Cerebral palsy

A parent's perspective to help others understand cerebral palsy, some early signs and what things might help support you and your family.

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This booklet is to introduce you to the topic of cerebral palsy

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Why I made this booklet

My name is Sarah and I am a parent of four children. When my twin daughters were born I got into the rhythm of being a parent but did notice that the girls weren't developing as I would expect. It was not obvious at the time, but they weren't sitting up when my first child would have been, they weren't saying as many words, or pulling themselves up to stand.

I did lots of googling and trying to get help but there was not much out there to explain about cerebral palsy, some of the investigations or things to think about to help.

This booklet is to try and help other parents and professionals, think about cerebral palsy and different things to support and help. However, please remember that I am a parent, I am not a medical professional and this is just a starting point for your journey.

I want to make it a bit easier for you, when things were quite difficult for me.

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Cerebral palsy

I have been asked 'what could have caused the cerebral palsy' and the answer is "I don't know". I didn't have an obvious birth trauma although I was very unwell during pregnancy. However, my twins were at increased risk because they were born prematurely (before 38 weeks) and were part of a multiple birth. I didn't know these were risk factors. It might be helpful that if you are a health visitor reading this, or someone involved in early years development that this is something you think about when supporting families.

Cerebral palsy is a life-long condition that effects people in various ways. Some people it might be more obvious that they have cerebral palsy, whilst for others it is not as noticeable. The world "cerebral" means having something to do with the brain, "palsy' means weakness or a a problem with how muscles are used. Cerebral palsy isn't degenerative, it doesn't get worse, although the effects of growing up may change how someone manages their condition. Cerebral palsy is caused by damage to the developing brain, usually occurring before, during, or shortly after birth. The exact cause can vary, and in many cases, the precise reason for the brain damage remains unknown. Several factors can contribute to the development of cerebral palsy:

Before birth (prenatal)

While most cases of cerebral palsy are not directly caused by genetics, certain genetic conditions or mutations may increase the risk.

Infections such as rubella (German measles), cytomegalovirus, or toxoplasmosis during pregnancy can lead to brain damage in the developing foetus.

During birth (perinatal)

Oxygen deprivation during a complicated birth, especially if it leads to asphyxia, can contribute to brain damage.

Babies born prematurely are at a higher risk of developing cerebral palsy.

After birth (postnatal)

Infections or injuries to the brain after birth, such as meningitis or head trauma, can contribute to the development of cerebral palsy.

If left untreated, severe jaundice can lead to a type of brain damage known as kernicterus, which may result in cerebral palsy.

What to expect at paediatric appointment

Lots of questions!

The doctor wants to find out whether you have risk factors relating to cerebral palsy or other conditions. They are likely to ask if there are other disabilities in the family, if it was a difficult pregnancy or birth or if there were any infections or issues after the birth. This is to find out if there are prenatal, perinatal or postnatal factors that could indicate your child may have cerebral palsy.

Some tests...but not all of them

If you are at hospital which includes blood testing facilities it might be that you have a blood test at the same time. There are different reasons for this. Blood tests might include to show things such as creatine levels. High creatine levels means there might be damage to the muscles and could indicate something other than cerebral palsy. Whilst low creatine levels might be because a child has muscle weakness (hypotonia).

If there is no obvious reason, or perhaps your child also has other things going on such as seizures, then you might be booked from an MRI scan. I will tell you a bit more about that later.

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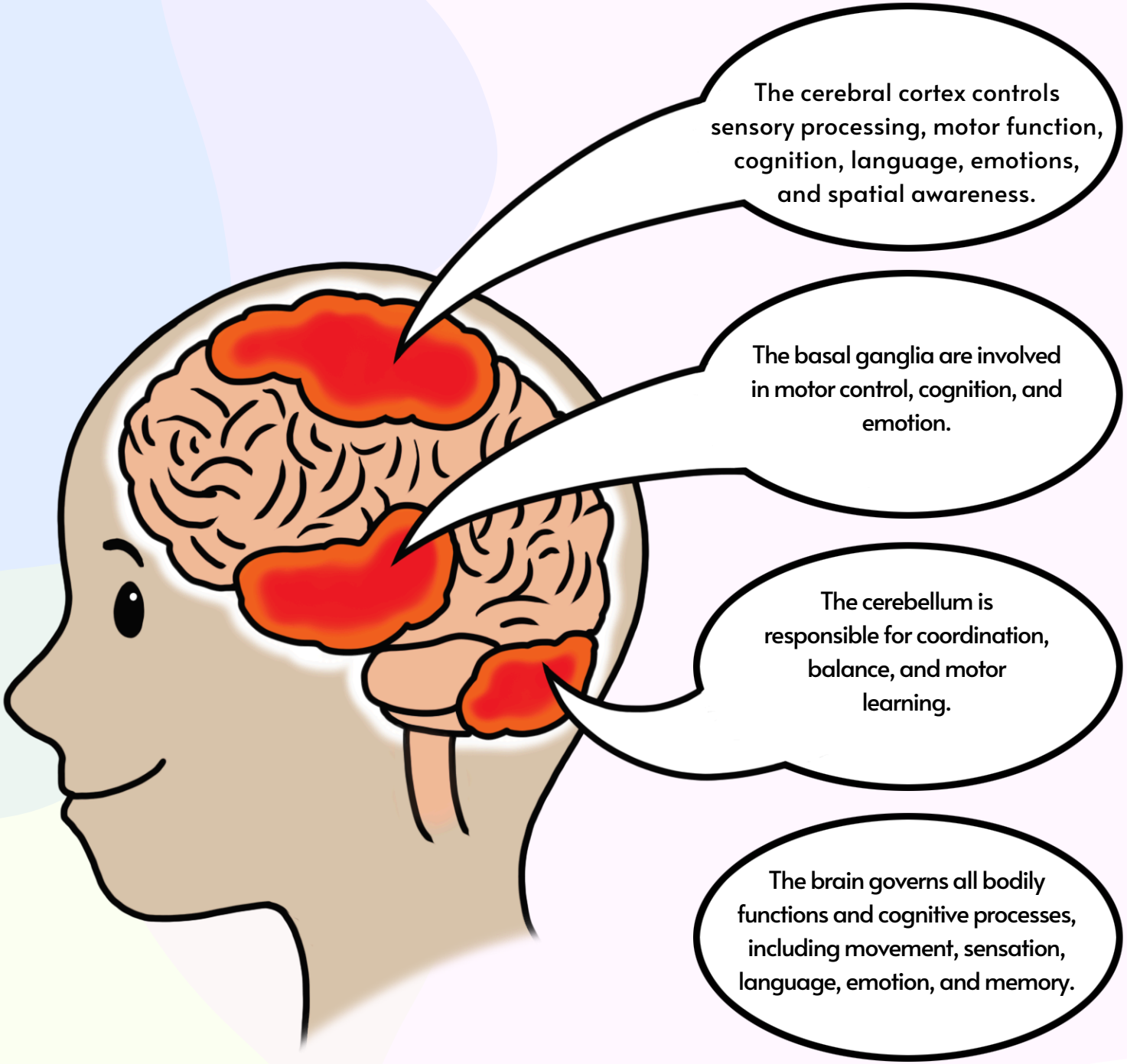
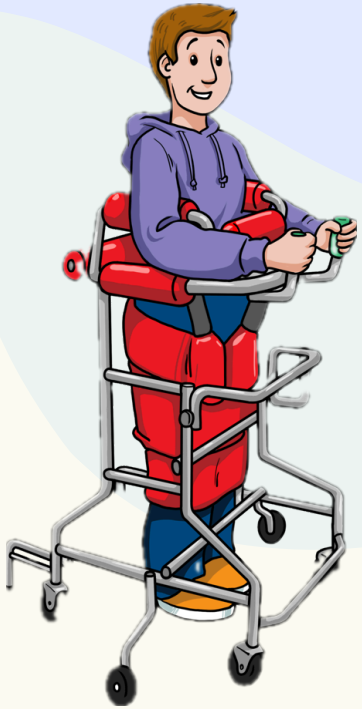
Types

