



**CP-PACK**

Module 1

**TRAINEE BOOKLET**

# Knowledge about CP

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This is primarily a theoretical training module that will approach different aspects of the subject based on the latest knowledge about the brain and neuroplasticity. We consider, additionally, that parents and teachers contain a lot of valuable knowledge and skills that result from practical experiences. Therefore, the course will also be a place where participants (parents/parents, teachers/teachers and parents/teachers) get an opportunity to discuss and share their own practical experiences. This way, participants will be inspired by each other in how to translate the latest knowledge into praxis.

## **Goals**

The main goal of this module is to improve participants' knowledge about cerebral palsy – what it is, how it occurs and what can be done to compensate for accompanying difficulties. Specifically, we intend to:

1. Improve awareness of the most recent knowledge derived from research about how the brain works, and the complexity of the diagnosis.
2. Improve the understanding of CP in its aspects of motor- cognitive- and learning disabilities.
3. Improve the understanding of the special conditions of having a disability in adulthood.

## **Aim**

### ***In General***

Cerebral Palsy is a condition to which there is no definite cure. Nevertheless, the brain can be trained and, therefore, be able to work and function in a better way, increasing the ability to learn new skills.

The aim of this module is to increase the understanding of different essential aspects about CP.

## **Learning outcome**

With this module, we expect participants to be informed about CP based on the most recent knowledge derived from research. This includes knowledge about CP as a brain damage and how the brain works. Viewing CP as a brain damage, participants will also be aware about the complexity of the diagnosis and the understanding of CP in it's aspects of motor- cognitive- and learning disabilities. As such, participants will know that CP occurs within the specific child in it's own particular and personal 'edition', even though some traits may be common among children with CP.

Also, the participants will become aware with other parents' and teachers' experiences, acquire new/different perspectives upon their own situation and may be inspired by others when it comes to new initiatives and actions.

***For Parents***

Participants are aware that these are important issues in order to understand and meet their own child with CP and it's individual CP related challenges in every day life.

***For Teachers***

In general, participants will learn that it is possible and desirable to comply with CP related challenges among the students, if their work is based on updated knowledge about CP in order to identify and work with adequate pedagogical approaches, strategies and tools.

# Chapter 1

## General Knowledge about CP

### Learning Outcomes

The participants will know the latest definition of the diagnosis “cerebral palsy” and will understand the condition as a brain lesion to which there is no definite cure. The participants will know the etiology of the diagnosis and they will know about the wide range of symptoms that are possible consequences of the brain damage.

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#### Cerebral Palsy today

Today, cerebral palsy is regarded as a multifaceted disorder typified and marked by developmental disorders that have versatile affects within the enormous diversity and complexity of the brain. This implies that cerebral palsy must be described and defined as an ample complex condition characterized by great individual differences and bridging the overall range from motor to cognitive behaviour.

Despite of the fact that there is no definite cure for cerebral palsy, rehabilitation strategies, including training and learning programs, can often increase the capabilities of the individual child if provided in sufficient amount and within up-to-date best-practice. The main objective is to enhance the individual potential to live a full life by doing everything possible to surmount the impairments and realize new ways to compensate and thereby accomplish the tasks that comprise difficulties.

Rehabilitation strategies should be directed, if at all possible, at preserving and improving the developmental process through all its facets and stages at appropriate ages. Research demonstrates that directive techniques aimed at specific disabilities do not bring better results.

#### What is cerebral palsy?

By far, the greater numbers of the developmental malfunctions in the brain that lead to cerebral palsy occur before birth. A few characteristic types of brain damage establish the core contributory causes to a broad range of cerebral palsy cases.

These brain damages cause either the appearance of degeneration or crumbling of brain tissue, or some type of haemorrhages within the brain tissue, which result in varying degrees of damage of the nerve fibres.

These damages imply that the extremely complex communication materializing in the neural circuits is disturbed and damaged by disruption or regular destruction of the nerve fibres, thereby compromising the fragile interaction from neuron to neuron. Subsequently, injuries of this nature could have substantial influences on the fundamental function of the large-scale circuits in the brain.

