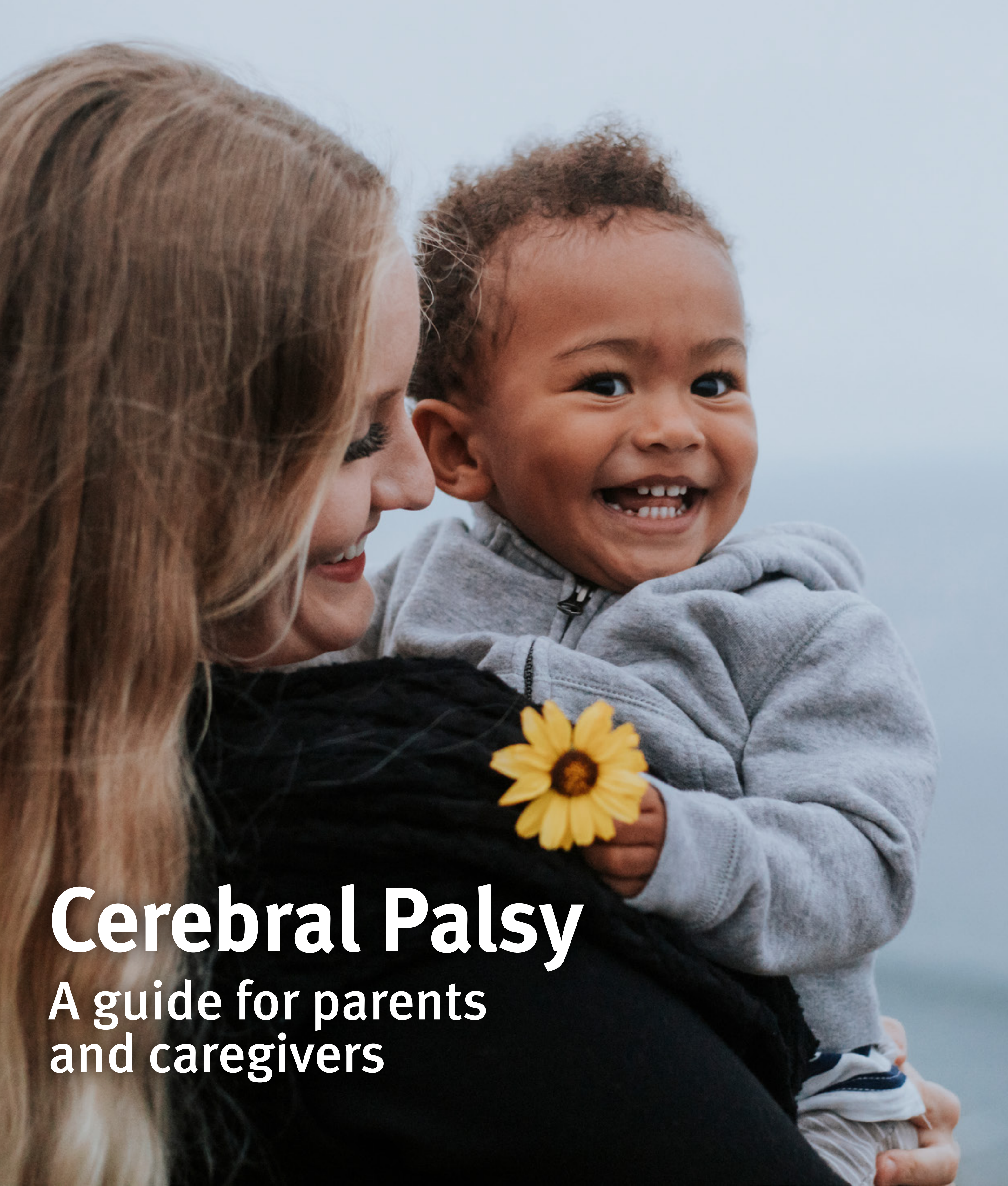

# Cerebral Palsy

## A guide for parents and caregivers

Queensland Children's Hospital

Queensland Government

**Acknowledgements:**

- Thank you to the caregivers who provided feedback on the first version of this booklet. Your input was invaluable.
- The Royal Children's Melbourne: *Cerebral Palsy – An Information Guide for Parents*; 5th Edition; 2008.
- National Health Service (Grampio), Combined Child Health Service brochure: *Cerebral Palsy – Diagnostic and Patient Care Pathways*. Diagnosis to School Leaver; 2008.

Updated: February 2021

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# Introduction

We understand that learning that your child has cerebral palsy means that there will be lots of information for you to take in, and naturally you may feel overwhelmed, concerned, and/or potentially upset. You might also be feeling some relief, if this diagnosis relieves you of feelings of uncertainty. It is not unusual to feel shock, sadness and grief when you learn that your child has cerebral palsy as you may grieve the loss of the child that you were expecting. It is important to give yourself some time to adjust to this news, to have the opportunity to ask questions, to gather information and to share your feelings with others. You may choose to share these feelings with friends and family, or with qualified professionals. There are no right or wrong ways to feel, and every individual will have their own feelings and experience.

It is important to remember that your child's diagnosis of cerebral palsy is one part of who he or she is, and who he or she has the potential to be. Every child with cerebral palsy is an individual, with different strengths and challenges. Your child's diagnosis does not have to prevent them from achieving their personal goals and aspirations.

Learning that your child has cerebral palsy also means that you are needing to develop a greater understanding of what this may mean for your child and your family. Like many other parents and caregivers, you may have many questions about cerebral palsy, even about some of the terminology being used by professionals. You may be concerned about how you will manage and whether you will cope at home, caring for your child. You may also have questions about available medical and therapeutic supports and services.

This booklet has been developed by the Queensland Paediatric Rehabilitation Service's Initial Physical Assessment Clinic team based in the Queensland Children's Hospital. It aims to answer some of the general questions parents and carers have about cerebral palsy, and provide the information you need to feel confident to make choices and set goals for your family and child.

This booklet does not replace the extensive knowledge of your child's team, so please always discuss specific questions or concerns about your child with them. No question is too big or small.

## Feedback

If there are any questions you have about any aspect of this booklet, or if there is information you think would be useful to include that isn't in it, please complete the feedback form that is clipped to the back page (a self addressed envelope is included). We appreciate any feedback you may have.

## Contact us

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## Section 1

# What is cerebral palsy?

## What is cerebral palsy?

Cerebral Palsy is an ‘umbrella term’ that results from injury to the developing brain in the first few years of life (during pregnancy or shortly after birth). It is the most common condition that causes physical disability in childhood. The impact cerebral palsy has on a child can range from very mild to very severe.

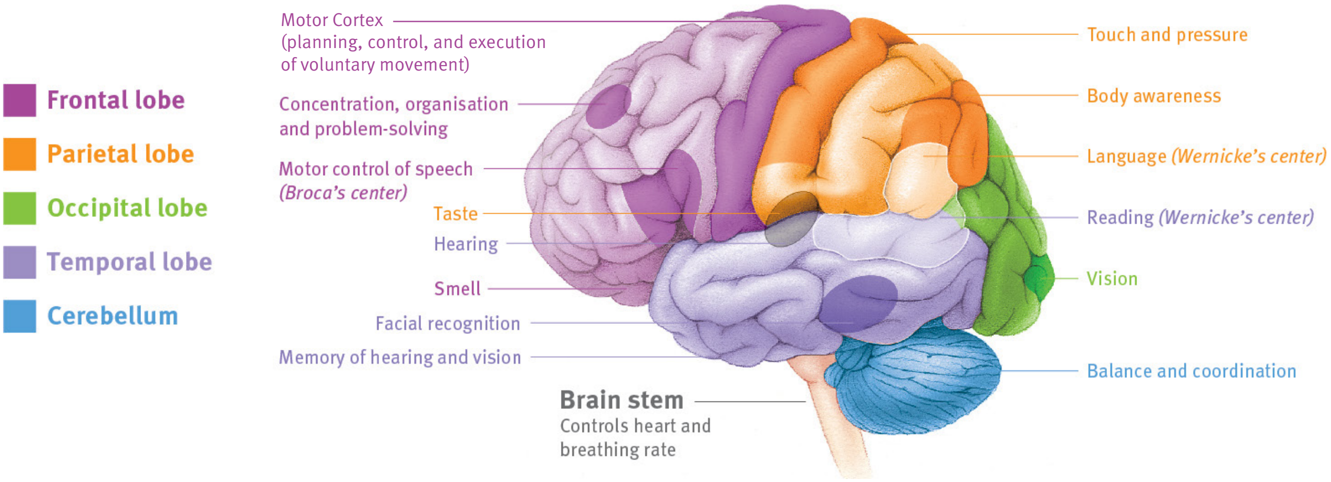
***Cerebral***
‘of the brain’

***Palsy***
‘lack of muscle control’

## About the brain

The brain is a very complex structure with designated areas that control movement, balance, speech, eating and drinking, sensation, thinking and planning. When an area/s of the brain are injured (e.g. from bleeds, lack of oxygen) this can affect how it controls these different functions and can result in movement difficulties and changes to muscle tone (the amount of tension or resistance to movement in a muscle).

