
- The person standing must move closer and closer until the other person can say what the pictures are.
- They must say what they can see and which one is easier to see.
- Once the person sitting has chosen which picture is easier to see, the pairs can swop positions and do the same activity.
- The person now standing will use the pictures from their pack which are different to the ones that have already been used.

8 Bright colours and contrast

Let us do some activities to learn what things are easier for a child with a CVI to see.

You will need:



Ask everyone to pick up the two pictures that were easier to see and put them in the middle of the group so that everyone can see them.

?

Why do you think that these pictures were easier to see?

- **Yellow and red are brighter colours, than blue and green.**
- **Bright colours stand out more than the dark colours.**

LEARNING ABOUT CONTRAST:

The word contrast, means "very different". It is easier for children with a CVI to see when two colours are very different from each other. Pictures that are black and white have a lot of contrast because they are very different, but pictures with grey, have less contrast and are more difficult to see. The same with colours - a dark and light colour are very different from each other and are easy to see, but colours that are similar are not easy to see.

Put up the pictures and explain what contrast means .

Tell the group to hold up their plastic sheets and look through them at the pictures you have put up.

Check if there are any questions.

ACTIVITY:

- Put the two pictures up on the wall at eye level.
- Ask everyone to come and look at each picture through their plastic sheets.
- They can then return to their seats.

IT IS EASIER TO LOOK WHEN THERE IS A PLAIN BACKGROUND:

As we mentioned earlier, it is difficult for a child with a CVI to look at one object when there are many. If we show a child an object and there are lots of colours and objects in the background, it is once like trying to find your sister in a crowd at a soccer stadium.

If you are putting something in front of the child on a table, then make sure that there is nothing else on the table at that time. If you are showing something to your child, face them towards a plain wall where there are no pictures hanging. If you do not have a plain wall, you can put up a plain sheet to make a plain background.

9

A plain background

You will need:

Does everyone agree that it is easier to see the person when the background is plain?

- **Yes.**

Explain why it is easier for a child with a CVI to see when there is a plain background.

ACTIVITY:

- Do the activity in pairs.
- One person sits on a chair and faces away from the window. If there is no window, then they must face away from the light. They must hold up the plastic sheet in front of them as in the picture.
- The other person must stand in front of them with the shiny board.
- They must first hold the board still so that it reflects the light, then they must move or shake the board back and forth so that the light flashes.
- Then let the pairs swop so that each person has a turn.

10 Light and reflection

You will need:

?

Does everyone agree that it was easier to see the board when it reflected the light?

- **Yes**

?

Do you think it would be easy to see the board if you were facing towards the window? Why?

- **No, the light cannot reflect off the board.**
- **The light coming in from the window is brighter than the board.**

?

Was it easier to see the board when it was still or being shaken?

- **When it was being shaken.**

Did everyone see that we can use light reflecting off objects to make it easier for the child with a CVI to see? If they still are not looking, we can move or shake the object to make it even easier for them to see it.

?

Can you think of some examples of other things that reflect light?

- **Mirrors, Christmas decorations, a shiny pot, a CD**
- **Shiny sweet wrappers or the inside of a chips packet**

ACTIVITY:

- Ask everyone to hold their plastic sheets in front of their eyes.
- Light up a cell phone and make sure that you face it towards each person so that everyone gets a chance to see it.
- Then make the room darker by closing the curtains or blocking the windows and turn the light off.
- Do the same activity again while the room is dark.

USING LIGHT TO HELP A CHILD WITH A CVI TO SEE MORE EASILY:

We can make objects easier for the child to see by shining a torch on them. The light makes the object look brighter than what it is and so it becomes easier for the child with a CVI to see.

BUT:
We must never shine the torch directly at the child's eyes, as it can cause damage to the eye.

You will need:

Were you able to see the light the first time?

- **Yes**

Was it easier to see the light when the room was light or dark?

- **When it was dark.**

Can you think of some examples of what we can use as a light?

- **Torch, cell phone, any toy that lights up**

You have seen that we can use both light and reflected light to make something easier for a child with a CVI to see. This works very well for children who can only see light and dark, but it is also helps other children with a CVI to see better.

Explain how to use light to make objects easier to see.

Check if there are any questions.