Among the symptoms resulting from these types of brain damage are, most importantly, a reduced overall attention and capacity of sustaining attention. More specifically, people affected by these types of brain damage are lacking in capacity for completing a process, some degree of absent concentration and imbalance of tonus (tightening) in the muscles. Also, motor behaviour controlling balance and precision of single movements are affected. Studies on brain imaging indicate that the brain damages, preceding cerebral palsy, are often found in the deep-lying areas of the brain's white matter around the brain nuclei where supporting handlings of decoding sense stimuli are concentrated.

These fundamental processes systematize the global task of organizing, controlling and managing all the sense stimuli that is computed in the brain. The brain is a multisensory processor in which inputs from different senses complement, modulate, and interact with each other, regardless of the specific senses involved in order to select, regulate, increase or inhibit, integrate memory and simulate motor actions etc.

## Suggested Readings

Further material: [www.cp-pack.eu](http://www.cp-pack.eu) / Knowledge about CP

## Chapter 2

### General Knowledge about the Brain and Neuroplasticity

#### Learning Outcomes

The trainees will achieve a generic understanding of how the brain works in circuits and how these are not static or rigid, but quite reversible and they will understand the consequences of this knowledge on how to address the symptoms of Cerebral Palsy.

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The human brain contains approximately 120 billion neurons each assumed to be in contact with up to 10.000 other neurons within large-scale networks that span over several areas of the brain. The single synapses within the active circuits develop and work in interplay with other synapses to adjust the neural connectivity across the brain.

The whole nervous system, including the brain, continually undergoes structural and functional modifications adapting to changes in both inner and outer environment and to new information to be processed and stored.

The fundamental systemic mechanism of the brain is characterized by neuroplasticity, i.e. the capability of the neural circuits to change and remodel in accordance with learning and new experiences. The concrete functional shaping is generated by altering the number of active synapses and adapting the strength of the single synapses.

The circuits of the brain are not static or rigid but, quite the opposite; they are extremely adaptable, permanently changing to mirror the modifications that emerge in the individual neurons. The neurons, on their part, respond to changes in our body and in the outer world. Furthermore, the adjustments of brain circuits represent and echo that an individual, in one way or the other, is in continual action. Even in so called states of resting or daydreaming the brain is never idle – it is ready to remodel at any time. The fundamental property of the brain is plasticity, i.e. the ability to change in accordance with inner and outer demands. As individual beings we are persistently on the move.

Sometimes we are close to other beings (people or animals), other times we move away from them. In the world of hands-on we move to touch objects and then move

away again or, as we sense a taste, we are also bound to experience that the taste goes away. Being engaged in a conversation implies that it will come to an end. Sensory inputs from the body parallel different emotions. In fact, the full context in which the brain is situated is under constant changing either from pre reflective influence or from the stimuli of our actions. The circuits of the brain develop permanently in an appropriate way. So, in terms of biology, there is no off switch in the brain.

One pivotal aptitude of the brain is the feature of learning. It implies functional changes within the circuits, which has the effect of strengthening the synapses. A more powerful synapse is one that improves in firing and so facilitates the interaction of neurons. Training and learning are, in this respect, two sides of the same coin. Also the capacity of memory originates in this process. Memory is information kept within stable networks and is retrievable when synapses open up the network by being activated.

### **Suggested Readings**

Further material: [www.cp-pack.eu](http://www.cp-pack.eu) / Knowledge about CP

## Chapter 3

### Training and Learning Based on Neuroplasticity

#### Learning Outcomes

The participants will know which theoretical aspects must be taken into consideration, if any remaining and positive results from training shall be expected. On this basis, participants will learn about ideas and tools to implement training in many everyday activities at home and in school/institution.

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Intensity and sufficiency Children with brain damage require multi-faceted training and learning strategies. The present economical resources do not allow offering sufficiently intensive and persistent motor and cognitive training. Therefore new technology must be taken into account in order to concentrate the intensity of the rehabilitation programs.

Learning and training is a process that, irrespective of the method of learning, is imparted through the body by means of the senses and motor function. At the core of this approach is the understanding that awareness, cognition and movement are really indivisible, and that the development or recovery of ability within any of these domains requires the integrated co-operation of the individuals with impairments and their brain in all of these aspects of rehabilitation. This signifies that isolated impairment in “movement” or “awareness” or related “cognition” is a human impossibility.