### Functions of the brain



Adapted from the College of Liberal Arts and Sciences, Arizona State University

> Every child with cerebral palsy is an individual and the ways in which they are affected will depend on how, where and when the injury occurred to their developing brain.

## Cerebral palsy by numbers

**2 Australian children** are born with cerebral palsy **every day**.

**34,000** Australians are living with cerebral palsy (17 million worldwide).

The **worldwide incidence** of is
**1.4 in 1000 births**

## What causes cerebral palsy?

There can be many different causes of cerebral palsy that can occur during pregnancy, around or after the birth of a baby. Multiple births and premature births are more well-known risks, but many other factors can cause cerebral palsy (e.g. genetic factors, infections). It is sometimes possible to find the reason why a child has cerebral palsy, while in other cases a direct cause cannot be identified.

## Adjusting to a new diagnosis

No matter your situation, it is common for parents to feel a great sense of loss following the diagnosis. Grief is expressed in many ways and it can affect every part of your life; your emotions, thoughts and behaviour, beliefs, physical health, sense of self and identity and your relationships with others. Grief can leave you feeling sad, angry, anxious, shocked, regretful, relieved, overwhelmed, isolated, irritable or numb.

Grief has no set pattern and everyone experiences it differently. Some people may grieve for weeks and months, while others may experience grief for much longer. You may also find that your grief is reactivated as your child progresses, or is slower to progress through different developmental stages. Through the process of grief, you will begin to create a new relationship with your child that accommodates those feelings of loss, but which leaves room for hope and a positive outlook.

It is important for you to know that all of these feelings are common and you may find that it is helpful to discuss these feelings with your family members and those involved in the care of your child. You may also seek out the support of a qualified health professional, who is trained to provide psychological intervention which assists in understanding and processing your grief. There is always support available so please ask for this if you feel it would be helpful.

## How is cerebral palsy diagnosed?

Current guidelines suggest that a clinical diagnosis of cerebral palsy *can* and *should* be made as early as possible in a child's life. However, there is still no single test that can reliably diagnose cerebral palsy. Currently, a diagnosis is made over a period of time, using a combination of the following:

1. **History:** a detailed birth and developmental history.
2. **Examination:** this may include a clinical neurological examination, as well as video recordings of your child's movements, which can be carried out by a trained professional (usually a GP, Paediatrician, Rehabilitation Specialist or Allied Health professional).
   a. The recommended clinical neurological examination is called the 'Hammersmith Infant Neurological Examination' (HINE) which is useful for infants between 2 and 24 months corrected age.
   b. 'General Movements' (GMs) are assessed through video recordings of your child between birth and 3 months' corrected age. Typical and non-typical movements can be recognized and assist with identifying infants 'at risk' of cerebral palsy. You may be able to video your child's 'General Movements' at home through an App called 'Baby Moves'. Your therapist will discuss this with you if relevant.
3. **Investigations:** these can include a cerebral ultrasound, MRI brain and blood tests.
   a. Ultrasounds are an easy and non-invasive test which can be performed on infants in their first few months of life when their soft spot (anterior fontanelle) is still open.
   b. Magnetic Resonance Imaging (MRI) of the brain can also be done as a 'Feed and Wrap' study in a special incubator designed for premature small babies. However, as babies grow and develop, sedation is required to ensure no movement occurs at all during their brain MRI.
   It is recommended that all infants with cerebral palsy have a repeat brain MRI at age two once their brains are fully developed. Children aged five and above may be able to lie still for their MRI. At the Queensland Children's Hospital, we use a practice MRI to assess whether these children require a general anaesthetic.
   c. Sometimes, other investigations need to be carried out, such as investigating genetic or metabolic causes of a child's condition. These are usually blood tests, some of which can take a few months before results are available. Urine tests may also be requested and you will be shown how to collect these from your child.

International guidelines have been developed to help clinicians detect babies at high risk of cerebral palsy early in their lives. If the diagnosis of cerebral palsy cannot be made with certainty, then the clinical diagnosis of 'high risk of cerebral palsy' is encouraged, with ongoing assessment/monitoring through standardised assessments and investigations. Early identification is recommended so that early intervention can be targeted and caregivers can receive advice and support.

## Types of cerebral palsy

Cerebral palsy is described according to the type of movements (motor type), as well as the area/s of the body affected (distribution). You may see these terms written on documentation about your child (e.g. clinic letters).
The most common motor types seen in cerebral palsy include:

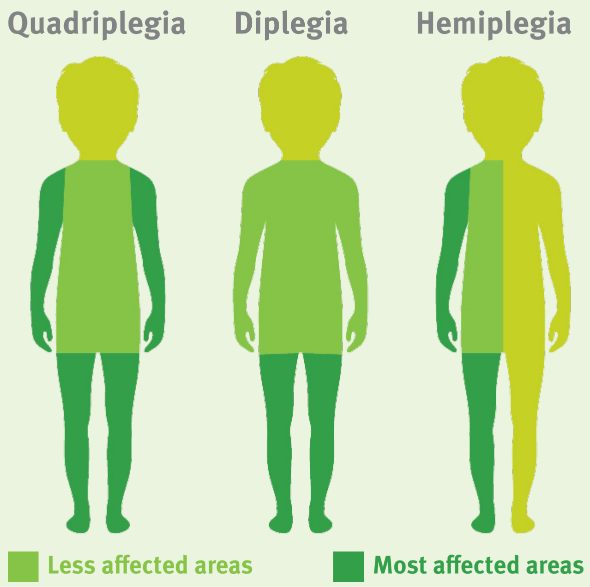
1. **Spastic:** This is the most common motor type. It describes 'stiffness' in muscles which worsens with speed and movement. The faster you move a child's limb, the more stiffness or resistance to that movement you will feel. It may also increase when the child is excited, sad or scared (extremes of emotion), or when he/she is trying really hard with an activity.
2. **Dyskinetic:** Movements are altered and involuntary, with the main types being:
   - **Dystonia –** This describes movements which have sustained or intermittent muscle contractions which cause abnormal postures, repetitive and/or twisting movements. A child's muscles may fluctuate between being floppy and stiff and will be relaxed when asleep.
   - **Athetosis –** Movements are slower, more continuous and look like a writhing action.
   - **Chorea –** Movements are often random and ongoing, appearing in smaller fragments.
3. **Ataxic:** Children with ataxia are often more floppy and have difficulty with their balance and orienting their body in space. Tremors (shaky movements) are common.

Children with cerebral palsy will often have a mixture of the above motor types. Your treating team will be able to discuss which types are predominant/present in your child and the evidence-based options available to best manage this.

## Which body parts are affected?

Cerebral palsy can affect various parts of the body and each child presents differently. Common terms you may come across include:

- **Quadriplegia/bilateral (quad=four):** Both arms and legs are affected, usually also involving the child's trunk.
- **Diplegia/bilateral (di=two):** Both legs are affected. A child's arms may also be affected, but to a lesser extent than their legs.
- **Hemiplegia/ unilateral (hemi= half):** Only one side of the child's body is affected (one arm, one leg).



