Erasmus MC
Universitair Medisch Centrum Rotterdam

Sophia Kinderziekenhuis

Kinderchirurgie
Kinder- en jeugdpsychiatrie

Growing up after a serious illness

The possible long-term effects on school performance

For children who have been seriously ill, long-term memory or attention problems can occur. We would like to give you some tips on how you, your child, your child's teacher or counsellor can deal with this in a more effective manner.

CHIL Team

In the Surgical Long-Term Follow-up Team (CHIL Team) we monitor the growth and development of children with either

- (severe) congenital pediatric surgical disorders
- or children who have received extensive treatment in the intensive care unit

From our contact with parents and children, we have found that there is a need for advice on how to deal with the cognitive limitations in this specific group of children (cognition: the extent to which you are able to absorb and process knowledge and information). The situation can lead to uncertainty and incomprehension at home and at school, which is in part due to unfamiliarity with the medical situation and the learning problems that can ensue. This can cause further problems for a child, in addition to the problems that they may already be experiencing.

Research into long-term consequences

Due to new medical developments, more and more newborns can survive a period of very serious illness and intensive care treatment. Although the direct results of such a period are constantly improving, little was known about the long-term results until recently. By following these children in their childhood years, we have been able to learn much about their growth and development.

Children treated with ECMO or born with diaphragmatic hernia
Compared to healthy peers, twice as many children treated with Extracorporeal Membrane Oxygenation (ECMO) or born with a diaphragmatic hernia (hole in the diaphragm) have problems at school later in life. Their intelligence however, is generally within the norm.

Why there might be issues at school was unclear for a long time. However, it was recently discovered that the problems at school may be caused by a risk of specific deviations in the development of the brain. The hippocampus - the centre for memory in the brain - seems to be especially vulnerable to a period of severe illness in the first phase of life. This vulnerability leads to an increased risk of memory problems in later life, which can have potentially severe consequences for school functioning.

Also, we see issues with attentiveness as well as occasional issues in executive functions, which are higher cognitive processes such as choosing, deciding, judging, reasoning, organizing (in order to be able to plan) and leading activities. Sometimes we only notice these problems, such as memory problems, when a child reaches a new stage of development as they have no need for the affected function until a later phase of their development ('growing into deficit'). For example, we can only notice mathematical problems once a child starts doing mathematics at school and a problem reveals itself.

We now believe that the problems in school may be a result of a child being seriously ill in a critical phase of its life: a phase in which, among other things, the brain is undergoing full development. It is possible that this development is disturbed by illness and can cause learning disabilities at a later date. The extent of the disability or (cognitive) limitations can vary from one child to another. The majority of these children do not experience any limitations.

Treatment
Unfortunately, there is still a great deal of uncertainty about the treatment of these long-term problems. Research has been carried out at Erasmus MC-Sophia into the effect of online memory training (Cogmed). In 43 children who had been treated with ECMO and/or were born with a diaphragmatic hernia, we investigated whether following this training would improve attention and/or memory. The research shows that this type of training for these children can be useful to improve visual-memory problems. Unfortunately, the training does not solve all the problems that these children have, meaning it's not effective for every child.

Other conditions
There are also indications that children born prematurely or born with a complex heart defect may be at risk for memory problems. However, it is still largely unclear whether this statement is consistently valid and what exactly the cause is in the various groups of children. Erasmus MC-Sophia is in the process of investigating this as well.

Memory problems

Memory problems are relatively common in the children we follow. The types of problems can differ depending on the age at which a child was treated as well as various other things. For example, children treated immediately after birth may have difficulty remembering and retrieving what they have learned. Another example is that children treated extensively in intensive care at a later age tend to forget things learned in the past and have to re-learn things again. Or they might remember what they have learned in the past but have difficulty absorbing new concepts. Memory problems often present themselves not only when remembering and retrieving learned information, but also when trying to meet expectations and demands at school. This can include tasks such as doing homework, following instructions and learning and processing new information. The different problems are related to the different phases of the memory process, specifically retrieving, imprinting and recalling information. This means that learning will have to be done in a different manner, depending on which part of the memory is affected.