Motor function and muscular activity are entirely controlled by ‘feedback’ from our bodies and brains, and so, movement control is guided, very directly, by the cognitive resources that guide all of our behaviours. They will be weaker or stronger, enabled or disabled together. Neurological processes that control the flow of cognition and thought are not really different from those that control the flow of movement — and, in fact, are totally and utterly entangled.

Inducing the brain’s plasticity in order to drive beneficial changes requires a carefully laid out individual learning or training program with precise stimuli delivered in a proper sequence with accurate timing. To obtain this, the training program must be:

1. Intensive - and continuous over a sufficient period of time.
2. Repetitive - and progressively challenging.
3. Executed with total commitment - and paying close attention.



Sensory experiences apply a powerful influence on the function and future performance of neuronal circuits in the brain. Remodelling of synaptic connections is believed to be one mechanism by which neural circuits store information about the sensory world. Learning and daily sensory experience leave minute but permanent marks on neural connections and storing of lifelong memories is confined to such large stable connected networks.

## Learning

The expansion of the neural networks is a transient occurrence that serves to expand the pool of neurons that respond to behaviourally relevant stimuli so that neural mechanisms can select the most efficient circuits to accomplish the task.

To be more precise, neural plasticity is used to recognize the minimum number of neurons that can accomplish any given task.

Learning results when individuals select the most efficient circuits and essentially relate these neural responses with the appropriate behavioural response.

The steps to follow in learning and training comprise the following:

1. Initial learning generates a population of new connections in the neural circuits
2. This population is then reduced to a small subset; and
3. Skilled performance is maintained by this small but stable subset of new connections

The conclusion is that the brain is plastic and dynamic and that it functions in large-scale complex networks – (circuitative). Furthermore, there appear to be no true difference between cognition and motor behaviour – they share the same subjacent systems (circuits). Obviously there are areas in the brain that may be “critical” for a particular behaviour, but the behaviour itself arises from combined actions of many areas.

Training and learning programs that motivate simultaneously body and thought are, therefore, well suited to improve ability in the child with cerebral palsy.

## Suggested Readings

Further material: [www.cp-pack.eu](http://www.cp-pack.eu) / Knowledge about CP

## Chapter 4

### Food - the Importance and Effect Related to Neuroplasticity

#### Learning Outcomes

The participants will obtain increased awareness about dietary effects on the brain and practical advice about the implementation of a healthy diet.

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Just as the muscles need protein to be able to gain from training, the brain needs a variety of important substances to be included in the diet (sometimes exclusively from the diet: vitamins, minerals, essential amino-acids and essential fatty acids, including omega-3 polyunsaturated fatty acids) to be able to develop and function optimally. For a long time, it was not fully accepted that food can have an influence on brain structure and function, including cognitive and intellectual performances. But most micronutrients (vitamins and trace-elements) as well as macronutrients (glucose, amino acids and fatty acids) have been directly evaluated in the setting of cerebral functioning.

So, while the brain is active – which means around the clock, all life through – it needs nourishment and energy.

The greater part of the nutrients that the brain uses are produced in the brain itself with the remaining deriving from other organs in the body. The necessary condition for the correct nutrients to be produced is the adequate access to precursors of these ingredients. There is only one source from where the precursor nutrients can enter the organism, and that is our diet.

“The belly rules the mind”. This is certainly true when it comes to the brain and the nutrients needed to develop the neural networks and increase the efficacy of the synapses. Fortunately, it is quite easy to obtain the right ingredients as most of them are found in what could be characterized as “ordinary” food.

Two main aspects exist in relation to diet and cerebral palsy:

1. Impact from the congenital brain damage on intake and metabolism: A brain damage often has an effect on the metabolic control resulting in lack of intake from the food being digested.
2. Optimal learning and plasticity depends on special precursors in the diet: This is true for all brains.

The relative quantity of specific nutrients might affect cognitive processes and emotions. Dietary factors can have a direct influence on neuronal function and synaptic plasticity and research have revealed some of the vital mechanisms that are responsible for the impact of diet on brain health and mental function.

