

Flashcards Cerebral Palsy



These flashcards contain information about working with children who have Cerebral Palsy (CP) in low resource areas. These Flashcards are made for the use of fieldworkers.

rehapp

These flashcards are based on the information about Cerebral Palsy in the RehApp (application for rehabilitation)



The goals of these flashcards are:

- To meet the needs of children with disabilities and their families
- To improve the functional capacity of fieldworkers, children with disabilities and their families
- To enhance participation in daily, family and community life
- To improve the quality of life of children with disabilities and their families
- To support you (as fieldworker) in the process of guiding a family

What can you do with these flashcards:

- Making an inventory of the needs of the child and family.
- Learn about the implications of a disability for the child and family
- Use them to do an assessment
- Use them to set goals for the child with cerebral palsy
- Use them to help you choose interventions
- Use them as guideline for client records
- Use them as guideline to monitor process

Index:

Note: These flashcards consist of two parts, the first part contains information about cerebral palsy and the second part contains what you (as fieldworker) can do according to the rehabilitation cycle.

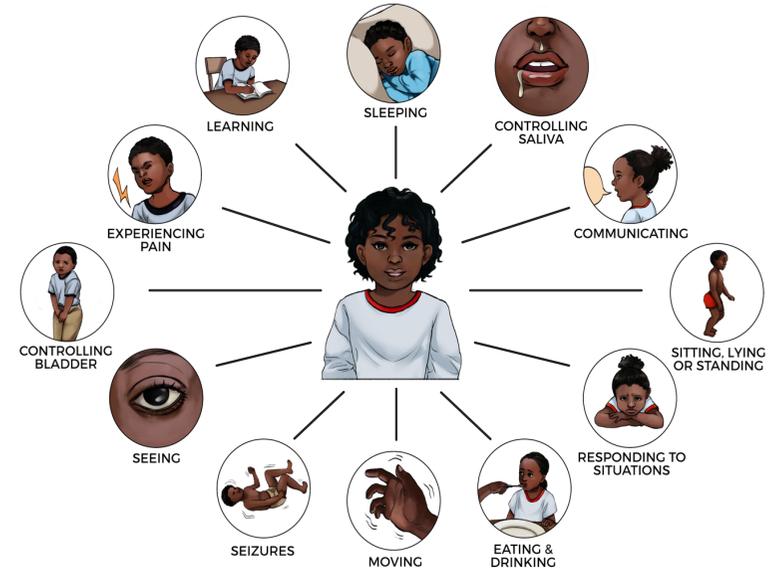
Information about cerebral palsy	What can you do
 Introduction	 Intro rehabilitation cycle
 Body functions and structures	 1. interview
 Activities	 2. observe
 Participation	 3. write
 Personal factors	 4. action!
 Environmental factors	

Card 1

Introduction

What is CP

Cerebral Palsy (CP) is a disability that affects the development of controlling the muscles and posture. It comes from damage to parts of the brain, mainly the ones that control movement. Apart from making it difficult for some children to sit, stand and walk, CP can cause difficulties in other skills such as: controlling the bladder, controlling saliva, talking and eating. Some children may also have difficulties with seeing well, or general learning. They may experience pain and may have seizures and these things can affect their behavior and their ability to sleep. Experiencing one or more of these issues makes going about the normal activities of daily living more difficult. Every child is affected in a different way and to a different degree.

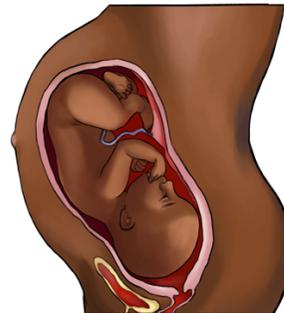


Possible causes of CP

There are many reasons why a child may have cerebral palsy. A cause can be any incident that causes damage to a part of the brain, or which affects the development of the brain, such as lack of oxygen. This damage can happen either before birth, during birth, or shortly after birth. Often the doctors don't know what caused the CP in a child. Here are some examples:

Before birth:

- Use of alcohol and other drugs
- Infections or illnesses of the mother while she was pregnant



Around the time of birth:

- Lack of air at birth
- Injury to the baby's brain during birth
- Born too early

After birth:

- Brain infections
- Malaria
- Head injuries
- Lack of air



Different parts of the body

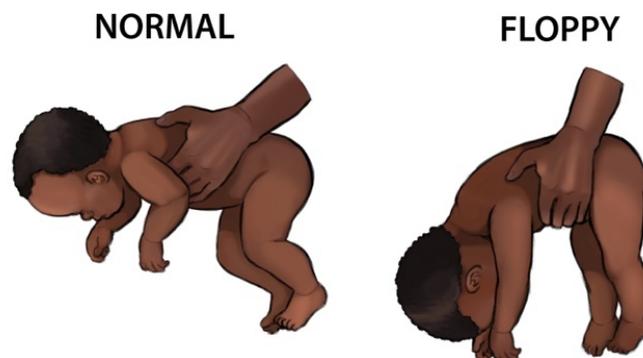
A child with CP has trouble controlling and moving their muscles. The parts of the body that are affected depends on which part of the brain is damaged. It can affect one side of the body, both sides, just the legs or both arms and legs.



Both arms and legs One side Just the legs

How does CP affect the body

At birth, a baby with CP may appear limp and floppy. Stiffness appears seldom right after birth and usually after a few months.



Sometimes babies with CP do not appear any different from other babies. Children who have CP are affected differently depending on where and how the disturbance in brain development occurred. There are four main ways in how children's movements might be affected:

1. **Ataxia:** Shaky movements, poor balance and lack of coordination. The child has difficulty sitting and standing. S/he walks with their feet wide apart, has a tendency to fall or stumble, has difficulty walking in a straight line and they might seem very clumsy when using their hands.
2. **Spastic:** Stiff muscles. Most children with CP have spasticity. Different parts of the body can be affected. In spastic quadriplegia, both arms and both legs are affected. The muscles of the trunk (body), neck, face and mouth are often also affected.

In spastic diplegia both legs are affected but the arms may be affected to a lesser extent. In spastic hemiplegia only one side of the body (one arm and one leg) is affected.

3. **Dyskinetic:** Involuntary movements. These children experience uncontrolled movements in their arms and legs, which seem to be moving all the time. Sometimes the arms and legs push backwards and become stiff when the child tries to move.
4. **Mixed CP:** Some children can show more than one type of movement pattern.