## Other conditions associated with cerebral palsy

Children with cerebral palsy may, *but won't always*, have other medical issues (co-morbidities). It is important to be aware of these, as treatment options are available. If you notice any of the following, talk to your doctor and treating teams.

- **Behaviour:** Irritability, frustration with movement or communication difficulties, reduced attention, anxiety, hyperactivity, compliance issues and autistic behaviours.
- **Dental:** Cavities, drooling.
- **Developmental skills:** Delay in one or more areas, such as gross motor, fine motor, social, speech and language, thinking and problem-solving.
- **Disrupted sleep:** Due to discomfort, spasms and hunger. Children with impaired vision can also have altered diurnal (day/night) rhythms.
- **Ears:** Middle ear infections (glue ear) and conductive/neural hearing loss.
- **Epilepsy or seizures.**
- **Eyes:** Squints, field defects and cerebral visual impairment (when the brain cannot process what the eyes see).
- **Eating and drinking:** Sucking, chewing and swallowing difficulties.
- **Gastrointestinal:** Gastroesophageal reflux (GOR), oesophagitis, constipation and bladder control issues.
- **Head/neck muscles:** These may be affected to varying degrees which can affect feeding and communication.
- **Learning/intelligence:** Learning and perceptual difficulties.
- **Nutrition:** Slow weight gain and growth (requiring supplementary feeding) or excessive weight gain.
- **Orthopaedic:** Hip subluxation or dislocation, muscle or joint 'tightness' (contractures) with growth, fractures, osteoporosis from inactivity and decreased weight bearing, pain and scoliosis (curvature of the spine).
- **Recurrent chest infections.**
- **Sensory:** Loss of sensory awareness or over-sensitivity.

# Frequently asked questions

## Will my child walk?

Unfortunately, it can be difficult to answer this question as every child with cerebral palsy is affected differently. Your treating team will get to know your child well and over time will be able to give you more accurate predictions. Movement patterns and tone in very young infants may change and can take a while to become established, so as your baby grows and develops it may be clearer to see how cerebral palsy has affected them. After two years of age the brain is fully matured and hence a more accurate prediction of their functional ability is possible.

At two years of age, the GMFCS classification (see Appendix 1) can give us a more reliable indication of whether your child will learn to walk. A child classified as Levels I and II ('mild' cerebral palsy) will walk independently and a child classified Level III (moderate cerebral palsy) will learn to walk with the assistance of an aid (e.g. sticks or a walking frame). Children classified Levels IV and V (more severe cerebral palsy) will generally use a wheelchair as their primary form of mobility.

## Will my child talk?

Cerebral palsy can affect a child's ability to develop spoken language skills in several ways and this is difficult to predict in very young children. Cerebral palsy may impact a child's ability to finely coordinate the muscles around the face, mouth and tongue that are needed for speech, as well as the coordinated breathing that is needed to support it.

Children with cerebral palsy develop communication skills that are unique to their own developmental trajectory. Some children with cerebral palsy will be able to use speech to communicate without difficulty. Others may develop some speech but will have difficulty controlling their movement enough to produce speech that is clear and easily understood by others and may need some help from a speech pathologist.

Other children with cerebral palsy may not develop skills to produce spoken language and may need to use augmentative or alternative communication (AAC) strategies with the help of a speech pathologist and occupational therapist. As your child grows, their treating team will be able to advise you about accessing the therapy support and any special equipment/technology they need to best develop their communication skills.

## Will my child have behavioural problems?

Any injury to the developing brain can cause behavioural difficulties – this depends on the areas of the brain impacted by the injury. Getting to know your child from an early age will assist you to help them control their behaviour. For some infants, this can present as irritability, poor arousal or difficulties settling and tolerating daily activities.

As children become older they may experience their own grief about their physical differences and the impact of these on their participation in everyday activities, especially when comparing themselves to their friends. This grief is frequently expressed in their behaviour – getting frustrated or upset and sometimes suffering from low self-esteem. In some children, this frustration may be short-lived, while others may need some support to deal with their emotions.

Some children with cerebral palsy have trouble developing attention and concentration skills – especially at school. Children with certain co-morbidities, such as intellectual impairment, epilepsy and communication difficulties, may be more likely to develop behavioural issues. Your child's GP or paediatrician can offer advice about this throughout childhood and can guide you toward appropriate interventions or supports, such as 'Stepping Stones', a positive parenting program developed specifically for parents of children with special needs. Community therapists and childcare/school staff may also be able to assist with managing your child's behaviour in both the short and longer term.

## Will my child grow out of cerebral palsy?

Cerebral palsy is a permanent, life-long condition that your child will not grow out of and the injury to the developing brain does not worsen with time. The brain does have the potential to adapt through a process called 'neuroplasticity', however, and this occurs most in the first few years of life. It is therefore important that your child is given the opportunity to access early intervention to give them the best opportunity to stimulate these neuroplastic changes to their brain to enable them to reach their full potential.

Most children with cerebral palsy will have a typical life expectancy. However, some children with extremely severe cerebral palsy (GMFCS V) or those with significant co-morbidities (e.g. severe epilepsy) may have a shortened life span as they are more likely to have life-limiting conditions such as pneumonia and prolonged seizures.

## Will my next child have cerebral palsy?

It is extremely unlikely your next child will have cerebral palsy. However, there are many different causes of cerebral palsy, some of which are genetic. If you are concerned, speak to your GP, who may refer you to a specialist who can assess the individual risks for your family (e.g. a geneticist or obstetrician/gynaecologist).

## How do I explain cerebral palsy to my child?

At some point, your child will likely ask you “Why am I like this? What is cerebral palsy?” If not before, these questions are often asked around the developmental age of 8-9 years, when all children are becoming aware of differences between themselves and others. How you have this conversation with your child is a personal choice and should be discussed with loved ones and professionals who you feel comfortable with and whose opinions you value. The following key concepts, from the United Cerebral Palsy Association of Greater Indiana may give guidance in how to approach the subject with your child.

- **Compassion:** Understand and acknowledge that having a disability can be tricky for your child.
- **Communication:** Use kind and honest language to explain as much as you can about the disability so that a child does not become frightened by the unknown. Use the term ‘cerebral palsy’. Be prepared to answer their questions.
- **Comprehension:** Make sure your child understands that having a diagnosis of cerebral palsy isn’t their fault.
- **Competence:** Make sure your child is aware of their strengths as well as their ability to make progress and learn new things. Emphasise the things that are not changed by their diagnosis.

Some children can understand the brain as the 'body’s computer' which controls the muscles of the body. Try telling your child: “Cerebral palsy affects how the computer can send messages to those muscles, so they don’t move as easily.”

## Do I have to tell others about my child’s condition?

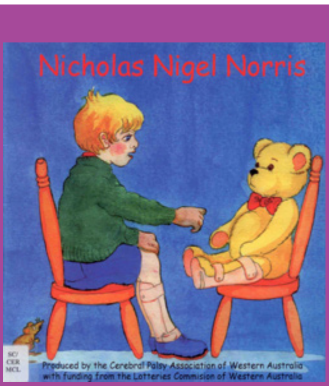
When you choose to start talking about your child’s diagnosis, who you talk to and what you say is up to you. It is OK to give yourself some time to process your child’s diagnosis and understand what it means to you before telling others.

Talking about your child’s diagnosis may be an important part of your own adjustment and may help you to make sense of how this diagnosis might impact on your beliefs, values, family dynamics and relationships. You may wish to talk about this with friends and family or seek professional support from a social worker or psychologist.

It may be helpful to talk to your close network of family and friends so that they can be available to support you practically and emotionally. Sometimes, it is appropriate to discuss your child’s diagnosis so that people who are involved with them (e.g. teachers) can understand your child better. This will help them to support your child to achieve and participate to the best of their ability. From there, you might decide who to tell based on your relationship with them and how supportive you think they might be.