It has been demonstrated that the rates at which brain cells produce a number of the most important compounds, for example the neurotransmitters serotonin, dopamine, and acetylcholine - depend on brain concentrations of their precursors.

Infants with significant prenatal brain damage have increased nutritional requirements in the first postnatal year so these children require a greater-than-average energy and protein intake to achieve appropriate growth rates or to catch-up growth in the first year.

Just like a muscle needs protein to be able to gain from training, the brain needs the right precursors of substances to be able to learn and develop. The three fundamental nourishment needs in relation to the brain are:

1. Building materials,
2. Control of mood, motivation and learning capacity,
3. Source of energy.

### Questions for reflection

- How often and what type of food does the child eat during the day?
- Does the child eat breakfast (and if yes, what kind of breakfast)?
- Does the child eat a great variety of food, or is he/she very fussy about what he/she eats?
- Does the child seem tired or moody throughout the day?
- How well does the child's glucose-regulation work. Could it be monitored for a few days?
- How many of the micro- and macronutrients does the child eat on a regular basis?
- What kind of fats and proteins are the most prevalent in the food of the child?
- Is it relevant to make any changes about the "type and timing" of the meals?
- Do we ever notice any difference in mood and behaviour of the child that could relate to intake or avoidance of a particular food-item?

### Suggested Readings

Further material: [www.cp-pack.eu](http://www.cp-pack.eu) / Knowledge about CP Food, the importance and effect related to neuroplasticity (by Kirsten Caesar) - [www.cp-pack.eu](http://www.cp-pack.eu) / Knowledge about CP Figure showing the core ingredients regarding the brain (by Peder Esben Bilde) - [www.cp-pack.eu](http://www.cp-pack.eu) / Knowledge about CP

## Chapter 5

### Behavioural and Cognitive Difficulties and Compensation Strategies in Relation to CP

#### Learning Outcomes

The trainees will gain a better understanding of how sensory input is processed. This session will cover a brief walk through the seven senses with emphasis on the proprioceptive sense, the vestibular sense and the visual sense, and how it affects a child with CP when sensory integration does not work properly. In addition, participants will gain insight of some of the compensatory strategies that can be used and integrated into daily life.

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Sensory Integration is not an either/or matter. We don't have perfect sensory integration or none at all. None of us organizes sensations perfectly. If the brain does a poor job of integrating sensations, this will interfere with many aspects of life. There will be more difficulties and less success and satisfaction in life. Sensory Integration takes place unconsciously, by organizing the impression from all 7 sensory systems (balance and movement, muscle and joint, sight, feel, hear, smell and taste) and giving meaning to what we experience by sorting all the information we receive and selecting what to focus on. This makes it possible for us to act or respond appropriately to the situation we are in and that is the foundation on which learning and social behavior rests in.

Many children with CP have difficulties in terms of developmental disabilities due to insufficient processing of sensory information. These difficulties can sometimes lead to major limitations in their learning and mastery of activity in daily life. In this session, the main focus will be on sensory function, the sense of touch and the proprioceptive and vestibular sense.

Children who are hypersensitive (overly sensitive) in the tactile area, do not like clothes that are tight, have marks or seams. Often they have a few favorite things that they want to wear all the time - jogging pants and soft shirts. They hate and fear getting their face washed, getting dirty hands, and getting their nails clipped, etc. They do not like to touch greasy sticky stuff like clay, finger paints, etc.

They can get very upset over an unexpected touch and it can cause trouble distinguish between threatening and non-threatening touch.

Eating Problems can also be caused by tactile hypersensitivity. Some children with CP do not like to get food with a certain consistency in the mouth. Tactile sensitive children have often difficulty in moving from milk to solid food, and they often get food stuck in the throat. Problems with sensory processing of the tactile area can also cause speech problems - the child may have problems shaping the sounds right because of difficulties interpreting and processing sensory impressions from the mouth and being able to feel the speech organ positions.

The proprioceptive sense, in children with CP, can be influenced by disturbances in the sensory process because the child gathers atypical sensory experiences because of motor disorders. It may be disturbances in the sensory system, leading to reduced sensory information from muscles and joints, causing difficulties in perceiving, processing and interpreting sensory input, focusing on relevant sensory input, placing them in a relevant context and being able to ignore irrelevant sensory input.