Finding out how much a child with CVI can see, and how near or how far they see best is difficult. It is important that you ask your therapist to help you do this because children with a CVI can be very different from one other.

MAIN MESSAGE

When working with children with a CVI we must make sure that the child is positioned well and is supported as much as possible.

We must also make sure that the room is quiet, and that we are patient and give the child enough time to respond.

We must remember that it is tiring for the child when we are doing these activities to encourage him/her to look and so we must give the child breaks.

It is easier for children with a CVI to see: bright colours, colours that are very different from each other, light and reflected light.

We should try use the same objects so that the child gets to know them well and can see them more easily.

We can make it easier for the child with a CVI to see by making sure that there is a plain background.

We can make it easier for the child with a CVI to see an object if we move it.

When we are using light to help a child with a CVI to see, we should make sure that the lights are off and that the child is not facing a door or a window.

ACTIVITY:

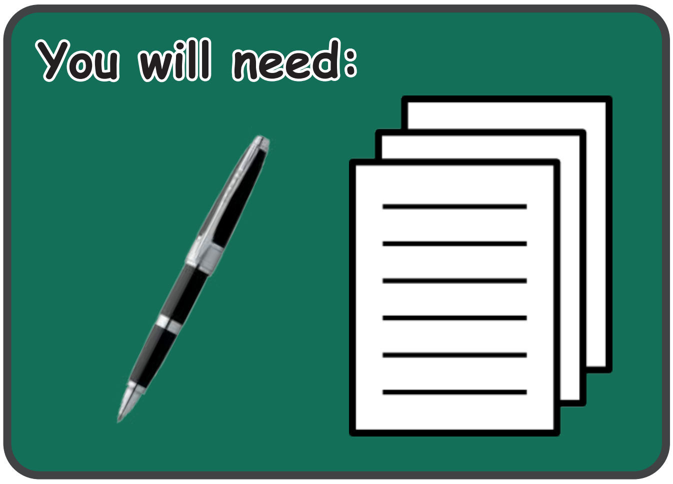
- Do the activity in pairs.
- Give each pair one of the following activities: Bathing
  Dressing
  Feeding
- Each pair must think of how they can help a child see better when they are doing that activity and write their ideas down on a piece of paper.
- Give them five minutes to do this.
- Then ask each pair to share their ideas with the group.
- After each pair shares their ideas, invite the rest of the group to add their suggestions.

11 Using what your child sees best

Now that we know what things are easier for children with a CVI to see, we must remember that each child is different and so the things that are easier for each child to see may be different. Because of this, it is important to work out what things your child sees best and then use those. You cannot just use all the ideas we have talked about, because some may not work for your child.

Children with a CVI also have different ways of looking. Some can only look for a second at something. Some children can follow an object with their eyes. Some children can only see a light. Some children take a very long time to look. Some children can only see on the one side.

It is also important to remember that we cannot make big improvements to how a child sees. Yes, we can make it easier for them to see things, but if their vision improves, it will be in little bits. The most important thing is to help the child to see as much as possible. Let us think of some ideas to help children with a CVI to see better during every day activities.



IDEAS FOR WHEN YOUR CHILD IS RESTING OR PLAYING:

Old CDs hanging in a tree reflect light as they move in the breeze. If your child is in a chair, you can put them by a tree with CDs hanging so that they have something to look at.

If the child is lying down, you can hang shiny things for them to play with. Cutting up a chips packet into long strands can work well.

If they can turn pages in a book, you can make books using the ideas we have spoken about. If they can't turn pages in a book, you can make pictures to put on the wall for them to look at.

If you have a window, you can cut out shapes and stick them on to give the child something to look at.

When you wash your sheets and towels and let them dry outside in a breeze, let your child sit near the washing. They will notice the movement as the sheets and towels wave in the wind.

12 Ideas for when your child is resting or playing on their own

Now that we have talked about ways to help children with a CVI to see during every day activities, we can also think of ideas for helping children to see when they are resting or playing.

Put up the pictures and ask the group to come up with more ideas that they can use at home.

13 End of the workshop

? **Now that the workshop has come to an end, does anyone have any questions before we close?**

? **After learning about CVI what will you do differently when you go home? If you do not have a child with a CVI, how will you help someone who does?**

Go through the parent handout with the group and check if there are any questions about it.

Close the workshop and make sure that everyone feels that their questions have been answered.