You do not need to give out all the details about your child’s disability – only reveal information you feel comfortable sharing. When talking to others about your child, it may be helpful to first focus on their strengths and what you love about them before talking about their special needs.
It is also important to give siblings an opportunity to voice their thoughts, feelings and questions about their brother or sister who has cerebral palsy. The same key concepts discussed above (compassion, communication, comprehension and competence) can provide some guidance in how to approach sibling conversations. Social workers can support you in planning and preparing for these conversations with your family, support networks and wider community if you find this challenging.

The children’s book ***Nicholas Nigel Norris***, published by the Cerebral Palsy Association of Western Australia, answers many of the questions children have as they grow up with special needs. It tells the touching story of a young boy, Nicholas Nigel Norris, who realises that he is different from the other children in his class, but decides to see the ‘helpers’ he needs as positives. You may also find it useful to speak with your child about how everyone has differences and ‘helpers’, and to consider some of the ways that their friends are also different and what helpers they need (e.g. glasses).



Download a free copy here:
*https://worldcpday.org/wp-content/uploads/2016/09/Nicholas-Nigel-Norris.pdf*

Other useful resources to help your child and their peers understand cerebral palsy include: ***Why do some people use wheelchairs?*** by Mary Atkinson and ***We can do it***, by Laura Dwight.

# 10 things I didn’t know about cerebral palsy (until I had a kid with cerebral palsy)

1. Cerebral palsy isn’t so rare.
2. It’s caused by brain damage.
3. There are different kinds.
4. There are varying degrees.
5. It messes with muscles, big and small.
6. It can make you tight or loose.
7. It can be different every day.
8. There is no cure.
9. It doesn’t disable your personality.
10. You shouldn’t feel bad for people with cerebral palsy.

Source: www.lovethatmax.com

## Section 2

# Encouraging your child's development

# Encouraging development

## How can I encourage my child's development?

You are the most important person to help your child to reach their full potential. Play is a vital part of this. It is much more than just 'fun for babies and children' – it is how they learn and how they work out who they are, how the world works and where they fit into it (Raising Children's Network).

Several key research studies have shown that simple strategies for enriching the environment of babies at risk of developmental delay improves their developmental outcomes. These include:

- **Build a strong relationship with your baby:** Get to know your baby as much as you can by spending time with them. Become familiar with your baby's personality – are they outgoing, shy, or sensitive to touch? Learn what your baby likes and what upsets them so that you can help them to self-soothe. Being able to respond to your baby appropriately helps them to feel safe and secure.
- **Develop good sleep and feeding routines:** This gives your baby the best opportunities to rest, grow and have calm, alert times to experience their environment with you and to develop new skills.
- **Talk to your baby during everyday activities:** Involve your baby in your daily routines (e.g., going outside to hang up washing). Read books and sing songs or rhymes and encourage your baby to join in by babbling, taking turns and touching everyday objects with you.
- **Play with your baby:** Time with you is far better than the best toys. Use simple toys and objects and show your baby how to play with them, talk to your baby about your play and encourage your baby when he/she 'has a turn' with the toys. Imitation is how babies learn and your positive response is the best way to motivate them to learn new things.

Your child's **Personal Health Record** (or 'red book') and the accompanying booklet ***Your Guide to The First 12 Months*** includes information about child development milestones and what parents/carers can do to encourage their child's development. You can view them both online at:

**Personal Health Record**
www.childrens.health.qld.gov.au/personal-health-rec

**Your Guide to The First 12 Months**
www.childrens.health.qld.gov.au/peds/

## Useful online child development resources

**Ages and stages information sheets**
www.childrens.health.qld.gov.au/ages-stages

**Parents Evaluation of Development Status (PEDS)**
www.childrens.health.qld.gov.au/peds/

**An introduction to speech and language development**
www.childrens.health.qld.gov.au/intro-speech-language

**Baby's physical development**
www.childrens.health.qld.gov.au/phys-development

It's important that you do not compare your child's development to their peers as your child is unique and will develop within their own time frame. It's helpful to be aware of the building blocks of typical development and to help your child keep working towards the next stage that's relevant to them. Your child's therapy team will be able to guide you through these developmental milestones and provide ideas on how to enrich your child's environment and help your child develop to the best of their ability.

## Summary of typical developmental milestones

| | Speech development | Hearing and understanding | Play development | Physical development | Signs to watch for in physical development |
|---|---|---|---|---|---|
| **By 3 months** | • Sucks and swallows well during feeding<br>• Quiets or smiles in response to sound or voice<br>• Coos or vocalises other than crying<br>• Turns head toward direction of sound | • Turns head toward sound or voice<br>• Quiets or smiles in response to sound or voice<br>• Shows interest in faces | While lying on their back:<br>• Visually tracks a moving toy from side to side<br>• Attempts to reach for a rattle held above their chest<br>• Keeps head in the middle to watch faces or toys | While lying on their tummy:<br>• Pushes up on arms<br>• Lifts and holds head up | • Difficulty lifting head<br>• Stiff legs with little or no movement<br>• Pushes back with head<br>• Keeps hands fisted and lacks arm movement |
| **By 6 months** | • Begins to use consonant sounds in babbling, e.g. 'dada'<br>• Uses babbling to get attention<br>• Begins to eat cereals and pureed foods | • Listens and responds when spoken to<br>• Fears loud or unexpected noises<br>• Notices toys that make sounds | • Reaches for a nearby toy while on their tummy<br>While lying on their back:<br>• Transfers a toy from one hand to the other<br>• Reaches both hands to play with feet | • Uses hands to support self in sitting<br>• Rolls from back to tummy<br>• While standing with support, accepts entire weight with legs | • Rounded back<br>• Unable to lift head up<br>• Poor head control<br>• Difficult to bring arms forward to reach out<br>• Arches back and stiffens legs<br>• Arms held back<br>• Stiff legs |
| **By 9 months** | • Increases variety of sounds and syllable combinations in babbling<br>• Looks at familiar objects and people when named<br>• Begins to eat junior and mashed table foods | • Recognises sound of name<br>• Looks at familiar objects and people when named<br>• Follows some routine commands paired with gestures | • In a high chair, holds and drinks from a bottle<br>• Explores and examines an object using both hands<br>• Turns several pages of a chunky (board) book at once<br>• Imitates others in simple play | • Sits and reaches out for toys without falling<br>• Moves from tummy to back or sitting<br>• Creeps on hands and knees with alternate arm and leg movement | • Uses one hand predominately<br>• Rounded back<br>• Poor use of arms in sitting<br>• Difficulty crawling<br>• Uses on one side of body to move<br>• Inability to straighten back<br>• Cannot take weight on legs |
| **By 12 months** | • Meaningfully uses 'mama' or 'dada'<br>• Responds to simple commands, e.g. 'come here'<br>• Produces long strings of gibberish (jargoning) in social communication<br>• Begins to use an open cup | • Responds to 'no'<br>• Responds to simple directions, e.g. 'come here'<br>• Pays attention to where you are looking and pointing | • Finger feeds self<br>• Releases objects into a container with a large opening<br>• Uses thumb and pointer finger to pick up tiny objects | • Pulls to stand and cruises along furniture<br>• Stands alone and takes several independent steps | • Difficulty getting to stand because of stiff legs and pointed toes<br>• Only uses arms to pull up to standing<br>• Sits with weight to one side<br>• Strongly flexed or stiffly extended arms<br>• Needs to use hand to maintain sitting |
| **By 15 months** | • Vocabulary consists of 5-10 words<br>• Imitates new, less familiar words<br>• Understands 50 words<br>• Increases variety of coarsely chopped table foods | • Consistently follows simple directions<br>• Shows interest in pictures<br>• Can identify 1-2 body parts when named | • Stacks two objects or blocks<br>• Helps with getting undressed<br>• Holds and drinks from a cup | • Walks independently and seldom falls<br>• Squats to pick up toy | • Unable to take steps independently<br>• Poor standing balance, falls frequently<br>• Walks on toes |

Remember to correct your child's age for prematurity

## Tips to encourage development

**Activities for infants aged 0-4 months**

Babies develop skills for speech and language by listening to sounds around them.