Card 2

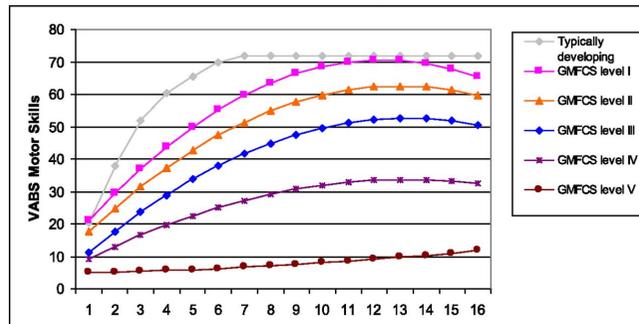
Body Functions and structure

Card 3

Activities: Levels of severity

Different levels of severity

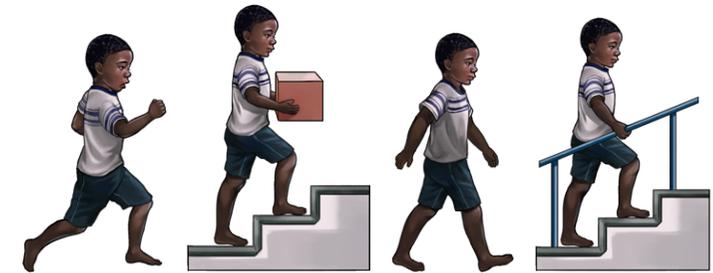
Some children are more affected by their CP than others. We call this 'severity level'. The level of severity influences what the child is able to do and learn in daily life. The 'severity levels' are mild, moderate and severe according to a system called Gross Motor Function Classification System.



Vos et al., 2013

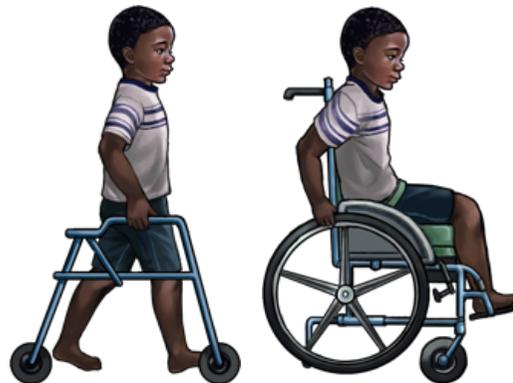
Mild

Mild (also called GMFCS* level I or II): The child can walk on their own, but the movements are a bit wobbly. The child might be able to jump and run as well. Walking long distances can be difficult.



Moderate

Moderate (GMFCS level III): The child can sit on their own and move around by themselves with a wheelchair or a walker. The child needs help over long distances.



Severe

Severe (GMFCS level IV or V): The child cannot sit by themselves and needs support. Some children can roll over from one side to another when lying down or lift their heads. This child does not walk by themselves but might be able to use a walker with support from another person. If using a wheelchair, they need to be pushed by another person.



How CP can affect daily life and development

Children with CP not only have different skills from each other but also have their own wishes and needs, as expressed in the picture below. It is important to look for the things they can do and learn and not only focus on what they cannot do. Don't assume they have no skills. Focus on developing skills in activities of daily life, even if it is in small steps.



A child with mild cerebral palsy may have some difficulties in moving and only require a little assistance to do things, whereas a child with severe cerebral palsy may need daily and long-term assistance to perform all activities of daily living.

Each child is unique and needs the right type of support – physically, mentally and emotionally – to allow them to reach their full individual potential.

As a child grows up into adulthood, a lot of help can be needed to maintain movement of the body and joints, and to maintain muscle strength. It is important not to over-help the child but to help the child just enough that they can learn to do more for themselves. The child with CP will become an adult with CP. Help the child to become an adult who can live with her/his disability and be as independent as possible.

Functional activities

The child's ability to walk is often one of the biggest concerns of parents. Walking is important both functionally and socially but in terms of the child's overall needs, other skills may be more important. For all children, whether they have mild or severe disabilities, to lead as happy and independent a life as possible, the following are also important:

- Having confidence in themselves and liking themselves
- Being able to communicate with others and have positive relationships
- Developing skills in self-care activities such as eating, dressing and toileting
- Being able to get from place to place
- (and if possible) walking



Walking

Walking is not the most important skill a child needs – and it is certainly not the first. Before a child can walk they need to be able to have reasonable control of their head, they need to be able to sit without help, and to be able to keep their balance while standing.

Many children with CP do learn to walk, although often much later than usual. In general, the less severely affected the child is and the earlier they are able to sit without help, the more likely they are to walk. If they can sit without assistance by age 2, their chances of walking may be good – although other factors may affect this.



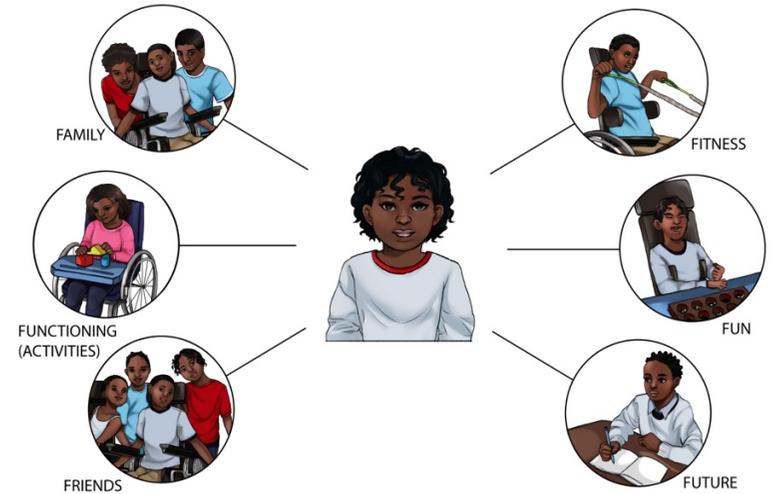
Card 5

Activities:

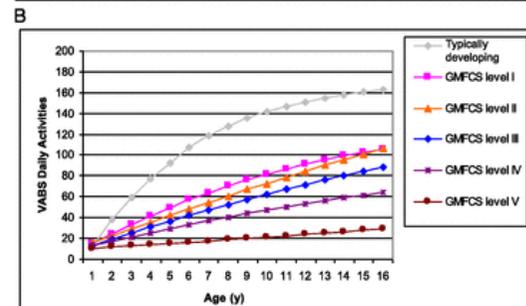
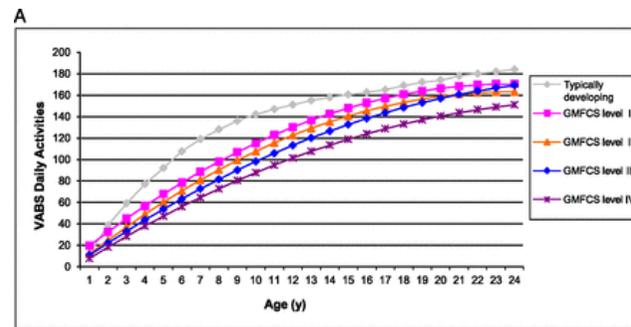
Helping children with severe disabilities

Helping children with severe disabilities

Some children have severe disabilities. They have difficulty moving, cannot move around or take part in all games. Some of these children may never walk but are able to enjoy their life in other ways. We need to accept this and aim for other important goals. Whether or not the child may someday walk, they need some way to get from place to place. There are different ways to do this, for example using wheel boards, wagons, wheelchairs, special walkers and hand-pedal tricycles.



CanChilds' Six Favorite words in the lives of children with disabilities (2018)



Vos et al., 2013

A, Data from participants without intellectual disability, aged 1 to 24 years. B, Data from participants with intellectual disability, aged 1 to 16 years.

Focus on their abilities, wishes and what they can learn, as the 'F-Words' show. They may like to hear stories, or just have someone touch them and hold their hand.

Remember that when children cannot speak or think well, it can be difficult to know what they are feeling. They may be lonely and unhappy, and need friends who will visit, laugh with them, talk and play.

Children with severe disabilities may be very intelligent, but their intelligence will not develop unless they are stimulated and given opportunities to learn and participate in daily life from an early age. Ways of enabling them to go to school can completely change their lives. Try and find out what they like and want by listening to them, looking at the sounds and movements they make, the signals they give and by taking notice of them.

How CP can affect participation in daily life

Every child needs to interact in all settings – at home with their family and friends, in the community at school. Every child has the right to learn and go to school. Participation in daily life is important for the development of the child's motor and social skills, for their education, for developing their social networks and a feeling of belonging and ultimately for their overall well-being.



- Many children with CP in low-resource settings do not go to school because the parents believe this is not possible or that their child will not be accepted. They might need extra help to get to school or be excluded because they need help when they are there such as with going to the toilet. With the right support from other people and/or assistive devices, like a wheelchair or walker, going to school may be possible.



- Children with CP are also often excluded from social activities in the community or with friends. A child with CP may need help getting to a friend's house or physical support to play with other children.



- Together with physical support to participate, social barriers also need to be tackled and fieldworkers can have an important role in doing this.
- It is important that the child is included in all social activities within the family and community.



Family counselling & mental support

Family members, like the family member with CP, may experience difficulties dealing with certain activities and situations. This can result in feeling hopeless, depressed or sad. You can support them by:

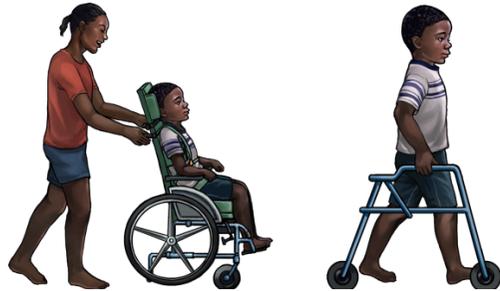


- Involving the child and all family members in the rehabilitation process by answering their questions and providing information.
- Listening to their stories, encouraging them to seek assistance from family and friends and providing a positive sense of the future.
- Providing the child and family practical and mental support for developing resilience and learning to live with their strengths and weaknesses and finding alternative ways to achieve their full potential.



Assistive devices

Children with CP that have difficulty walking could benefit from a wheelchair or walker to move around. Children who need support sitting upright can benefit from special seats. It is important to remember that the child needs to change their position regularly to avoid stiffness and pressure sores, and so must not sit in the same seat / or wheelchair all day.



Wheelchairs can be pushed by another person, manual or motorised. The seat on all CP wheelchairs should be designed so as to prevent skin problems, maintain posture and enhance independent mobility and functioning.



A wheelchair is considered appropriate if it:

- meets the individual's needs and environmental conditions;
- can be obtained and maintained in the country at an affordable cost;
- provides mobility;
- increases independence.

Besides mobility devices, there are also **assistive devices** to support sitting, self-care activities such as eating & drinking, and learning. These devices can improve playing, doing parts of or entire self-care activities, participating in social activities and much more. →



Card 8

Environmental
Factors: Assistive devices

Card 9

Environmental

Factors: Home modifications

Home modifications

Assistive devices can require home modifications, such as putting in ramps where there are differences in the height of surfaces within or around the house. Additionally, the child might benefit from handles being attached, for example to doorways and near the toilet, to support moving in and outside the house and maintaining balance whilst doing an activity.



Rehabilitation cycle

This cycle represents the steps of the rehabilitation process that you use when visiting families that have a child with disabilities. Look at the following information to learn more about each step.



1. Interview

See below three activities you do within this phase of the rehabilitation cycle:

- Preparing for the first visit*
- The first meeting*
- 'Ladder of Life'*

2. Observe

See below three activities you do within this phase of the rehabilitation cycle:

- Direct and indirect observation*
- How to observe*
- Log book*

3. Write plan

See below two activities you do within this phase of the rehabilitation cycle.

- Priorities*
- Goals*

4. Action

In the last step you are going to put your plan into action. You guide the caregivers through this process by giving them advice, working together on certain interventions, monitoring change together and support the family.