Cerebral Palsy is categorised according to the International Classification of Diseases, 10th Revision (ICD-10), based on how it presents and the specific area of the brain affected.



Types



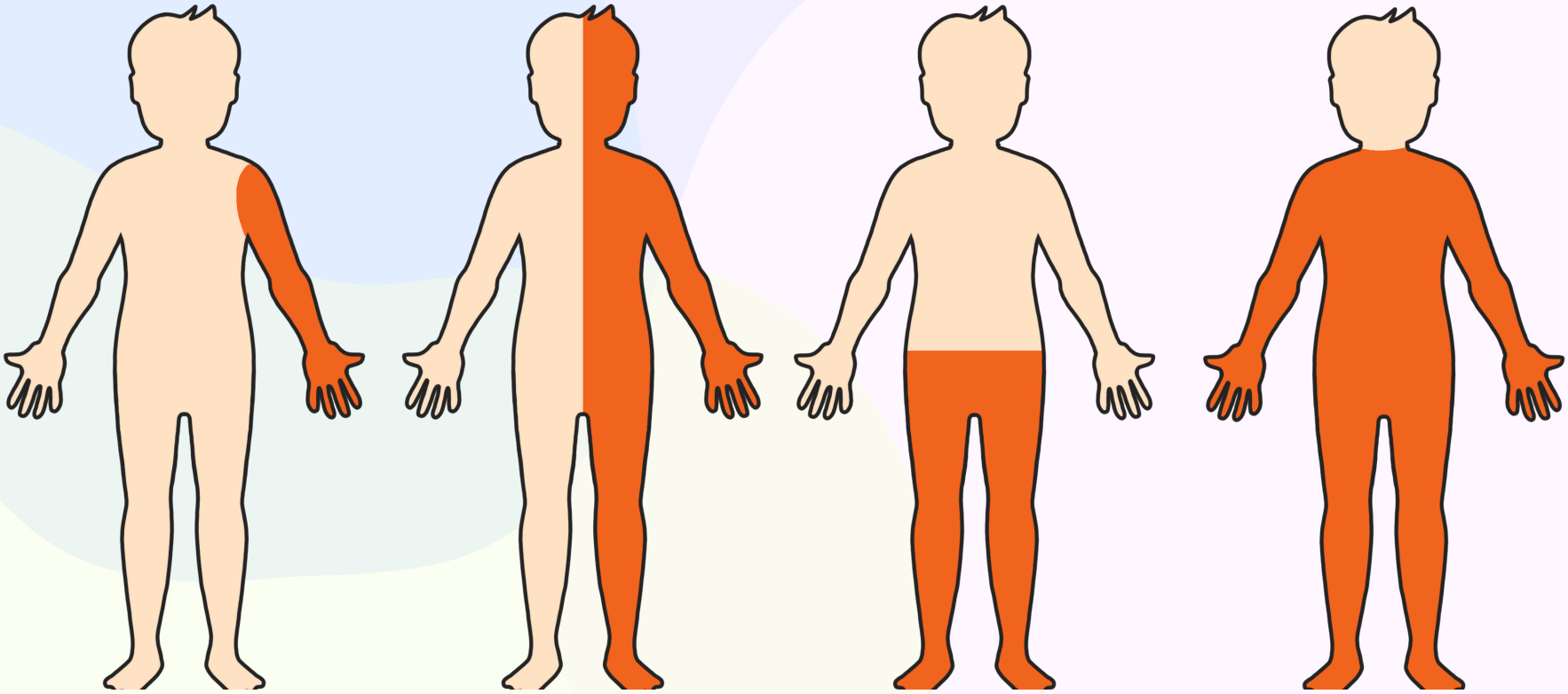
Spastic CP is the most common type, marked by muscle stiffness and tightness, which can hinder movement as the affected muscles resist stretching

Dyskinetic Cerebral Palsy causes uncontrollable, involuntary movements, which can be slow and writhing or rapid and jerky. It commonly affects the hands, feet, face, and occasionally the trunk.