Some activities apply to more than one development domain. Supervise infants at all times when enjoying these activities.

| Communication | Fine motor | Gross motor | Personal/social | Problem solving |
|---|---|---|---|---|
| Talk softly to your baby when feeding them, changing their nappy, and holding them | Place your finger in your baby's hand and watch how strong their grip is | When baby is awake, place them in different positions, such as on their stomach or side | Play music and sing to baby | Let your baby follow a rattle, spoon or toy with their eyes. Talk softly as you play |
| Read simple books to your baby | Put baby on different surfaces like rugs or mats so that they can feel the different textures | Put baby on their stomach when they are awake. Babies need tummy time every day | Make eye contact with your baby and smile, chuckle and coo at them | Play peek-a-boo with your baby |
| Make up songs to sing to your baby | Put toys near where baby can reach them | While baby is lying on their back, help them learn about their feet by playing games with their feet and toes | Encourage baby to smile back at you | Hold your baby up in front of a mirror. They may enjoy smiling and making noises at themselves |
| Don't forget that baby loves to hear your voice | Rub your baby's fingers and toes one at a time. Your baby will enjoy the way it feels | | Gently massage baby with lotion – talk and sing to them while you do this | |

**Activities for infants aged 4-8 months**

Babies are curious at this age and want to learn about the things they see and hear.

Some activities apply to more than one development domain. Supervise infants at all times when enjoying these activities.

| | | | | |
|---|---|---|---|---|
| Talk to your baby during everyday activities such as nappy changing and meal times | Give your baby a toy to hold in their hands | Put your baby on their tummy with a toy slightly out of reach. Encourage them to reach out for it | In a mirror, smile and wave to your baby | Make different sounds for your baby to hear. Watch to see if they search for the sounds |
| Give your baby things to look at while they are lying on their back | Give your baby a spoon to grasp and chew on | On the floor, sit baby between your legs, providing as much support as they need. Place a toy in front of them to reach for | Place your baby on your knee facing you. Bounce them to the rhythm of a nursery rhyme | Play peek-a-boo with your baby |
| Talk to your baby about what they can see and hear | Encourage your baby to pass a toy from one hand to another | Stand baby on your knees. Hold them so they look at you, keeping their heels down | Spend time outdoors with your baby. They will love being out and about with you | Place toys close to the change table and high chair so baby can reach for them |
| | Sit in front of your baby on the floor, supporting them. Drop a ball into a plastic container | | Read to your baby, making lots of different sounds | |

## Activities for infants aged 8-12 months

Your baby needs opportunities to explore and experiment with new skills.
Some activities apply to more than one development domain. Supervise infants at all times when enjoying these activities.

| Communication | Fine motor | Gross motor | Personal/social | Problem solving |
|---|---|---|---|---|
| Use single/simple words when talking to your baby. Repeat them over and over | Your baby will begin to use their index finger to poke. Encourage baby to point at objects too | Put toys on a table so that your baby can practice standing and stepping sideways while playing with them | Let your baby play with plastic measuring cups in the bathtub. Bath time is a great learning time | Your baby will be interested in banging objects to make noises. Show them how to bang things together |
| Read baby books or colourful magazines. Let your baby touch pictures in the book | Let your baby feed themselves. This gives them experience with textures in their hands and mouth | Find a big box that your baby can crawl in and out of. You can do this together, or with a sibling | Mirrors are exciting at this age. Smile and make faces together in the mirror | Let your baby make choices. Offer two toys or two types of foods and see which one they pick |
| Talk to your baby during everyday activities such as nappy changing and meal times | Make a simple puzzle for your baby by putting blocks inside a muffin pan or egg carton | Play ball games. Roll a ball to your baby. Beach balls or soft balls are great for this game | Name the body parts as your baby touches your face | Play pat-a-cake, clap hands together, or take turns |
|  |  | Clap hands with your baby. Encourage them to make sounds as they play |  | Play hide and seek games with objects. Help baby find the object |

## Activities for infants aged 12-16 months

Reading aloud, singing to your child and sharing stories assists with your child's development.
Some activities apply to more than one development domain. Supervise children at all times when enjoying these activities.

|  |  |  |  |  |
|---|---|---|---|---|
| Name the object your child wants. See if they can repeat the word back to you | Cut up safe finger foods (not foods that are a choking risk) for your child and allow them to feed themselves | Most children enjoy music. Clap and dance to the music together | Let your child help you clean up. Play 'feed the rubbish bin' or 'give it to mummy and daddy' | Children love games at this age. Try pat-a-cake, this little piggy went to market, or different ways of playing games |
| Play the naming game. Name body parts, common objects and people | Draw pictures on butcher's paper with your child and let them draw as well | Encourage your child to walk by holding their hand or pushing toys around | Let your child 'help' during daily routines. Encourage them to get the cup and spoon for meal times, for example | Loosely wrap a small toy in a paper towel nor tissue without tape. Your child can unwrap it and find a surprise |
| Make puppets out of a sock and play games with baby | Get your baby to put small objects into containers. Use safe objects for this game | Hold your child in a standing position, facing another person. Have them step towards the other person to get a favourite toy | Play 'pretend' with a toy animal or doll. Show and tell your child what the doll is doing (walking, going to bed or eating) | Make sound shakers by filling empty plastic bottles with rice. Be careful to secure lids tightly |
| Read your child a book and use lots of voices and sounds to attract their attention |  | Play simple puzzles with your child | Give your child a lot of things to roll, push, pull, hug, shake, poke, tum, stack, spin and stir |  |

## Your child's nutrition

To help your child grow, learn and develop, it is important that you consider their nutrition. Below is some information from the QPRS dieticians you may find useful:

The benefits of good nutrition for children with cerebral palsy include:

- Improved immune function
- Being less irritable
- Improved cognitive ability
- Recovering faster from surgery and illness
- Having better general wellbeing
- Improved circulation
- Improved weight and growth

Good nutrition means a **balanced diet** that provides enough energy, protein and micronutrients to meet a growing child's nutritional needs. The best way to ensure your child's diet is balanced is to offer a variety of foods from each of the five main food groups every day:

- Vegetables and legumes (beans)
- Fruit
- Grains and cereals
- Lean meat, poultry, fish, eggs, beans, tofu, nuts, seeds
- Milk, cheese, yoghurt or alternatives.

Some children with cerebral palsy have difficulty gaining weight and may be underweight for their height and age. Slow weight gain and growth were once thought to be a normal part of having cerebral palsy, but this is no longer the case. Slow weight gain can be caused by a number of things, including:

- Not getting enough nutrients
- Using more energy than they are taking in

**What are the causes of not getting enough nutrients?**

- Difficulties with eating or drinking
- Limited variety of food or drinks
- Taking longer to finish meals
- Behavioural issues affecting mealtimes
- Difficulty communicating hunger or thirst
- Poor appetite

**What are the common causes of using much more energy?**

- Inefficient or involuntary movements
- Epilepsy or seizures and other common problems such as chest or urinary infections.

## Swallowing or feeding difficulties

Children with cerebral palsy may have problems with muscle strength, movement, coordination or sensation, which may affect the muscles of the mouth, face and throat. This can make it difficult to suck, bite, chew, control and swallow food, fluid and saliva effectively. Also, children with cerebral palsy can often take much longer than usual to finish their meals.

**Reflux**

Gastro-oesophageal reflux is often seen in children with cerebral palsy and may contribute to not getting enough nutrients. It may cause children to associate pain with eating and drinking and lead to them refusing their food during mealtimes. If you are concerned that your child may have reflux, talk to your local G.P or Paediatrician about the different treatment options available.

**Constipation**

Constipation is also a common issue of cerebral palsy and may affect a child's appetite, behaviour and general wellbeing. It may be a result of immobility, incorrect positioning, abnormal gut motility, side effects of medication, or not getting enough fluids or dietary fibre.