Card 10

Introduction
Rehabilitation Cycle

Preparing for the first visit

- Make an appointment for the visit
- Arrange to be introduced to the family by a community member or rehabilitation worker
- Think of how you are going to start the session – for example ask to be shown around the house so you can observe if the house is easily accessible for the child
- Take basic equipment with you for example: tape measurer, log book, pen, paper, a few toys



The first meeting

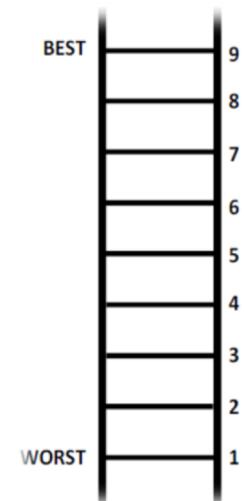
- Welcome
- Let the child/caregiver tell their story
- Let the child/caregiver describe a 'normal' day from waking up to going to bed
- Ask about the family's situation, for example:
 - Socio economic conditions such as income and educational background
 - Who is living at home at home
 - Who is involved in taking care of/playing with the child
 - Ask: How do you feel in general? Are you okay? Can you manage physically and mentally? Do you feel supported? (use the 'Ladder of Life' below as a start to talk about this)
- Ask about the child's main abilities and difficulties

The first meeting - continued

- Ask about what makes the child happy:
 - What does the child like and doesn't like?
 - Does the child play with other children or do other children come and play with the child?
 - What are motivators for the child? Motivators can be a specific activity such as singing, or specific play materials such as certain toys or objects.
- Ask the child/caregiver what would make the greatest difference to their lives right now.
- Ask any additional questions to make sure you have covered all the ICF domains from page 1 of the Rehabilitation Problem Solving (RPS) form
- Keep detailed notes of what you hear and see

'Ladder of Life':

- Where on the ladder do you feel you personally/your child stand(s) at the present time from worst to best possible life?
You can tell me your answer or point to a location on the ladder.
- What would help you move up the ladder?
- What would cause you to move down the ladder?



You have finished step 1 of the rehab cycle. Go to step 2 of the cycle.

Direct and indirect observation

Some of your observations of the child's abilities and difficulties can happen while you are talking to the caregiver.

Pay attention to the child all the time. What is the child doing in the background or on the lap, and how are they doing it?



How to observe

- Observe the child's abilities and main difficulties mentioned by the caregiver by letting the caregiver show what the child can do.
- Ask them to interact and play with the child. Does the caregiver, make eye contact, talk to the child and encourage the child during activities?
- Ask the caregiver/child about any strategies they have developed to cope with the disability and ask them to show you what they do.
- If the family has a phone with camera function, ask the family in advance of your visit, to take video clips at home to show you specific problems and factors involved in how an activity is done. Videos can also be a good method to see differences over time.
- Make sure you observe all of the following items. Go through each topic to guide you and add a summary to the RPS form:
 - Moving, Positioning & Carrying
 - Eating & Drinking
 - Communication
 - Self-care
 - Health & wellbeing
 - Psychosocial needs

Log book

Write a summary of the notes you made during the interview and observations on page 1 of the log book (the RPS form) – arrange in the correct sections of the page; make sure you have covered all four areas.

If you would like to receive the log book, send an e-mail to info@enablement.nl or fill in the contact form at <https://connect.lilianefonds.org/default.aspx>. The log book looks like this:



SUPPORT TOOLS ENABLING PARENTS

Liliane Fonds

REHABILITATION FOLLOW-UP LOG BOOK

Child:

Date of birth:
 Name of caregiver:
 Name of fieldworker:
 Address child:
 Telephone number caregiver:
 Telephone number fieldworker:
 Type of disability:
 Level of disability: mild (GMFCS I or II) / moderate (III) / severe (IV or V)*

*circle the correct level

REHABILITATION PROBLEM SOLVING FORM (RPS)

Date:

BODY FUNCTIONS & STRUCTURES: Information about the body and how well it is working	ACTIVITIES & PARTICIPATION: Information about what activities the child can and cannot do e.g. activities of daily life, learning, schooling
PERSONAL FACTORS: Information about the child's and caregiver's beliefs (e.g. religion), feelings, dreams, attitude	CONTEXTUAL FACTORS: Information about the family and community, physical environment, socio-economic factors, access to services

You have finished step 2 of the rehab cycle. Go to step 3 of the cycle.

Priorities

- With the caregiver and child, discuss which area/s to focus on
- Keep in mind the strengths and weaknesses of the child and caregiver
- You may need to explain and educate the caregiver to get agreement on:
 - o The need to prioritize caregiver practices such as feeding– for prevention of complications, ill-health and to promote development – before focusing on functional goals for the child such as moving
 - o Why it is not possible or realistic to go straight from complete dependence to independence; or from inability to sit, straight onto standing and walking

- Always work on small steps and celebrate small changes. Explain to the caregiver also what he/she does well and not only what needs to change.
- The goal is not to make the children better – the CP cannot be fixed, but their lives can improve.
- Write down the priorities for the caregiver and field worker on page 2 in the logbook. Decide together on the three main priorities for the next month. If there are only two, that is also fine. Focus on what is realistic.



Priority Areas	
According to caregiver / child	According to fieldworker (from interview and observation)
1.	1.
2.	2.
3.	3.
Goals - what do you agree needs to change within the next 1-3 months	
1.	
2.	
3.	
Action plan	
1.	
2.	
3.	

*For each goal, let the caregiver score how the activity currently goes on a scale of 1 'not good at all' to 5 'very good':



Goals

- Set goals together with the child/caregiver based on the priorities identified by them as well as by yourself as the fieldworker.
- Try out your ideas for functional strategies, to help you to set a SMART goal.
- Make the goals SMART: Specific, Measurable (what would progress look like in activities of daily life), Attainable, Relevant and Timebound (for example “..... within 1 month”). An example of a SMART goal: “Hope dresses herself in the morning, while sitting on a small chair, with verbal support from her mother within 1 month”.
- Make a plan of the interventions and actions to be taken within the next 1-3 months
- Write down the goals and ideas for actions on page 2 of the log book
- Give the log book to the caregiver to keep. Make photos with your phone of the pages you filled in together.

You have finished step 3 of the rehab cycle. Go to step 4 of the cycle.

Priority Areas	
According to caregiver / child	According to fieldworker (from interview <u>and</u> observation)
1.	1.
2.	2.
3.	3.
Goals - what do you agree needs to change within the next 1-3 months	*
1.	
2.	
3.	
Action plan	
1.	
2.	
3.	