Ataxic CP poses issues with balance, coordination, and fine motor skills, leading to shaky movements during tasks such as writing or buttoning a shirt. It also results in an unsteady gait and tremors.

In Mixed CP, individuals may exhibit a blend of features from multiple CP types. For instance, someone might show both spasticity and dyskinesia (more than one area of the brain).

Which parts of the body?



Monoplegia

Affects one limb

Hemiplegia

one side affected

Diplegia

Two limbs affected

Quadraplegia

Four limbs affected

Blood tests

Doctors may order blood tests to confirm a diagnosis of cerebral palsy. These tests can help rule out other conditions that might have similar symptoms.

Blood tests can sometimes reveal underlying causes of cerebral palsy, such as genetic mutations or abnormalities. This is a more unusual cause of cerebral palsy. DNA arrays, in particular, look at a person's genetic makeup to see if there are any variations that could be linked to cerebral palsy.

Regular blood tests can help monitor the overall health of a child with cerebral palsy. They can check for things like anaemia, infections, or other health issues that might affect their health.

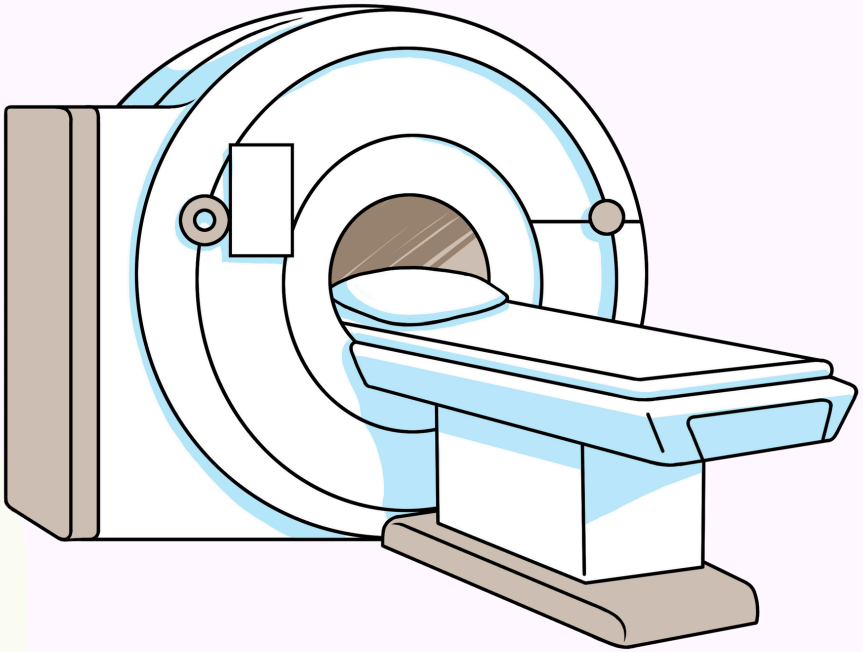
The results of blood tests, including DNA arrays, can help doctors tailor treatment plans to the specific needs of the child. For example, if a genetic mutation is identified, it could inform decisions about therapy or medication options.

MRI

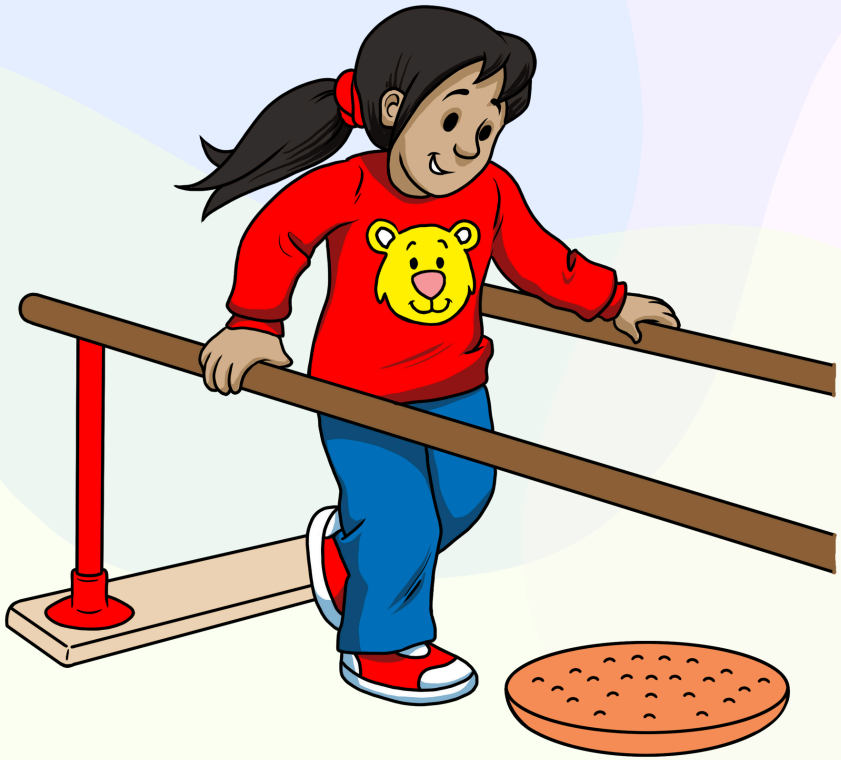
If cerebral palsy is suspected, doctors may recommend an MRI scan to get detailed images of your child's brain. MRI is a safe, painless procedure that helps identify any changes or abnormalities related to cerebral palsy.

For young children who may struggle to stay still, anesthesia might be needed. This is usually given via a mask to help them remain calm during the scan. The MRI machine is a large tunnel and makes loud noises, but this is normal.