## When should I be concerned about my child's nutrition or feeding?

If your child has any of the following signs you should seek help and advice from your child's doctor, dietician or speech pathologist:

- Slow growth
- Weight loss
- Not gaining enough weight
- Difficulties eating and drinking, which can include:
  - Coughing, choking or gagging while eating/drinking
  - Multiple swallows to clear food or fluid
  - Wet, gurgly breathing or wet voice both during and after mealtimes
  - Refusal to eat or drink
  - Difficulties with or refusal to eat certain food textures (e.g. lumpy foods, chewable foods)
  - Difficulty coping with certain foods or fluids (e.g. increased coughing with thin fluids)
  - Prolonged mealtimes
- Frequent illness, particularly chest infections
- Frequent vomiting
- Chronic constipation or diarrhoea

## Section 3

# Your child's care team

## Who may be involved in my child's care?

Your child may be involved with a multidisciplinary team, depending on their individual needs. Some of the common team members may include:

### Education professionals

- **Teachers**
- **Teacher aids**
- **Special Education teachers**
- **Guidance officers:** Specialist teachers who provide psychoeducational assessments, advice and counselling for student support and wellbeing.

### Medical specialists

- **Gastroenterologist:** Diagnosis, investigation and managing problems in the digestive system.
- **General practitioner:** Oversees general wellbeing and referrals to other specialists.
- **Neurologist:** Diagnosis and management of neurological (brain and spine) conditions, including epilepsy.
- **Orthopaedic specialist:** Diagnosis and management of conditions affecting the bones and muscles.
- **Ophthalmologist:** Diagnosis and management of eye conditions.
- **Paediatrician:** Specialises in child health and development.
- **Rehabilitation physician:** Diagnosis and management of tone and movement issues
- **Respiratory paediatrician:** Diagnosis and management of lung function and breathing issues.

### Paediatric allied health professionals

- **Dietician:** Provides assessment, support and advice to ensure your child's nutritional needs are being met.
- **Neuropsychologist:** Provides assessment and support for learning, behaviour and emotional wellbeing.
- **Nurse:** Provides support for medical and physical wellbeing.
- **Occupational therapist:** Provide assessment and treatment to help your child achieve their daily occupations that may include self-care, school and/or play.
- **Orthotist:** Provides orthotics, splints and prosthetics as required.
- **Physiotherapist (physio):** Provides assessment and ongoing management to maximise mobility and physical skills.
- **Social worker:** Provides both short and long-term counselling, practical assistance and psychoeducation for your child and family.
- **Speech and language pathologist:** Assessment and ongoing management of any swallowing and communication difficulties.

### Other specialists

- **Audiologists:** Diagnose and assess hearing issues, including auditory processing.
- **Dentists:** Manage teeth health.

Your family and your child are the most important members of the team. As the best advocate for your child, you must raise any concerns or questions you have. Each professional will be able to provide information which is specific and relevant for your child and family. To ensure your child is given the best care and opportunities, it is necessary for the whole team to be informed about what is happening. Please make sure contact lists are kept up-to-date so information about your child can be shared with the whole team.

## Queensland Paediatric Rehabilitation Service

The Queensland Paediatric Rehabilitation Service (QPRS) provides coordinated family-focused rehabilitation and tertiary health assessments and interventions for children and adolescents with a range of disabilities resulting from injury, illness or disease. Our goal is to maximise function, prevent or minimise predictable complications and ensure the best quality of life and participation.

### Who we care for

Our team cares for children and adolescents with:

- Acquired neurological injury or illness (e.g. brain injury).
- Spinal cord dysfunction.
- Cerebral palsy (CP) and similar conditions.
- Limb differences (congenital and acquired).
- Rare complex conditions (e.g. achondroplasia).

### Our services

- Multidisciplinary assessments and rehabilitation planning.
- Intensive inpatient and outpatient rehabilitation for acquired neurological disability.
- Rehabilitation following a range of orthopaedic interventions for children with cerebral palsy.
- Hip surveillance and management.
- Outpatient rehabilitation following amputation and for prosthetic training.
- Group programs (e.g. post Botulinum Toxin-A therapy, mobility, social skills and school readiness).
- Orthotics, prosthetics and rehabilitation engineering.
- Education and research, including translation of research into practice.
- Comprehensive walking (gait) assessment including three-dimensional (3D) gait analysis.
- Statewide clinical outreach and telehealth.

### Multidisciplinary clinics and their specialties

- **Rehabilitation medicine:** Acquired brain injury, spinal cord injury, other acquired neurological disability.
- **Neurocognitive:** Acquired brain injury.
- **Spinal:** Spina bifida and other congenital spinal conditions.
- **Limb difference:** Congenital limb difference and amputees, prosthetic prescription.
- **Physical assessment clinic (PAC):** Physical management of children's movement disorders due to cerebral palsy and similar conditions, including management with intrathecal baclofen.
- **Initial PAC:** Diagnostic and complex care coordination for children 'at risk of' or possible CP or like conditions.
- **Botulinum toxin (BoNTA):** Spasticity management with BoNTA injections, including injecting clinics and review.
- **Orthopaedic:** Children with CP and similar conditions requiring assessment and intervention.
- **Hip surveillance:** Assessment and x-ray monitoring of hip development with coordination of management as indicated.
- **Family therapy** – counselling sessions with all family members to explore and understand how family patterns and challenges are currently impacting family life.

### Statewide outreach clinics

Outreach clinics occur twice a year in Cairns, Townsville, Mackay, Rockhampton, Mount Isa, Hervey Bay, Gold Coast, Toowoomba and Bundaberg.

### The team

Our multidisciplinary team features expertise from many health streams including:

- Paediatric rehabilitation medicine
- Paediatrics
- Paediatric neurology
- Paediatric orthopaedic surgery
- Neuropsychology and psychology
- Nursing
- Nutrition and dietetics
- Occupational therapy
- Orthotics and prosthetics
- Physiotherapy
- Social work
- Speech pathology
- Music therapy

### Contact us

**Queensland Paediatric Rehabilitation Service**
Level 6 (outpatients) | t 07 3068 2950
Level 8 (inpatients) | t 07 3068 2140
e qprs@health.qld.gov.au

## What should we expect when my child is referred to the QPRS?

For your child to be able to access the QPRS, we need a written referral from a medical practioner. Once we have the referral, the following process will begin:

Referral will be triaged (prioritised based on the urgency of care) at the weekly referrals meeting

A clinic appointment letter will be sent at least four weeks before the appointment

**At the clinic appointment**

- Present to the Queensland Children's Hospital 6g outpatients reception, 15 minutes before your appointment.
- Your child may have their height and weight measured by nursing staff.
- Your child will be reviewed by QPRS specialists. They will listen to and address any concerns you may have about your child and their movement difficulties.
- Your child will also be assessed by the clinic therapist/s which may include a musculoskeletal assessment (measuring joint ranges of movement and tone) and observation of how your child moves. Your child's walking may be videoed if appropriate. The therapists will answer any specific questions you may have and offer advice.
- Your child may be referred for a hip X-ray or to other specialists (e.g. orthopaedic consultant, ophthalmologist) as needed.
- A referral to the 'Queensland Early Detection and Intervention Network' (QEDIN-CP) may be recommended, as well as information given to you about relevant research opportunities your child may be eligible for.
- The clinic doctor will tell you when they would like to review your child and give you a paper slip to give to administration on your way out.