*For each goal, let the caregiver score how the activity currently goes on a score of 1 'not good at all' to 5 'very good':



Card 14

Write Plan

Explanation

Start your plan and interventions during home visits:

- Refer to specialists if needed and available. Make an address book of specialists.
- Test out your ideas on different ways of supporting the child to see what works (for example different positioning or other ways of communication)
- Check the 'attention points' for support
- Practice skills with the child and caregiver and modify the strategy/technique if needed according to what works best
- Coach the family on how to perform these actions and how to work on these goals within the activities of daily life when you are not there
- Arrange for assistive devices if needed
- Make agreements on actions for the following week

Monitoring

- Monitor and evaluate the actions and goals during each home visit and write down a summary of your notes in the log book
- Evaluate the progress of the child and goals monthly in the log book with the caregiver
- Adapt goals or set new goals if needed based on the progress in the log book

Follow-up visits:

- Let the child/caregiver show you what they have practiced
- Modify any strategy/technique if needed
- Repeat any necessary training on interventions during the weekly home visits
- Make agreements on actions for the following week
- Monitor and evaluate progress and goals



INTERVENTION & MONITORING

Date of intervention:
Evaluation results of previous week:
Actions for the fieldworker today and until next week: <i>(Exercises, actions, arrangements, bring next time)</i>
Actions for the child and caregiver today and until next week: <i>(Exercises, practice, actions, arrange for next time)</i>
Feedback of the child and/or caregiver: <i>(Wishes, questions, opinions)</i>
Date of next home visit:
Signature caregiver:
Signature fieldworker:

MONTHLY EVALUATION

Goal 1:
a. How would you score the goal now? (let the caregiver give the score):

Not good at all 1 2 3 4 5 Very good
b. What has changed:
c. What was the main reason for the change:
Goal 2:
a. How would you score the goal now? (let the caregiver give the score):

Not good at all 1 2 3 4 5 Very good
b. What has changed:
c. What was the main reason for the change:
Goal 3:
a. How would you score the goal now? (let the caregiver give the score):

Not good at all 1 2 3 4 5 Very good
b. What has changed:
c. What was the main reason for the change:

Card 16

Action:
Monitoring

Referral

It may be very well that you won't be able to help the child and his/her family yourself. That could be for various reasons for example:

- You may not have the right expertise,
- You or your organisation may not have the means to assist: for example assistive devices.
- Other interventions may be needed than those that your organisations offer. For example, the family may be very poor and you may need to refer to a social work department or poverty alleviation programme for assistance.
- The child may need medical attention, for example medication.

- Epilepsy unit:
- Eye doctor:
- Orthopaedics (joints, bones):
- Prosthetics (for children missing limbs):
- Orthotics (special shoes or splints):
- Cardiologist (heart):
- Burns:
- HIV:
- Dermatology (skin):
- Ear, nose and throat doctor:
- Oncology (cancer):
- Obstetrician & gynaecologist (pregnancy, feminine problems):
- Family medicine:
- General Surgery:
- Internal Medicine:

Address book

Please develop a list of local organisations or persons to refer to. Always make sure you refer in time and to the right person or organisation!

You can think of finding these persons for your list:

Specialists/special units

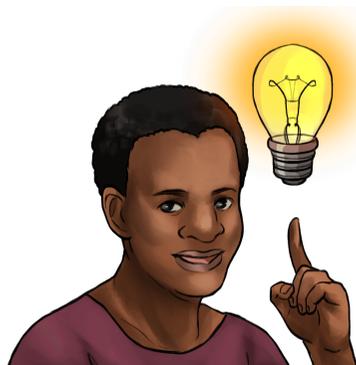
- General doctor:
- Paediatrician:
- Neurologist:
- Nutrition unit:
- Physiotherapy:
- Occupational Therapy:
- Psychology:
- Speech & Language Therapy:

Suppliers (specialist or shop):

- Assistive devices (e.g. wheelchairs, seat, toilet chair, stroller, walker):
- Hearing aids (e.g. hearing device):
- Visual aids (e.g. communication book/board; iPad):
- Medication:

Attention points

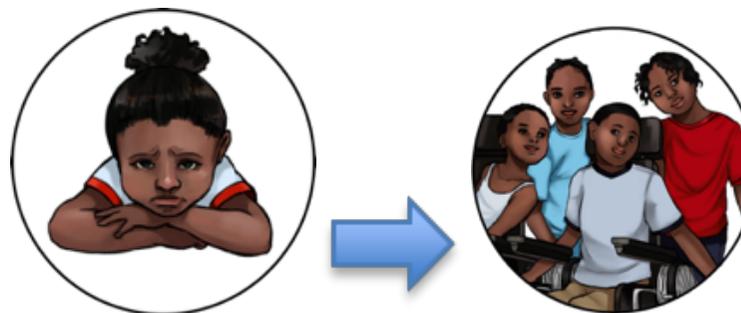
Look at the attention points in the topics below to support your interventions. These are ideas to think of. Show the family and do it together.



Psychosocial needs

- Pay attention to the child's / caregiver(s)'s perceptions of disabilities.
- Pay attention to community members' perceptions of the child's disability.
- Make sure the child has some form of social support (e.g. from caregiver(s), family members, friends/peers, community members or other).
- Make sure the caregiver(s) has some form of social support (e.g. from spouse, family members, friends, community members or other).
- Make every effort to ensure the child attends school and that the school is inclusive (adapted to the needs of all learners, including children with disabilities).

- Check whether the caregiver is employed and/or has sufficient financial support to afford basic needs for the household.
- Check whether there are physical barriers preventing the child from moving around in or accessing the house, neighbourhood or public places. For example big rocks in the road and differences in height when accessing a building.
- Check whether there are social barriers preventing the child and/or caregiver(s) from accessing public places. For example because the child or caregiver is afraid to be stared at or not being accepted.
- Pay attention to whether the child shows signs of emotional distress (e.g. exhaustion, worry, depression, anger)
- Pay attention to whether the caregiver(s) shows signs of emotional distress (e.g. exhaustion, worry, depression, anger)



Card 18

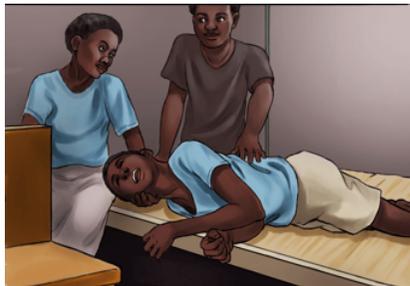
Action:
attention points

Card 19

Action: attention points

Positioning

- If you or the family have access to equipment like buggies and special chairs, then use them. If not, refer to a service to help them get the most helpful items for their child.
- Putting the child in a good position helps to prevent ill-health and pain.
- Why do you need good positioning:
 - To help a child with CP to develop as much as possible
 - Make it easier to pick up the child, carry and handle the child every day
 - Safe eating and drinking
 - To prevent problems as: pressure areas, contractures, deformities e.g. back/hips
- Use a table at the elbow height of the child so that she can play with something.