Doctors use the MRI images to check for brain abnormalities, looking at the size, shape, and any signs of damage. After the scan, your child will wake up from the anesthesia, and the doctor will review the results with you. Sometimes, it can take a while to get the results, as was our experience. In our case, the MRI didn't show abnormalities, leading to further genetic tests.



Physical examinations



When evaluating your child for cerebral palsy, doctors will conduct physical examinations to gather crucial information about their condition. These exams include:

Reflex Testing:- Gentle taps or stimuli are used to check automatic muscle responses. Abnormal reflexes can indicate nervous system issues.

Muscle Tone and Movement:- Doctors observe your child's movements and walking patterns, looking for abnormalities such as 'scissoring,' where the legs involuntarily cross over each other.

Posture and Alignment:- Examination of muscle stiffness, weakness, or imbalances that could affect movement and function.

Developmental Milestones:- Assessment of milestones like reaching, crawling, and walking. Delays or difficulties can signal cerebral palsy or other developmental concerns.

These examinations are essential for diagnosing cerebral palsy and understanding your child's motor impairments, helping doctors create tailored treatment plans.

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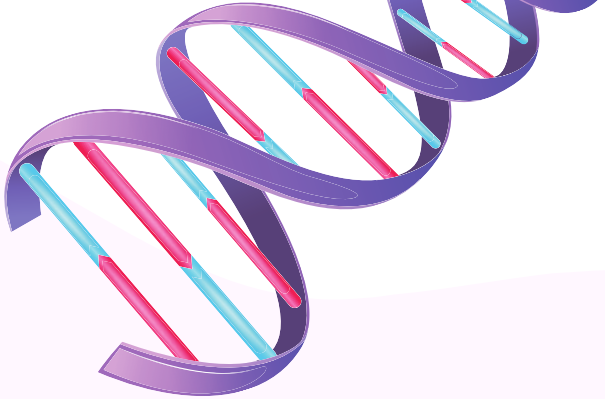
Genetic tests



I'm not a scientist, and this topic is complex. For accurate information, please consult your pediatrician. Here's a simplified overview that might help: Some children's difficulties may not have an obvious cause, like birth trauma, and MRIs may not show clear results. In our case, we also had genetic tests to gain more insights. We're still waiting for the results of whole genome sequencing, which can take a long time.

Imagine your child's DNA as a vast library, with each book representing a chromosome and each chapter or letter representing genes. Whole genome sequencing (WGS) checks every letter in every book to understand your child's complete genetic makeup.

DNA genetic arrays are like magnifying glasses, focusing on specific chapters or paragraphs within the DNA library to identify variations. These variations, called single nucleotide polymorphisms (SNPs), are tiny changes in the genetic code. While many SNPs are harmless, some can affect gene function and contribute to certain conditions.

Understanding your child's DNA involves examining the entire genetic library, zooming in on specific parts, and identifying variations that might influence their health.

Impact

Motor skills

Difficulty with tasks like doing up a coat or zip due to challenges with fine motor control and coordination.

Speech and communication

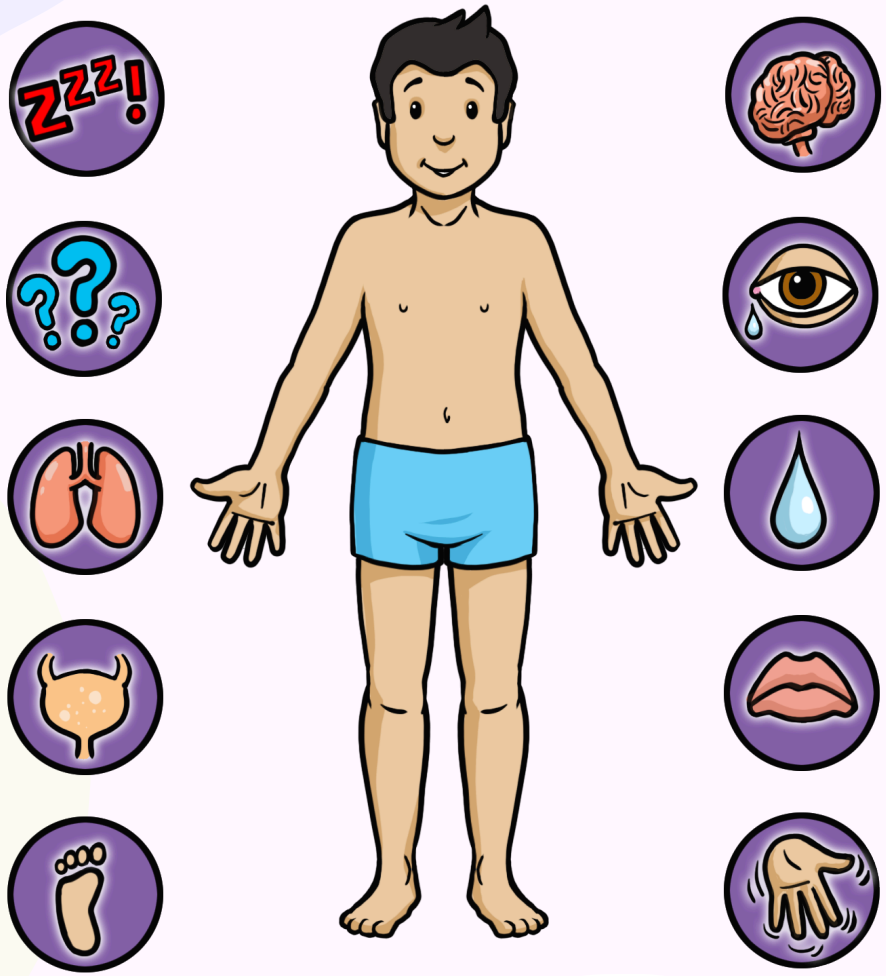
Speech difficulties can arise from muscle control issues affecting the mouth, tongue, and vocal cords, impacting speaking and understanding.