Tips for dealing with memory problems:

- Attract the child's attention by using something tangible or visual. Play on the child's different senses and try to identify and use the sense that seems to be the most effective in receiving information.
- Communicate the lesson material actively and vividly.
- Be concise.
- Make sure you have a clear core topic in the lesson and connect the rest of the material to it.
- Provide links between new information and existing knowledge.
- Place the information in a relevant context or associate the subject matter with a subject that is of interest to the child.
- Use so-called 'cues' or clues (e.g. special words, examples, visual aids) or let children think of 'cues' themselves to support the retrieval of information from their memory.
- Teach the child how to divide the material into smaller pieces.
- Ensure sufficient repetition of the lesson material, including asking questions.
- Use multiple choice questions, if possible, as it's easier to recognize information than to recall it verbally.
- Plan tests at the beginning of the day and consult with colleagues to ensure that there are not too many tests on the same day.
- Encourage the child to use its own strategies like repeating new material in writing or by summarizing, categorizing and visualizing, but don't make it too complex.
- Teach children to use tools for reminders, such as a diary, notes, smartphone and/or a checklist.
- Allow the child to use tools such as an alarm watch, calculator and tablet.
- Have the child keep a 'to-do-list' and/or a schedule, and check (or have a fellow student check) whether the child fills in the list or schedule after each lesson.
- Give the child a folder with the daily schedule and fixed activities. Some children might also need a list of names/photos of teachers and/or students.
- Consider using a memory training course to improve memory, especially if there are visual-memory problems.

Attention problems

Attention problems are also relatively more common. For example:

- Many children have problems sustaining attention; i.e., staying focused on their work and listening for long periods of time. As a result, the children have problems performing tasks at school and following classroom explanations.
- Other children have difficulty dividing their attention. This could be between different tasks such as listening and taking notes at the same time.
- Children may also have difficulty with selective attention. Being able to focus their attention on a particular task without being distracted by environmental factors. Sometimes children can no longer respond selectively to stimuli, as well as showing stressful behaviour and/or having difficulty distinguishing between main and side issues.

Tips for children with attention problems:

- Provide a low-stimulation, predictable environment.
- Reduce unnecessary environmental influences such as background noise as much as possible (e.g. by using headphones or earplugs).
- Provide a place in the classroom where the child is distracted less (not by the door or window, nor at the front as the child tends to look back if something happens behind him).
- Place the child near classmates who are less distractive.
- Have the child only put the essential materials on the table.
- Present clear tasks, give clear directions and give the child an overview of the tasks to be completed.
- Limit the amount of new material presented. Short tasks allow the child to retain attention and complete the task so that he or she has a successful experience.
- Support the explanation in a visual way and write the homework on the board.
- Make eye contact and use attention triggers such as 'look' and 'listen'.
- Ask questions to check that the child has heard and understood the information.
- Let the child listen during the lesson and then give the instructions later briefly in writing. If the child takes notes, check that the notes are correct.
- The child should take a short break every now and then. Be creative in offering variety.
- Consider using training to improve the child's concentration.

Other problems

In addition to aforementioned problems, other problems may present themselves, such as issues with information processing, planning and organizational problems, trouble with tempo or difficulty in showing initiative. The psychologist can give you ideas on how to deal with this at home or at school.

Is more help necessary?

It is impossible to be complete with regards to all information on this subject. We have therefore chosen to limit ourselves to the most common problems. However, we can occasionally provide additional advice after an individual examination of a child.

You can discuss problems at school with the teacher. The teacher can, in turn, call upon the school's internal counsellor for expert advice. Each school has an educational support service, which supports the teacher team, the pupils and their parents.

For questions regarding other matters, please contact your doctor. He or she will be able to answer or refer questions, as well as being able to identify the signals of a problem for you. You can also ask for advice at a Youth and Family Centre (CJG) in your neighborhood.

If you have any questions, you can also always contact one of the psychologists on the CHIL team.

Contact

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