Children with proprioceptive dysfunction spend a lot of energy to concentrate on each movement, because although the brain may know what to do, they can't figure out how to make their body do it. They are more dependent on vision than others, knowing how much pressure is needed to complete a task for example hold a cup of water, hold and write with a pencil, turn the page of a book, etc. The ability to hold and maintain one's postural muscles and responses, giving you a sense of security during movement is very often difficult for children with CP. For them, it can be difficult to stand still for a long time; they may have a great need to support their head, hold a hand or both under it - or even put your head on the table to read and write. These children get fatigued faster than other children and may need many breaks during the day. Children who are unable to move and use their body effectively like others can, thereby, become frustrated, give up, and lose self-confidence. The vestibular sense provides information using the inner ear about balance and movement, and where our body "is" in space. It is the vestibular sense that can tell us whether we are sitting down or standing up, falling, and so on. The vestibular sense detects the body's ability to keep itself up against gravity, the body's equilibrium, which means that we can keep the body upright when we are walking and stabilize the eye, while the head is in motion, which enables us to maintain a stable visual field, so the things we see do not flicker when we move.

Because of intolerance to moving, the child may feel discomfort during fast movements, which, for example, can result in motion sickness.

Next to breathing, so is balancing security our main focus: to maintain attention to read a magazine or listen carefully to a radio broadcast, requires that we have a postural (balance) security. The same requirement applies for us when we are going to perform fine motor activities such as eating or writing. First, we secure ourselves

from falling, or restore balance to feel safe and physically comfortable. Only then we are able to read, listen or sew.

Visual perception is the process which ensures that we are able to perceive and interpret visual impressions. Many children with CP have visual perception difficulties. The child will be slow or unable to perform tasks, especially when the child is going to use an object or performing tasks that require cooperation with both hands. It may be difficult to brush one's hair while looking in the mirror or put on an elastic in the hair, put on a necklace or to take toothpaste on the toothbrush. Those things can be a big challenge. Clothes and buttons require also good visual perception. Coloring, puzzles, developing reading and writing skills can also be affected by poor visual skills. Just as it can be difficult to find your way around in the neighborhood or find things in a drawer. It can also be a challenge to learn to use computer keyboards and telephone. Play and leisure activities may also be limited by visual perception difficulties.

Arousal can be explained as a feature of the nervous system that describes how "awake" (alert) a person is in order to concentrate and stay focused on a task, that is appropriate for optimal learning.

Many children with CP can have difficulties obtaining, maintaining and changing arousal appropriate to the activity or situation that they are in. If you imagine that your brain and body is like a car engine, sometimes it runs too fast (high speed) and sometimes it runs too slow (low gear) and sometimes it runs just right. Through this engine analogy we can teach both children and adults with CP strategies to self regulate "their engine" so that parents, teachers and educators can give children with CP optimum opportunity for learning.

## Suggested Readings

Further material: [www.cp-pack.eu](http://www.cp-pack.eu) / Knowledge about CP

## Chapter 6

### Most Common Cognitive and Behavioural Problems and Strategies for Compensation Related to CP

#### Learning Outcomes

Participants will acquire up-to-date knowledge about common cognitive problems associated with CP drawn from recent, relevant empirical studies. Participants will become aware of how learning problems arise from individual cognitive problems but emerge in particular social settings and learning environments, where they are shaped by the organisation of the learning activities and the presence or absence of the right support of the child.

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This session will cover the relations between the brain lesions associated with CP, the most common cognitive problems and how they are expressed as learning problems that need to be addressed by teachers and parents in cooperation.

The cognitive problems associated with CP can be separated into non-specific and specific cognitive problems. The non-specific type of cognitive problems covers fatigue, varied performance level and slower information processing. Non-specific cognitive problems can be manifested in all types of activities. Even though they may be manifest in a daily basis, they are among the most invisible consequences of CP and are often misunderstood as laziness, reluctance or stupidity of the child.

In addition, CP is associated with a group of specific cognitive problems. The particular constellation and severity of cognitive problems vary a lot between children with CP. Specific cognitive problems cover visuo-perceptual and visuo-constructive problems, problems with attention, memory and executive problems and communication problems. In this session, special attention will be given to specific cognitive problems in attention and executive functions.