Cognitive function

CP may influence cognitive abilities such as memory, attention, and problem-solving, however, this will be to varying degrees depending on the severity and type of CP. About 45% of people with CP have a learning disability.

Epilespy

Individuals with CP may have a higher likelihood of experiencing seizures, requiring management and understanding of epilepsy symptoms and treatments.



Hints & tips

If you can, join some groups on Facebook or other social media sites. You might find out things that will help you understand things better and support you.

Sometimes children with cerebral palsy can feel the cold more. This can mean that making sure you use a swimming pool that is heated well can be really important.

If you seek private help, make sure the person you are seeking help from is registered to the appropriate body such as HCPC.

My husband and I have made a WhatsApp group where we post a picture of letters and put the date of appointment or received & what it is (physio/SALT, etc.). That means when we are asked we can find documentation quickly.

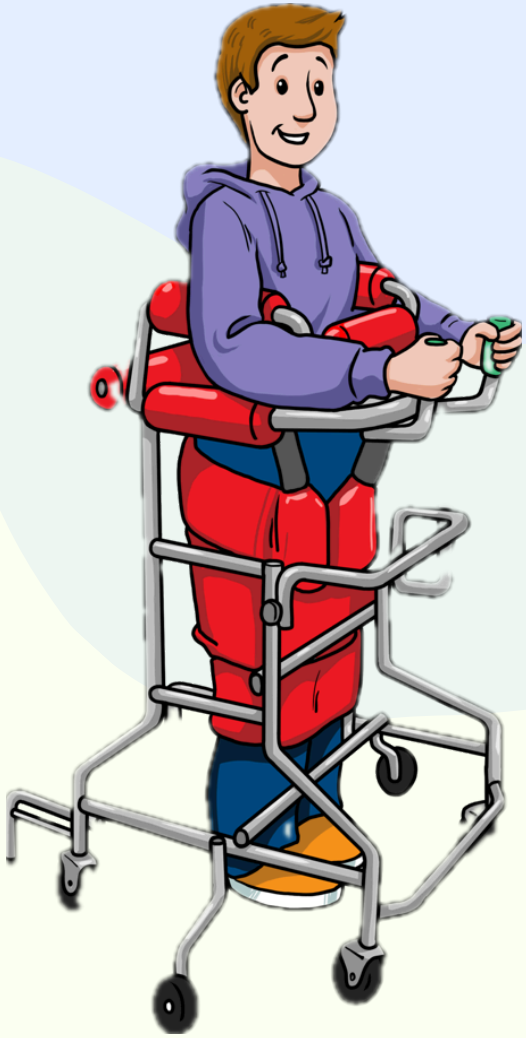
Kaye walker

A Kaye Walker, named after its inventor Dr. Harry K. W. Kaye, is a type of mobility aid designed to assist individuals with mobility challenges, such as those with cerebral palsy. It's particularly useful for those who may have difficulty with balance and stability while walking. The Kaye Walker is often used by children and adults alike.

The Kaye Walker is designed to provide stability and support for individuals with mobility challenges, especially those with conditions like cerebral palsy. It enhances mobility, improves balance, and promotes independence. It aids in developing walking skills, maintaining proper posture, and reducing fatigue.

Physiotherapists often use it in rehabilitation programs to target gait and balance.

Standing frames



A standing frame offers several benefits for individuals with cerebral palsy. It helps improve circulation by preventing blood pooling in the legs and maintaining bone density, thus reducing the risk of osteoporosis. Additionally, standing frames enhance flexibility by stretching and lengthening tight muscles, improving range of motion and comfort. Proper positioning reduces the risk of contractures, which are the permanent tightening or shortening of muscles, tendons, or other tissues, resulting in reduced flexibility and movement in the affected joints. Standing frames also strengthen muscles by engaging various muscle groups, enhancing overall mobility and stability. Furthermore, they allow individuals to interact with their environment at eye level, encouraging participation in activities.

Communicating

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Communicating

Communication is a fundamental aspect of human connection, allowing us to express thoughts, share emotions, and engage with the world around us. However, for some individuals with cerebral palsy, the traditional pathways of communication may present unique challenges. Cerebral palsy, a condition affecting movement and posture due to brain damage, can impact various motor functions, including those involved in speech and language.

The intricacies of muscle control, coordination, and oral motor functions may result in difficulties articulating words, leading individuals with cerebral palsy to seek alternative methods of communication. It is important to recognise and appreciate the diverse ways people express themselves, ensuring that everyone, regardless of their abilities, has a means to communicate effectively.

In this section, we look into the communication challenges faced by individuals with cerebral palsy and explore the innovative and empowering world of alternative communication methods. From high-tech solutions like eye gaze technology to low-tech, paper-based systems such as communication boards, each method is a unique avenue through which individuals can find their voice and connect with others.

Eye Gaze Technology

- For individuals with limited motor control, eye gaze technology can be transformative. This technology allows users to control a computer or communication device using their eye movements.
- A specialised camera tracks the user's eye gaze, enabling them to select letters, words, or phrases on a screen. This can provide a voice for those who may not have the ability to speak conventionally.

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Signing

There are different types of signing. You are likely to have heard of British Sign Language which as the name suggests is a whole language in itself with grammatical structures along with different signs.

You may have heard of Makaton and sign supported English. There are lots of ways to learn signing and you might already use gestures to communicate with your child and them with you. It might be that your child's cerebral palsy makes signing back to you difficult.