X



✓

- Which activities require good positioning: play, eating & drinking, school activities, communication and participating in family and community activities
- Good positioning helps the child to do more for themselves as the child has better control of the hands and the head. The child can see what is going on around them and learn. It makes daily activities easier for the child and to be more involved in family life.
- Make sure the child cannot fall or hurt himself. Use pillows and soft straps for the hips and chest, but only if needed.
- Being in a good position is like giving therapy at home – it is that good for the child.
- Sometimes the child needs time to get used to a new position. Don't give up but gradually build up.
- Remember, if you leave a child in one position for many hours, she may develop pressure sores and her body may gradually stiffen into that position which will increase her disability. She needs to be placed in a variety of helpful positions throughout the day.

• A good position is:

- The child is sitting up straight with the head and back supported.
- The child sits on his bottom.
- The hips are bent, at least in the hips.
- If possible, have the child's feet supported.
- The right muscles are working to move the body and keep it upright.
- The hands are free to grab, point and play.
- The child's arms are helping him/her to sit.
- The shoulders should be slightly forward so that her arms and hands are in front of her body, and she can explore objects and her own body.
- Think of: head and body, legs and feet, shoulders and arms.

Lifting the child

- Take care of your back! Try yourself and teach the caregiver(s).
- Bend your knees and keep your back straight or even slightly hollow.
- It is easier to pick the child up with one foot slightly in front of the other one.
- Hold the child as closely to your body as possible before lifting.
- Lift by using the strong muscles of your legs, and not your back.
- If the child becomes much bigger and heavier, preferably do not lift her alone, but ask someone to help you.
- If lifting with another person, count before lifting so that both people lift at the same time.
- Think of: head and body, legs and feet, shoulders and arms.



X



✓

Carrying

- It is not possible to be doing something with the child all of the time or to be carrying the child all day long. Sometimes you need to leave the child sitting or lying on their own.
- If the child doesn't have to be carried: don't. Let the child help wherever possible with transfers and moving from one place to the other.
- Carrying children that grow heavier increase back problems of caregivers.
- If the child has poor control of the head, make sure the head is supported and not falling back.
- Think of: head and body, legs and feet, shoulders and arms.
 - Keep the child in an upright position so she can hold her head up and look around, even shortly.
 - Use positions that keep the hips and knees partially bent and the knees separate.
 - Make sure she can hold on with her arms or use her arms freely.



X



✓

Card 20

Action:
attention points

Assistive devices

Assistive devices have a great effect on being able to perform activities and participate in daily life. When you observe the child has activity limitations, consider if adapting daily materials can support the activity. You can also choose to refer to an organization that provides assistive devices, especially large devices like a wheelchair, supportive seat or walker.

When do you need to refer:

- The family does not have but needs an assistive device for the child.
- The child is always crying when placed in the assistive device.
- The child cannot sit or stand up straight in the assistive device.
- The assistive device is too small.
- The assistive device is broken.
- The family has but does not use the assistive device: find out first why.

There are several types of devices and adaptations. These devices can help children to:

- Move around
- Eat by themselves or feeding easier
- Communicate
- Go to school
- Play by themselves
- Play with their friends

We name and show you a few:

Daily life



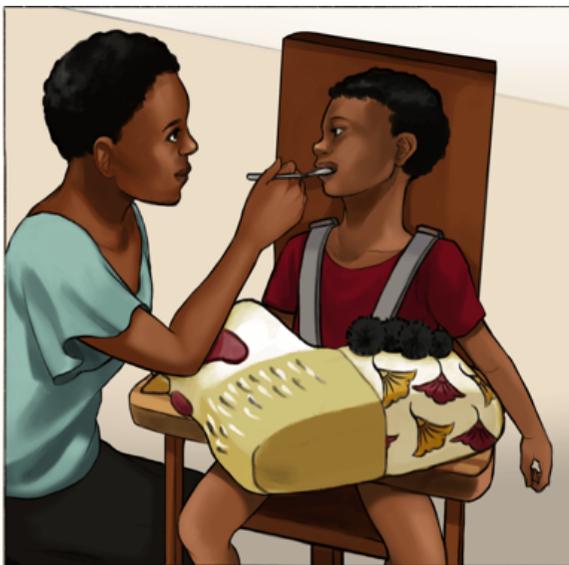
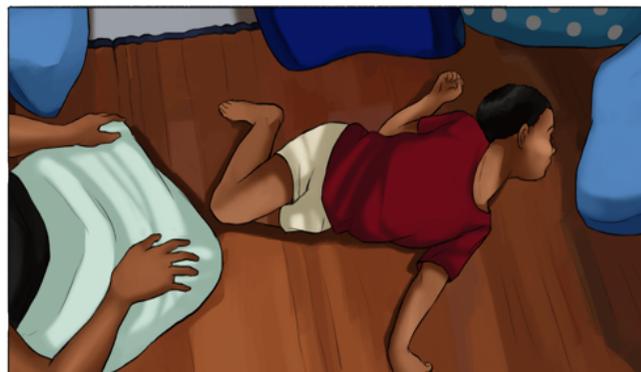
Communication