Impairments in attention and executive functions give rise to problems in many areas of learning, but often they are more pronounced in particular situations and school subjects than others. Attention is a compound function that covers both the ability to direct and shift attentional focus. Other parts of attention are the ability to control and maintain attention and to work with material within the attentional system. The last two are also considered part of the executive system. The executive

system is another compound function that covers many different sub-elements: planning, monitoring, shifting, working memory, initiative, inhibition, and emotional regulation. They are subserved by

different neural networks in the frontal and subcortical part of the brain and because they draw on information from many parts of the brain, problems in executive

functions are common in children with CP. Often, they are most pronounced in behavioural problems: impulsive or interruptive actions, uncontrolled emotional reactions, chaotic behaviour, lack of flexibility, lack of ability to organize school work and many more. Executive functions mature late and must always be evaluated in relation to the age of the child. Problems in attention and executive functions often cause problems in both learning and social participation.

It is important to know about the cognitive impairments associated with CP, because the knowledge may help to interpret the child's way of acting. However, the cognitive impairments are only one side of the learning problem. The other side is how the learning of the child is organized through the teacher's demands and structural support. Cognition can be supported or constrained by both brain lesions and the learning environment. The learning problems experienced by many children with CP arise from a mismatch between the child (with brain lesion and cognitive impairments) and his or hers learning environment (without the right support). Barriers for learning are not solely in the child, but exist in the relation between the child and the learning environment. If supported rightly, the cognitive activities of the child have the potential to give feedback to the neural system and change and develop it. However, the development of both cognitive functions and neural processes are dependent on the proper support of the child's participation in learning activities.

The typical learning problems of children with CP emerge and evolve in relation to the pedagogical and didactic structure and demands throughout the child's school trajectory. At times, the learning goals will be similar to same-aged peers without CP, at other times the learning goals need to be adapted to the current developmental level of the child. Relevant learning goals can be reached by roundabout ways (e.g. computers for writing) or scaffolding (e.g. the teacher structures the work process for the child that cannot identify the steps on its own).

In primary school, it will often be necessary to evaluate the adequacy of the teaching and the teaching material in relation to the cognitive challenges of the particular pupil with CP. The child with CP might work towards the same goals as his or her peers, but the teacher might need to adapt the child's learning activity according to the child's particular impairments. For example, due to motor, visuo-perceptive or visuo-constructive impairments, handwriting is often more strenuous for children with CP, over and above the challenges experienced by all new writers. If the goal of the activity is to practice calculation rather than the writing of numbers, then



child might solve the exercises orally, on a computer or by getting someone else to write the solutions. Another typical challenge can be found in children with executive dysfunctions who need explicit instructions and training in how to get ready to learn. If the child with CP has attentional dysfunctions, support of the child will include a reduction of distracting stimuli.

In middle school, new subjects and an expanding curriculum increase the challenges experienced by children with CP. A slow writer or slow reader might be supported by the introduction of new aids that enable the child to focus its effort on the content of the material. The slow information processing might become more salient with rising demands and the teacher may need to adapt the learning activities of the child accordingly, either by granting extra time or by reducing the content to be covered by the child, e.g. amount of reading or number of exercises.

Demands on the child's executive functions usually increase through middle and secondary school, as the child is required to work more independently and with more complex exercises. The executive dysfunctions of many children with CP become increasingly salient and require support and/or explicit teaching of how to plan and work with larger assignments.

### **Suggested Readings**

Further material: [www.cp-pack.eu](http://www.cp-pack.eu) / Knowledge about CP

## Chapter 7

### Pain/Pain Management – How to Deal and Compensate

#### Learning Outcomes

The participants will increase their knowledge about pain; its complex, psychological nature and how different elements influence the experience of pain. This knowledge will make it easier to understand the specific child's experience and the way he or she handles the pain.

The participants will know complementary treatments and to influence the way the child will cope with pain and, by that, help the child in decreasing the feeling of pain.

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Because of inappropriate weight on joints, inappropriate ways of moving and working with the muscles, involuntary movements, uneven growth of the spine, etc., some children with CP may develop pain which can be acute, but can also develop into chronic pain.