Depending on the specific nature of some of the challenges for communication you might choose to learn Makaton or some other approach. I would suggest start with key words that your child is likely to enjoy or need. In our house we prioritised the words:

- drink
- food
- tired
- cat
- mummy
- daddy
- sister
- ball
- tower

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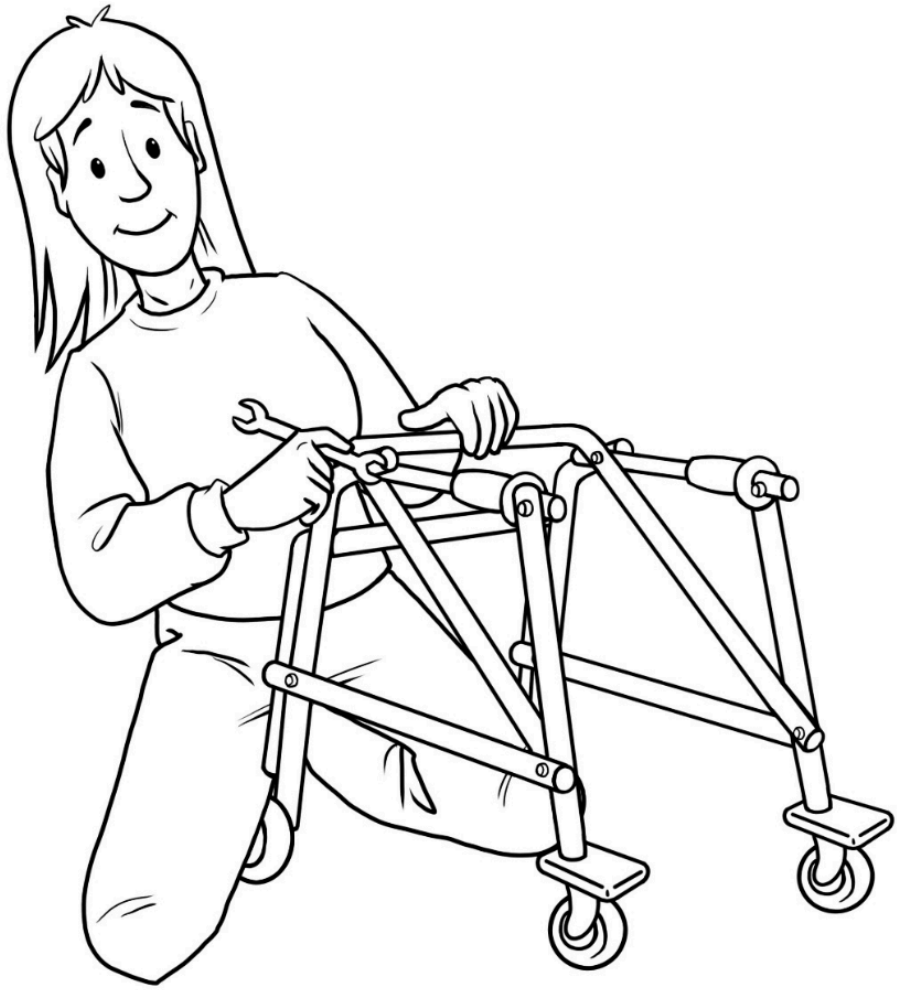

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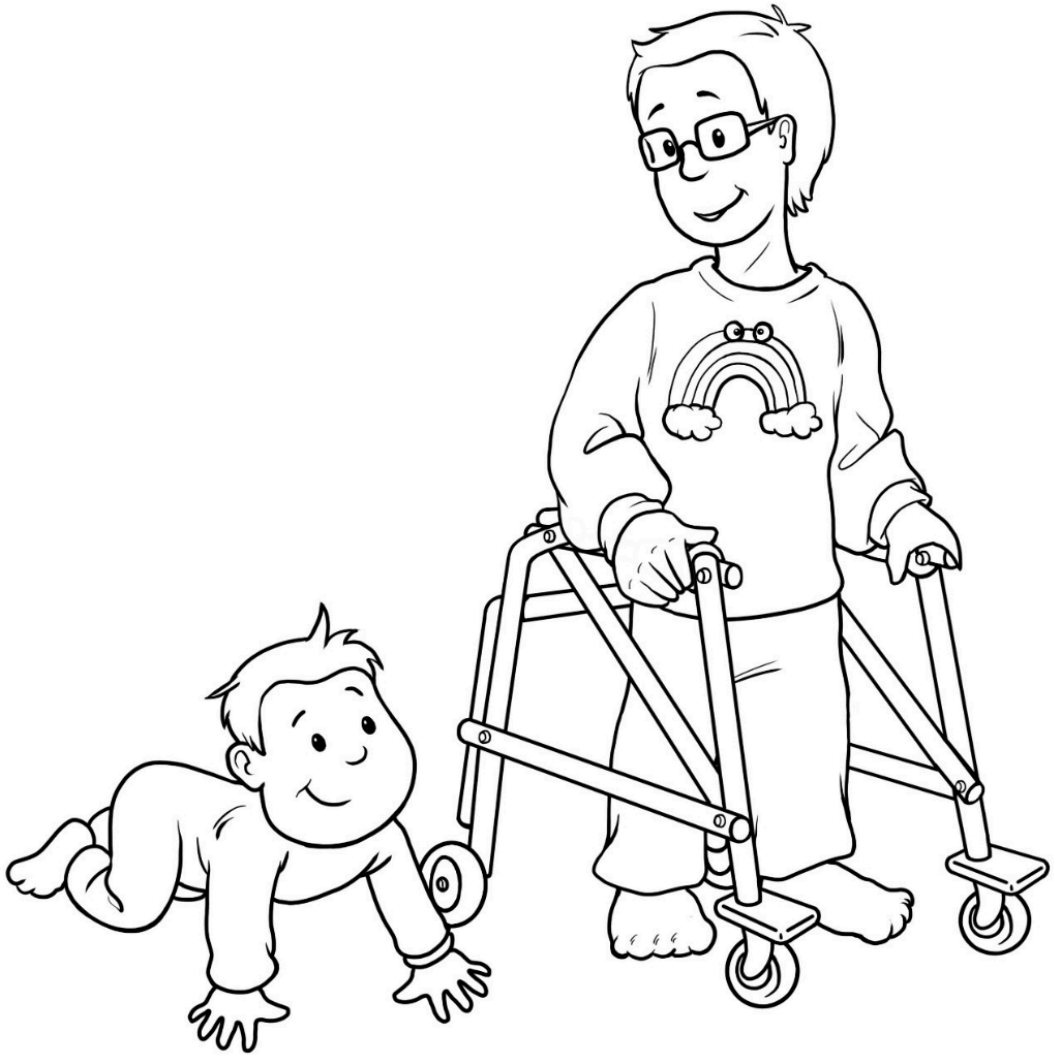