Home



Positioning



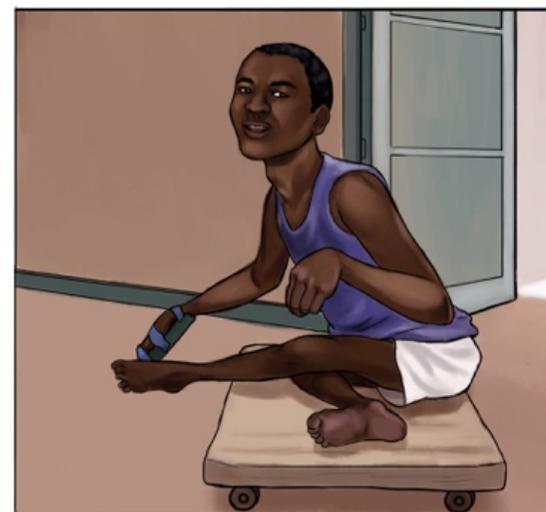
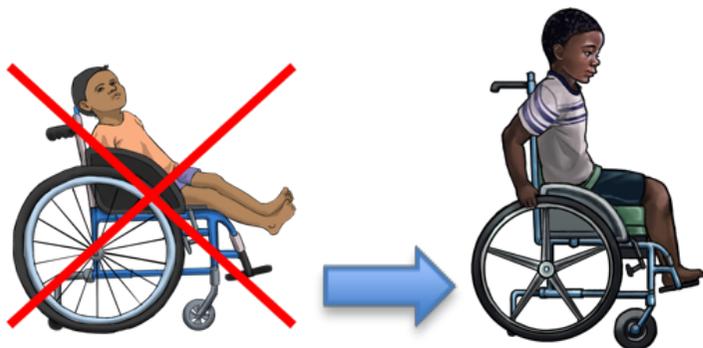
Card 22

Action:
attention points

Card 23

Action:
attention points

Moving around



Eating and drinking

Advice the parents:

- As with ALL children, follow good hygiene practices for food preparation and feeding.
- Make sure the diet is balanced, and extra high in nutrients (for health) and calories (for strength).
- Give smaller meals more often (for example 3 main meals and 2-3 snacks) (meals should not last for more than 30 minutes or else the child will get too tired and not be able to chew or swallow).
- Position: support the child in upright position with the chin slightly down (use a special seat if needed and possible). Provide jaw and lip support if needed.
- Make sure the food is of a smooth texture and with no bits in it.

- Use the correct utensils (small plastic cup & small plastic spoon).
- Feed sensitively: small mouthfuls, slowly, watching & pausing. NEVER FORCE.
- Communicate with the child in a positive manner.
- Give the child at least 1 liter (5 cups) of water per day.

Following these following attention points will reduce the child's risk of serious ill-health and help him/her to be strong, more able and happier.



Eating hand-over-hand



Eating by yourself with an adapted spoon



Card 24

Action:
attention points

Card 25

Action:
attention points

Good positioning when eating and drinking



X



✓

Communication

Advise the parents:

- Make sure the child is sitting up and able to see what is happening around them during the day.
- Encourage people to interact with the child.
- Talk to the child throughout the day – tell them about what is happening. Use lots of facial expression and gestures.
- Before asking the child a question or explaining something specific:
 - get their attention by saying their name and using eye contact;
 - make sure you are facing one another, on the same level, and with the child sitting well supported.
- Show an object that represents what you are asking/talking about.

- Take turns and encourage participation.
- Praise and encourage – clapping, cheering etc.
- Offer choices. Make sure the child has objects and/or pictures in front of them to show you what they want.
- Encourage the child to indicate what they want by using their skills of looking, pointing, touching, gesture etc.
- When you communicate with the child, also use pointing, touching, gesture as well as talking. This way the child will learn.
- Do not force the child to speak but encourage and respond to any attempt to communicate.

Some ideas to consider:

Choosing between two options



Using a booklet with pictures to communicate



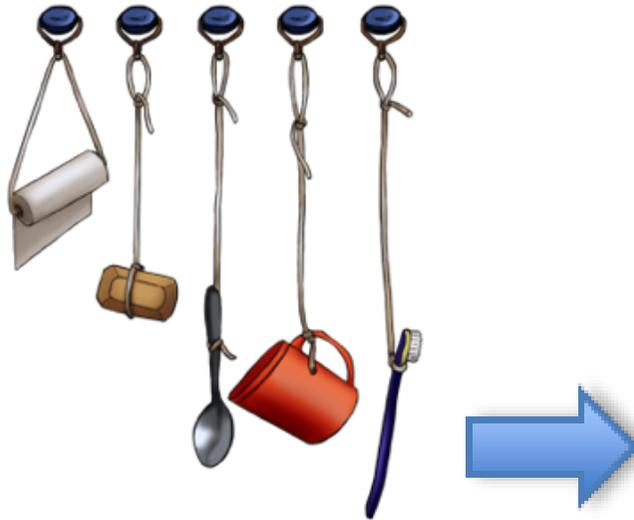
Card 26

Action:
attention points

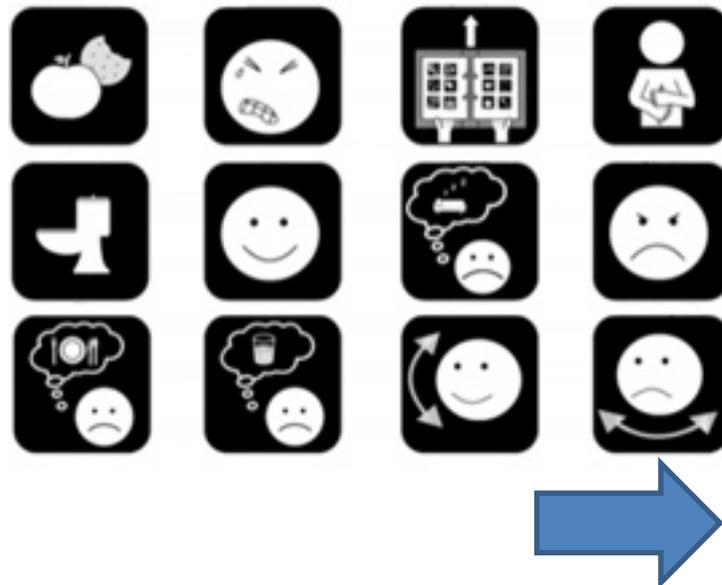
Card 27

Action:
attention points

Using daily objects to choose and communicate



Using a picture card to communicate choices or feelings



Self-care

The child with CP will become an adult with CP. Help the child become an adult who can live with their disability and be as independent as possible.

Families can do a lot to help these children carry out activities and participate happily in daily life. Even children with severe CP can often learn important basic skills.

Most important is that the caregivers and other family members learn not to do everything for the child. Help the child just enough so that they can learn to do more for themselves. For example, if the child is beginning to hold up their head, and to take things to their mouth, instead of always feeding them yourself, look for ways to help your child begin to feed themselves.