This session will present a short description of the difference between acute and chronic pain, the subjective nature of the pain as well as how it will be able to influence the child's sleep, appetite, social life, physical activities, school life and other everyday activities. Also a pain scale and a pain figure will be introduced as tools that can help when talking to a child about pain.

Most people know the feeling of an acute pain, i.e. the pain one feels when visiting the dentist, having a blood test or falling and hurting oneself. But for some people – and among these are some children with CP – it becomes a condition growing up and living with chronic pains, which means pain lasting more than three to six months.

These feelings of pain can become very serious, resulting in an affection on the ability to sleep through the night, on concentrating on other things during a day, and on the motor and social life and development, as the pain may prevent the child from physical activities and playing with peers as well as being able to fully concentrate on what is going on in the classroom, with the consequence of reduced learning ability. This means that the child is in risk of feeling different and left out as well as developing the feeling that some experiences will be lost as a direct result of the pains. The feeling of pain is subjective. It is very different from person to person

to which extent the perceived pain is registered. Some people have a lower pain threshold than others. Therefore it is not

possible to perform a direct measurement of a pain, the only way to get a knowledge about how a person experiences his or her pain, is to interview them about this, and using a pain scale or figures where the child gets the opportunity to mark the pain. In these cases it is very important to understand how the age of the child and the mental development influences the child's ability of thinking and experiencing pain.

Every child is unique and has its own personality, its own resources and its own vulnerabilities as well as its own handling strategies – exactly as the expression of the cerebral palsy condition appears very differently from child to child.

The most important factors that may increase the child's feeling of pain will be explained. Among these are fear, depression, loss of control, focus on the pain. Also the way the surroundings react and handle the child's pain influences the way the child experiences pain. In order to meet the needs of the child and to support it in the best possible way, it is important to investigate how the pain influences the individual child. In which situations does the individual child feel that the pain is influencing in a negative way and how does people around the child respond to this? In other words, both the surroundings and the psychology of the child have an impact on the way the child experiences and is able to cope with the feeling of pain. This means that there are some psychological factors that will affect the feeling of pain both in a positive and a negative direction.

Some aspects with an impact on how intense the feeling of pain is for the individual child are the ability of coping and the way the child acts in relation to the pain. It is known that a lack of understanding of the causes of the pain, and/or fear or insecurity of the child or the parents related to the pain, can increase the feeling of pain, like when feeling helpless and with negative thoughts. Opposite to that it is known that distracting strategies can cause a considerable pain-killing effect (i.e. reading a story, watching television, talking to a pet animal or drawing), as well as being comforted and getting the feeling that the parents are understanding and supportive. The focus in this session will be on which exact factors will be able to decrease the feeling of pain (i.e. distraction) and on complementary treatments that will be mentioned (i.e. visualization, hypnotherapy, cognitive therapy, physiotherapy, white noise and acupuncture).

Depending on the age of the child and their cognitive abilities, it may be relevant to present a brief introduction to the parents about visualization and how the child can be supported by this technique – either by providing a CD containing pain visualization for children, or by visiting a psychologist who can produce a visualization CD for the specific child.

It is of great importance that the child learns to recognize the pain – learn how to listen to the signals from the body and take care of him- or herself. The child must know the consequences of overloading the body and how this may cause even more pain, and learn how to feel his or her needs and limits and become able to express what is acceptable and what is not.

## **Suggested Readings**

Pain/pain management

By Charlotte Jensen: [www.cp-pack.eu](http://www.cp-pack.eu) / Knowledge about CP

Further Material: [www.cp-pack.eu](http://www.cp-pack.eu) / Knowledge about CP

## Chapter 8

### Aspects of Developing into Adulthood, What is Special Concerning CP and other Disabilities When Growing into Adulthood and Getting Older

#### Learning Outcomes

The participants will know the importance of acceptance of the disability in order to be able to live an adult life as an active member of society.

The participants will know the threats to the mind and the physical and biological body of growing up with a physical disability.

The participants will learn – inspired from a discussion in the group – how these threats can be met before they take over.