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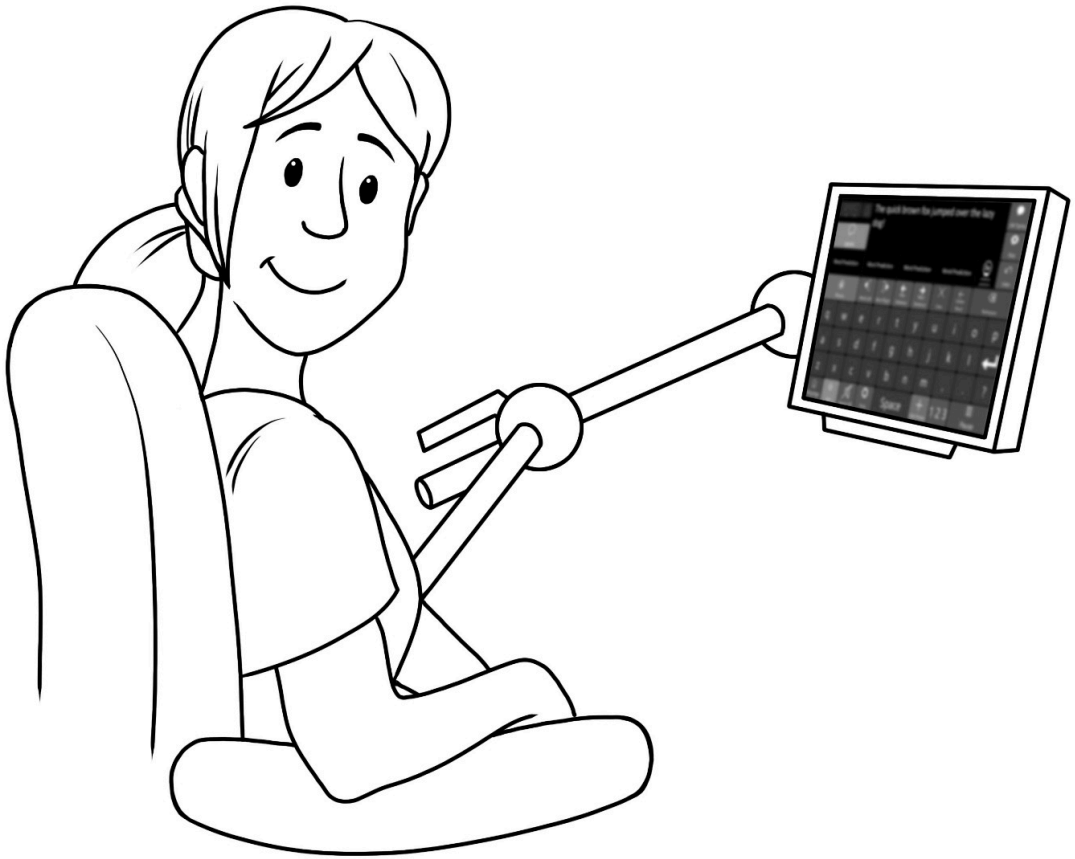

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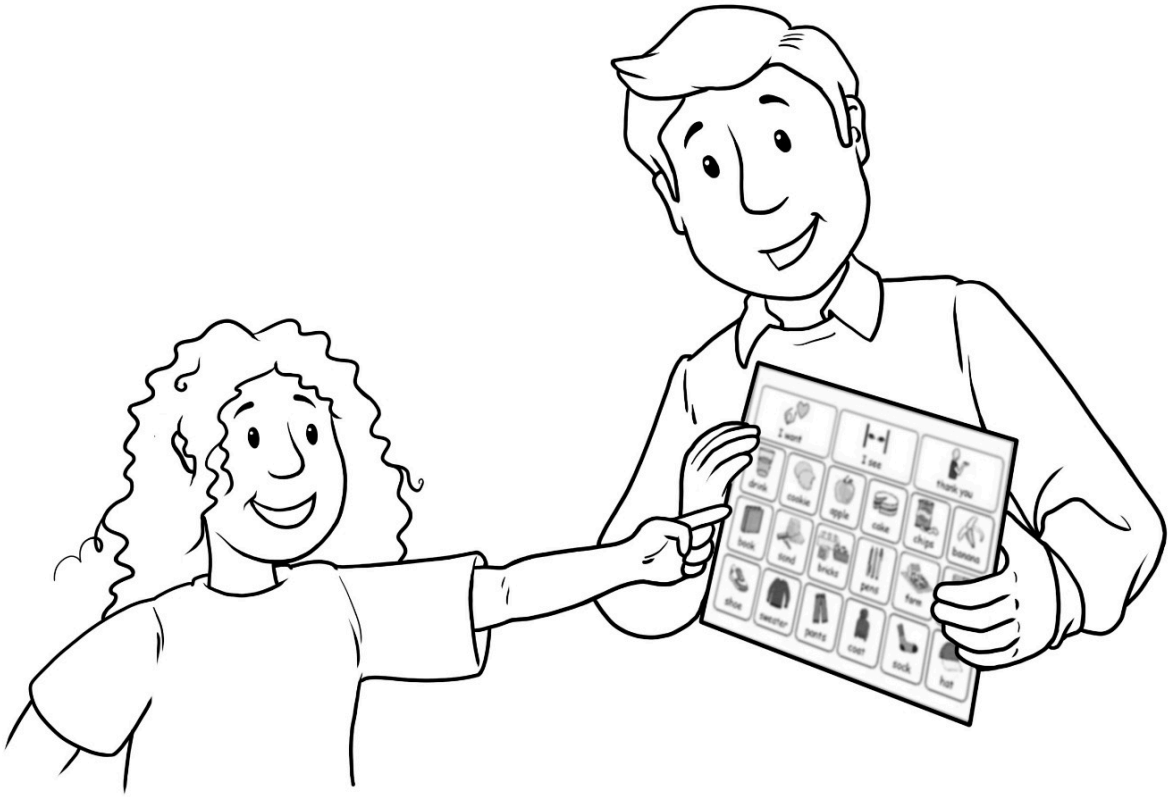