You can do the same for brushing teeth, dressing, washing and more activities of daily life:

Brush teeth in front of a mirror for the child to see their movements, while supporting the body.



Put the clothes in front of the child while sitting in the corner of the room. Help with words and if needed physically if child gets stuck.



Put your hand over the hand of the child to guide the movement of washing the body.



Make drawings that show the steps of washing the body. Let the child follow the steps, gradually more independent.



Look more advices about supporting self-care for a child with mild, moderate and severe CP on the Liliane Foundation portal.

Card 28

Action:
attention points

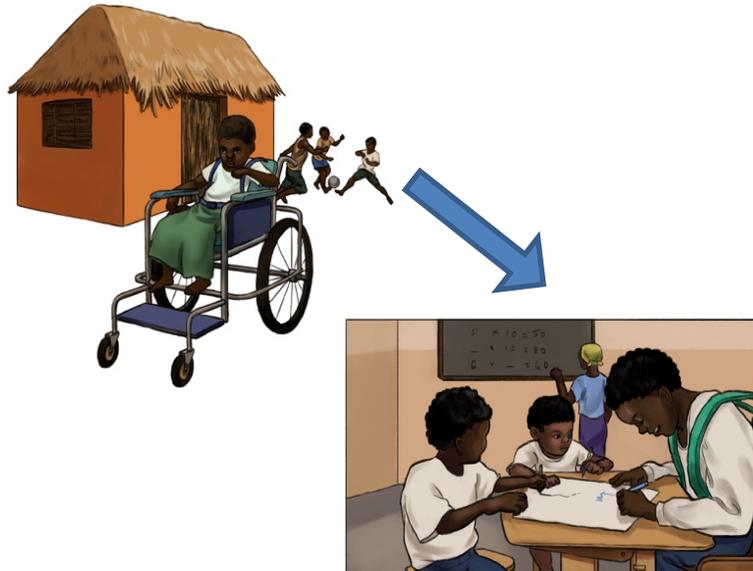
Learning and school

Help the child, to be able to go to school, learn, play with friends and move around the school. Work with the caregivers, teachers and head teachers to address the following:

10 action points:

1. All children want to be able to reach school: provide children with a disability (adapted) transport to school.
2. All children want to be able to enter and pass through the school: school buildings, furniture and grounds need to be accessible for children with a disability.
3. All children want to be able to visit the restroom: restrooms at every school need to be adapted for children with a disability.
4. All children want to receive 'honest' education: lessons and rules need to be adapted for children with a disability.

5. All children want to play: enable children with a disability to participate in sports and games at school.
6. All children want friends: teach children how they can be there for children with a disability.
7. All children want parents to help: stand up as parents for children with a disability.
8. All children want good guidance: train teachers how they can better council children with a disability.
9. All children want positive attention: children with a disability have the right to go to school.
10. All children want to just be a kid: let children with a disability advance and enjoy



Support for you

You have finished all the steps of the rehab cycle!
Repeat the steps to find out if there are new priorities.



If you have any questions, you can put them on the portal. You will receive an answer within a week from an expert team. You can put your question in writing and if needed, send a video or photo to support your question. You can find the portal here:

<https://connect.lilianefonds.org/default.aspx>.

CONTACT

Enablement

Antonie van Leeuwenhoekweg 38 A16

2408 AN Alphen aan den Rijn

The Netherlands

Phone: +3172 499 940

E-mail: info@enablement.nl

Website: www.enablement.nl



Card 30

Contact

Card 31

Colophon

These Flashcards are based on the CP app and is developed for the STEP project of the Liliane Foundation.



This was made possible with the support of:



When drafting the content of these Flashcards, several resources were particularly helpful:

Butterfly Basket Foundation (2018). *Development of children with disabilities through daily life*. Hanoi: Butterfly Basket Foundation.

CanChild (2018). Research in Practice: F-Words in Childhood Disability. <https://www.canchild.ca/en/research-in-practice/f-words-in-childhood-disability>.

Child-to-Child Trust (1992). *Child-to-child – a resource book – Part 2 Child-to-Child activity sheets*. London: Child-to-Child Trust.

International Centre for Evidence in Disability (ICED) (2018). *Getting to Know Cerebral Palsy*. Retrieved from:

<http://disabilitycentre.lshtm.ac.uk/key-publications/getting-to-know-cerebral-palsy/>.

International Centre for Evidence in Disability (ICED) (2018). *Display Materials Getting to Know Cerebral Palsy*. Retrieved from:

<https://disabilitycentre.lshtm.ac.uk/files/2013/11/Display-materials-Getting-to-know-cerebral-palsy-v1-lores.pdf>.

Liliane Fonds (2018). *Urgent action points to go to school*. Retrieved from: www.welcometoschool.org.

Multy-Agency International Training and Support (MAITS) (2017). *Caring for Children with Developmental Disabilities and their Caregivers*. Retrieved from:

<https://www.maits.org.uk/resources/>.

Multy-Agency International Training and Support (MAITS) (2017). *Working with Children with Developmental Disabilities and their Caregivers*. Retrieved from: <https://www.maits.org.uk/resources/>.

Rosenbaum, P., Gorter, J.W. (2015). The 'F-words' in childhood disability: I swear this is how we should think! *Child: Care, Health and Development*, 38(4), 457

463. doi:10.1111/j.1365-2214.2011.01338.x. Retrieved from: <https://onlinelibrary.wiley.com/doi/abs/10.1111/j.1365-2214.2011.01338.x>

Swinburn, K. (2018). *Aphasia Impact Questionnaire*. Retrieved from: <https://www.aiq-21.net>.

Vos, R.C., Becher, J.G., et al. (2013). Developmental Trajectories of Daily Activities in Children and Adolescents in Cerebral Palsy. *Pediatrics*, 132(4)

Werner, D. (2003). *Disabled Village Children (2nd ed.)*. Berkeley: Hesperian Foundation.

Zuurmond, M., Mahmud, I., Polack, S., Evans, J. (2015). Understanding the Lives of Caregivers of Children with Cerebral Palsy in rural Bangladesh: Use of Mixed

Methods. *Disability, CBR & Inclusive Development*, 26(2), 5-21. Doi: 10.5463/DCID.v26i2.414