#### Chapter Contents

To grow up and into a life of adulthood with a disability and at the same time to retain an individual personality intact is quite a challenge. It involves different steps of awareness and acknowledgement, which all are essential and necessary, to move ahead in the process of learning and accepting to live with cerebral palsy.

One of the most significant steps is to allow for mourning. Both the individual with disabilities, the family as such and in particular the parents are in a state characterized by grief when it becomes a fact that the diagnosis in question is cerebral palsy. Mourning is the first step to take, to make life with cerebral palsy as meaningful and comfortable as possible. This process is essential for both parents and child to prepare for the next step aiming at acceptance and recognition of the disability. If this process of self-development is neglected many will be induced to block out the fact of having a disability, which could result in another situation where motivation and focus are so narrowed down to the attempt of being normal that demands and expectations on the child with disabilities become unrealistically high. This often causes numerous daily defeats and frustrations. According to the research it is of vital importance for both parents and the child with disabilities to recognize the limitations that exist because of the impairment and this will only be possible if the process of selfdevelopment receives necessary attention.

By recognizing and accepting the impairment – its strong sides and also the limitations – it will become possible to live with cerebral palsy and to participate within social interaction and be an active member of the local community.

## **Medical Conditions and Ageing**

Before the Second World War, only a small number of children with cerebral palsy survived to adulthood and an even smaller number achieved to make it into old age. At that time, the standard showed an evident gap between life expectancy for people with cerebral palsy compared to people without disabilities. Nowadays, primarily due to improvements in medical care, development of rehabilitation, and assistive technologies, the majority of children with cerebral palsy live into their adult years and the gap in life expectancy is more or less eliminated. Living this long with a disability often involves an increase in medical and functional problems – some of them beginning at a relatively early age – including the following:

### **Premature Aging**

The majority of individuals with cerebral palsy will experience some form of premature aging by the time they reach their 40s because of the extra stress and strain from the condition. The developmental delays seen as a consequence of cerebral palsy keep some organ systems from reaching their full capacity. Organ systems such as the cardiovascular system (the heart, veins, and arteries) and pulmonary system (lungs) therefore have to work harder and they age prematurely.

Research show that the premature aging factor in people with cerebral palsy could range from 1.5 – 5 compared to normal aging.

### **Depression**

The rate of depression is approximately 25 % higher in people with cerebral palsy. There seems to be no obvious relation to the severity of the disability, but rather in how well people with cerebral palsy cope with his or her disability. The extent of emotional support, how good they are at coping with frustration and stress, and whether or not they have an optimistic outlook about the future, all have a significant impact on level of happiness and exclusion of depression.

### **Pain**

Living with pain often goes unrecognized by professional healthcare people because many individuals with cerebral palsy may have experienced some degree of pain right from birth and therefore do not comprehend the condition as pain. Others may

not be able to describe the extent or location of the feeling of pain. In cases where pain is managed properly, the condition often averts becoming chronic.

### **Pain, Fatigue and Weakness (PFW)**

Many adults with cerebral palsy at one time or the other experience what is known as PFW, a combination of pain, fatigue, and weakness due to overuse or misuse of the body because of muscle abnormalities, bone deformities, and arthritis. Fatigue by itself is often a challenge, as individuals with cerebral palsy use three to five times the amount of energy that people without disabilities use during their daily life to move about.

### **Additional Medical Conditions**

Adults with cerebral palsy have higher than normal prevalence of secondary medical conditions, such as hypertension, incontinence, bladder complications and dysphagia. Scoliosis (curvature of the spine) is seen in some cases to progress after puberty, when bones have matured. Also luxation of the hip appears in up to 12- 15 % of the children. People with cerebral palsy have an overall higher incidence of bone fractures.

Adults with cerebral palsy should attend regular visits to their general practitioner to make a point of on going evaluation of their medical status. It is important to have physical complaints analysed to make sure they are not due to an underlying condition. For example, adults with cerebral palsy are likely to experience PFW, but PFW also could result from an undiagnosed medical condition that might be treated.

Today it is a fact that increasingly more individuals with cerebral palsy than before outlive their families and caregivers. Consequently, the issue of long-term care and support should be taken into account and planned for in due time.

### **Suggested Readings**

Further material: [www.cp-pack.eu](http://www.cp-pack.eu) / Knowledge about CP



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