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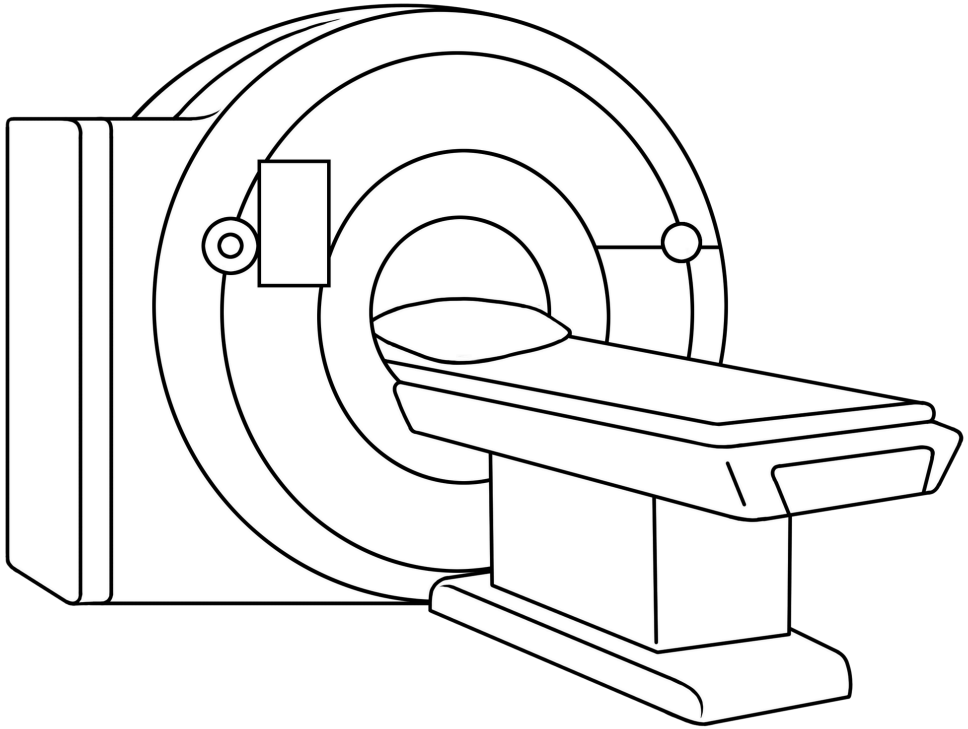

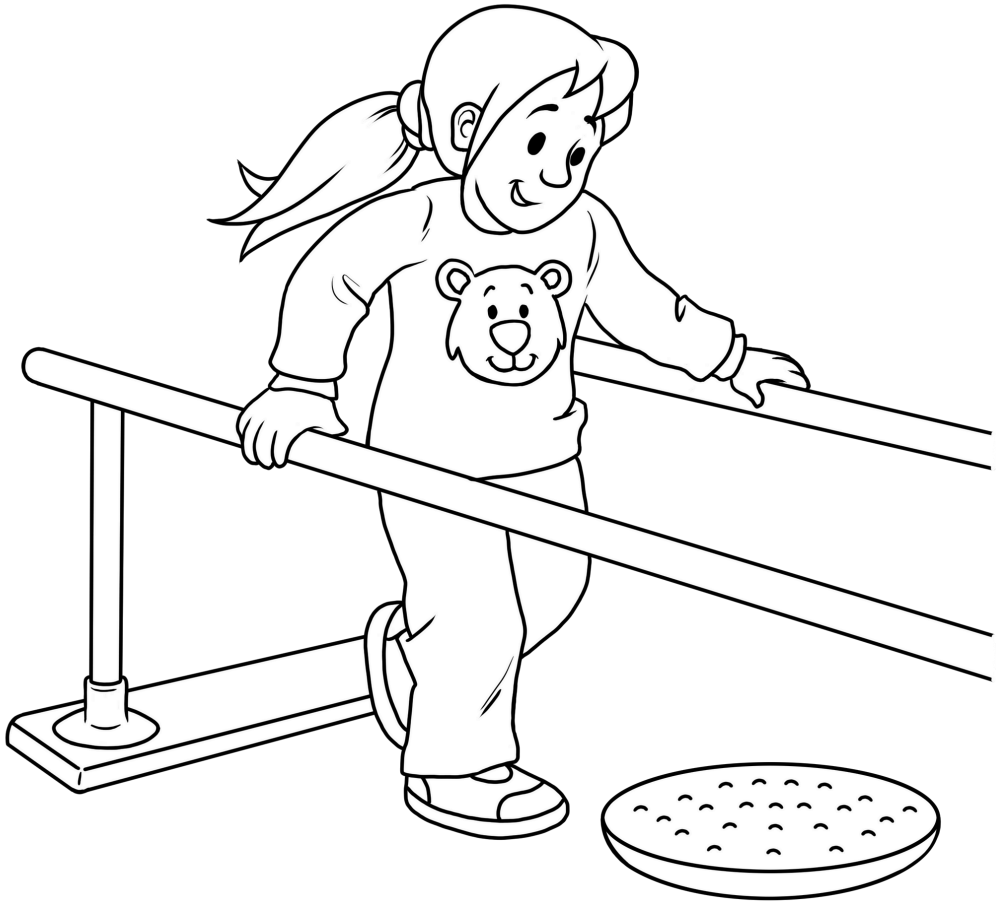

Books that you might like to share