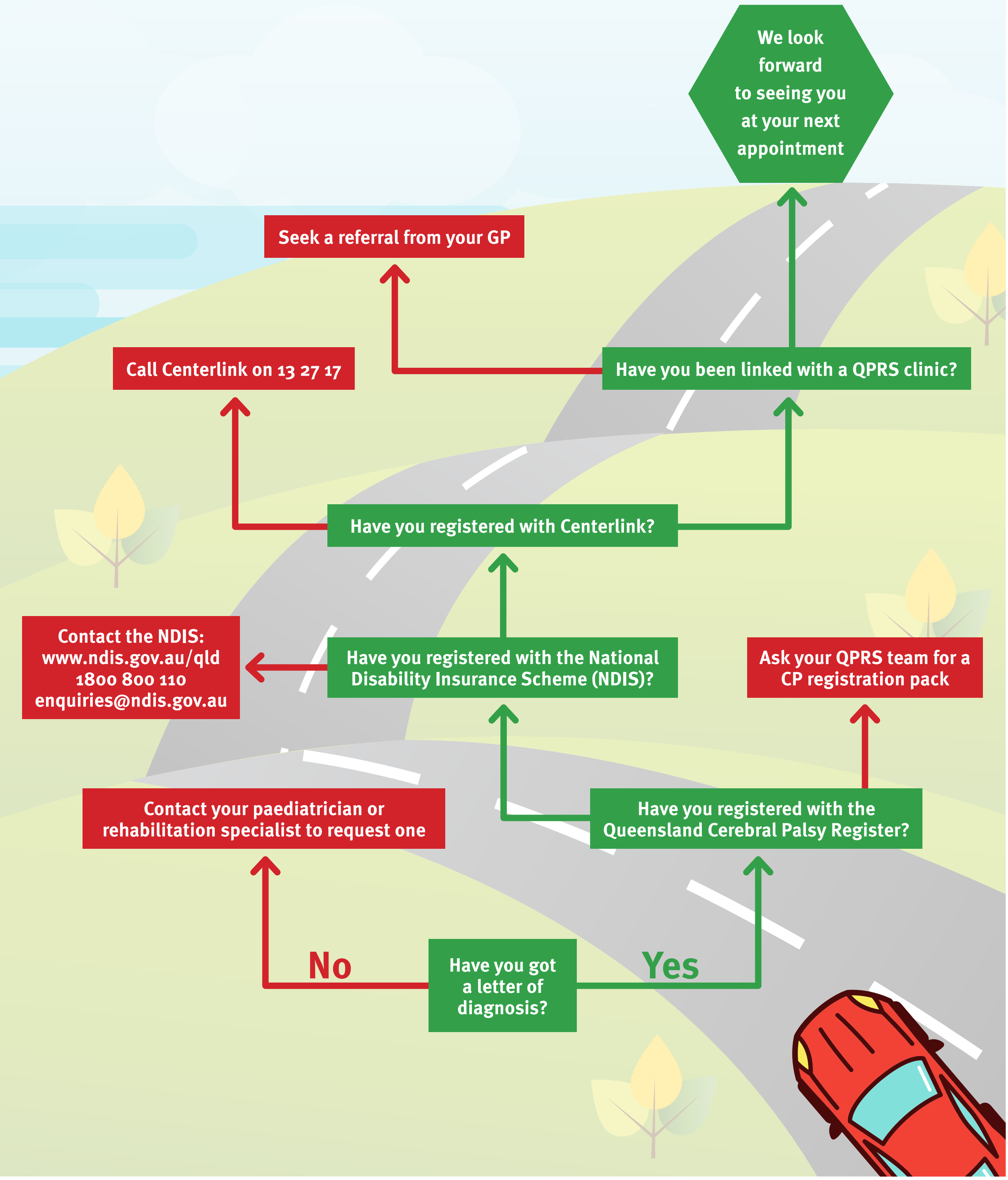
**After the clinic**

- A clinic letter will be sent to you and anyone on your contact list. Please make sure your details are kept up-to-date.
- You will be sent an Appointment Letter four weeks before your next appointment.
- Contact QPRS on (07) 3068 2950 if you have any concerns before your next appointment.

## Who else do I need to contact once my child has been diagnosed?

# Negotiating the referral road

When your child is first diagnosed with cerebral palsy, there are many different services you can link in with. This referral road aims to start you on your journey and help you to make these links. If you have any questions, or come up against unexpected obstacles, please don't hesitate to contact your team at QPRS on (07) 3068 2950.



## Activities and hobbies for children with cerebral palsy

There are many activities and hobbies that children with CP can participate in and it is important to encourage your child to engage in sports/hobbies that are appropriate for them and they are interested in.

Many centres run activities tailored especially for children with special needs whilst other clubs are able to adapt activities to suit individuals. It is important to discuss your child and their goals with the coaches/coordinators as many are open to doing what they can to involve your child in the hobby of their choice.

It is necessary for your child's therapy team to be aware of any activities/hobbies your child is keen to be involved in so they can make sure your child is able to participate to the best of their ability.

Below are just a few services, but there are many more centres that would welcome your child.

| **Play** | **Contact details** |
|---|---|
| CP Toys | www.cptoys.org<br>A phone App which suggests appropriate toys to assist with your child's play skills, development and goal areas |
| Playgroups | 1800 171 882   www.playgroupqueensland.com.au |
| Police Citizens Youth Club (PCYC) | www.pcyc.org.au |
| Toy Library | www.toylibraries.org.au |

| **Communication** | **Contact details** |
|---|---|
| Auslan (Australian Sign Language) | www.auslan.org.au |
| Hanen Programme | www.hanen.org |

| **Sports/hobbies** | **Contact details** |
|---|---|
| Aquatic physiotherapy/hydrotherapy | www.hydrotherapybrisbane.com.au<br>Private physiotherapists may also be able to provide aquatic physiotherapy in a local heated pool |
| Australian Paralympic Association | www.paralympic.org.au |
| Brisbane Paralympic Football Program | www.bpfp.com.au |
| JOOAY App | App available on Apple and Google Play that connects children and youth with disabilities to leisure and participation activities |
| Modified Rugby Programme (MRP) | www.mymrp.org |
| Powerhouse Dance Studio's Special Needs Dance Class | www.powerhousedancestudios.com.au |
| Race Running Australia<br>(3-wheeled running bike for all abilities) | www.sports.org.au   (search race running)<br>Facebook groups, search: 'race running Australia', 'race running Queensland' |
| Riding for the Disabled (RDA) / hippotherapy (therapeutic horse riding) | www.rda.org.au<br>www.equusterra.com.au<br>www.childrenstheraplay.org/hippotherapy<br>www.cerebralpalsy.org/about-cerebral-palsy/treatment/therapy/hippotherapy |
| Sporting Wheelies and Disabled Association | www.sportingwheelies.org.au<br>'The Gym' in Bowen Hills is also well equipped and accessible for children and adults with disabilities – see website for more details |
| Technical Aids to the Disabled (TADQ) | 'Freedom Wheels' Modified Bike Service<br>1300 663 243   www.tadq.org.au |
| The Tippy Toe Co. | www.tippytoeco.org<br>Not-for-profit ballet school for children and young adults with special needs |

Your child may be able to participate in many more activities than those listed here. The internet or recommendations from your treating teams/friends/families/Facebook groups/parent support networks are good places to start!

## Section 4

# Support and services

# Financial

There are currently a range of avenues for financial assistance in Queensland.

## Centrelink

You may be eligible for financial assistance from Centrelink if:

- you are caring for a child or children with disability
- the demands of your caring role mean you are unable to support yourself through paid employment
- your child has been diagnosed with a serious illness or medical condition, or disability due to an accident.

For more information call Centrelink on 13 27 17, visit www.centrelink.gov.au/ or attend your local Centrelink office.

## National Disability Insurance Scheme (NDIS)

NDIS provides support for eligible people with a permanent and significant disability, their families and their carers.

Children who meet the following criteria may be able to access the NDIS:

- Have a permanent and significant disability that affects their ability to take part in everyday activities.
- Are an Australian citizen, a permanent resident or a New Zealand citizen who holds a Protected Special Category Visa.

You can use the NDIS Checklist tool at: www.ndis.gov.au/ndis-access-checklist to find out if your child is eligible to receive assistance from the NDIS.

You can also get more information by calling the NDIS on 1800 800 110, visiting www.ndis.gov.au/qld or by eamiling enquiries@ndis.gov.au

If eligible, your child will be assessed in a planning and assessment process managed by the National Disability Insurance Agency (NDIA). Based on your plan, you will receive funding on an annual basis to purchase the supports, services, aids and equipment that he/she requires.

It will be helpful to gather the following information to take to your meeting:

- Letter of Diagnosis
- Any reports or letters with recommendations for your child (e.g. equipment, therapy, respite)

Your QPRS team or local community team can assist you with the planning process. You can also contact your Local Area Coordinator (LAC) to assess support with NDIS.

## Inclusion Support Scheme (ISS)

Inclusion Support aims to remove the barriers to access for children with additional needs. This is achieved through the Inclusion Support Agencies, Inclusion Support Subsidy and Flexible Support Funding. The target groups for inclusion support are:

- children with disability, including children with ongoing high support needs
- children from culturally and linguistically diverse backgrounds
- children from a refugee or humanitarian intervention background
- Indigenous children.

ISS assists eligible child care and early learning services to improve their capacity to include children with ongoing high support needs, including those with disability, so they can be cared for appropriately within a service. It may engage an additional child care and early learning educator to increase the educator-to-child ratio when a child or children with ongoing high support needs are in care.

Inclusion Support Subsidy is administered nationally by KU Children's Services, the National Inclusion Support Subsidy Provider (NISSP).

For more information call 11800 811 039, visit www.inclusionsupportqld.org.au or email inclusionsupportqld@ku.com.au

## Taxi Subsidy Scheme

The Taxi Subsidy Scheme subsidises taxi travel for people with severe disabilities. The total per trip is capped, please check our website for the latest information.

To be eligible you must be a permanent resident of Queensland and able to fully meet at least one of the six eligibility criteria listed below:

1. Physical disability requiring dependence on a wheelchair for all mobility outside the home.
2. Severe ambulatory problem that cannot functionally be improved and restricts walking to an extremely limited distance.
3. Total loss of vision or severe visual impairment (both eyes).
4. Severe and uncontrollable epilepsy with seizures involving loss of consciousness.
5. Intellectual impairment or dementia resulting in the need to be accompanied by another person at all times for travel on public transport.
6. Severe emotional and/or behaviour disorders with a level of disorganisation resulting in the need to be accompanied by another person at all times for travel on public transport.

www.qld.gov.au/disability/out-and-about/taxi-subsidy/

## Concessional parking

Concessional parking may be available in the Queensland Children's Hospital for:

- Patients and carers who are eligible for Centrelink payments or hold a current government concession card;
- Patients and carers who need to attend hospital for an extended period of time
- Patients and carers who attend hospital frequently.

Please refer to our website for concessional parking rates.

For further information on how concession parking is accessed, please read the full Children's Health Queensland Car Parking Concessions Policy.

Families who believe they may be eligible for concessional parking, please visit in the Patient and Family Travel Hub on Level 2 of the hospital, Monday to Friday from 7.30am to 6pm.

Families who require additional support are welcome to visit the Social Work and Welfare team on Level 6 (6f). Free parking may be available in certain circumstances where families can demonstrate urgent or extraordinary need. For example, when a child has been admitted from Emergency after hours and the parent or carer has no immediate access to funds or where there is no recourse to funds.

## Patient Travel Subsidy Scheme (PTSS):

If you live more than 50kms from a hospital, you can claim the cost of travelling to that hospital for appointments. You can also claim the cost of staying in local accommodation if you need to stay overnight for appointments over several days. Visit the Social Work and Welfare team on Level 6 (6f) to enquire if this is relevant to you.

## Companion Card

If you have a disability and a lifelong need for 'attendant care support' in order to participate in community activities and attend venues, the Companion Card can help with the costs of getting out and about with the support of a companion.

Attendant care support means significant assistance with mobility, communication, self-care or learning, where the use of aids, equipment or alternative strategies does not enable a person to carry out these tasks independently.

The Companion Card is issued in the name of the person who has a disability, and is valid for 5 years. A companion is any person who accompanies a cardholder and provides attendant care support. The cardholder's chosen companion may be a paid or unpaid assistant or carer, family member, friend or partner. Companion Card holders receive a second 'companion' ticket at no charge at participating venues and on public transport. The 'companion' ticket is also exempt from booking fees.

Visit www.qld.gov.au/disability/out-and-about/about-companion-card or call 13 74 68 for more information.

## Chronic Disease Management Scheme

The Chronic Disease Management Plan (CDMP, formerly called Enhanced Primary Care or EPC) — GP services on the Medicare Benefits Schedule (MBS) enable GPs to plan and coordinate the health care of patients with chronic or terminal medical conditions, including patients with these conditions who require multidisciplinary, team-based care from a GP and at least two other health or care providers. Cerebral palsy is recognised as a chronic medical condition and therefore you will be eligible to claim a rebate through Medicare for these services.

The CDMP provides a maximum of 5 total rebates per calendar year for all Allied Health services. This means that if you are accessing more than one Allied Health service, you are entitled to 5 rebates across all of the services combined, not 5 rebates per service.

www.health.gov.au/internet/main/publishing.nsf/Content/mbsprimarycare-chronicdiseasemanagement

## Other

There are a range of charities which may offer equipment or support specific fundraising activities (e.g. to purchase specific equipment for your child). Each charity has its own guidelines so we recommend you contact the charity directly to discuss this. Here are a few recommendations, but there are many other organisations that provide community grants.

- GiveAbility: www.giveability.com.au
- Variety Queensland: www.varietyqld.org
- Lions Club: lionsclubs.org.au
- Golden Casket: thelott.com/goldencasket/about/community
- Just Juniors Disability (sister site Aroha Angels): www.justjuniorsdisability.com

# Respite and support services

## National Disability Insurance Scheme (NDIS) respite:

As part of your NDIS plan, you can request funding for your child to access either in-home or out-of-home respite, with registered , approved carers. Visit www.ndis.gov.au/qld, call 1800 800 110 or email enquiries@ndis.gov.au for further information.

## Carers Queensland

Carers Queensland is a not-for-profit, non-government organisation and registered charity dedicated to supporting carers. It provides carers with:

- information to assist them in their caring role, including carer-specific publications and resources
- advice about the full range of services available for carers
- the opportunity to link together with other carers for companionship and support
- professional telephone and face-to-face counselling throughout Queensland
- training and education to support them in their caring role
- advocacy support to promote the rights and needs of carers with government service providers and others
- assistance to address issues of concern to carers.

Carers Queensland has offices in Brisbane, Gold Coast, Ipswich, Toowoomba, Sunshine Coast, Wide Bay, Rockhampton, Mackay, Townsville and Cairns.

Contact the Carers Queensland Carer Advisory Service on 1800 242 636 and Commonwealth Respite and Carelink Centre on 1800 052 222.

## Carer Gateway

If you care for a family member or friend, Carer Gateway can help by:

- providing practical information and advice
- supporting you to get the services you need
- providing free coaching to help you in your role
- connecting you with other carers through a community forum.

www.carergateway.gov.au

## Parent/carer specific programs

As well as support for all carers, there are parent/carer specific programs:

- MyTime playgroups are available across Queensland to help carers socialise and share ideas with others who understand about caring for a child with disability. Phone 1800 889 997.
- The Raising Children Network is an Australian Government resource for parents and carers of children with disability.
- Livewire, a program of the Starlight Children's Foundation, offers an online group for parents and carers of people living with a disability, serious illness or chronic health condition to connect and support one another via the internet. See www.livewire.org.au
- Benevolent Society Early Years Centre is a one-stop family hub that focusses on supporting families within the South Brisbane, Logan and Gold Coast area. They offer a range of free services including playgroups, toy libraries, parenting programs and family support services. See www.benevolent.org.au.

## Behaviour support

Behaviour support is usually needed when a child or young person's behaviour is interfering with their daily life, their ability to form relationships or their capacity to cope with or manage social situations.

Behaviour support services may help you to understand:

- why the behaviour might be occurring
- what triggers might be causing the behaviour
- how the behaviour can be supported or managed differently into the future.

Behaviour support is usually provided by a psychologist and is available to help you to develop strategies on how to prevent or reduce the behaviour and might involve providing education and support to you, your family, carers and others in your support network. You may wish to contact the following services to ask about behaviour support services:

- Choice, Passion, Life (CPL – forrmerly Cerebral Palsy League)
- Department of Communities, Child Safety and Disability Services
- Queensland Paediatric Rehabilitation Service
- Child and Youth Community Health Services
- 'Stepping Stones' Triple P (SSTP): Parents can register for free parenting sessions by going to www.triplep-steppingstones.net and clicking on the' Get Help' tab. The website also provides detailed information about the different types of programs available. Alternatively you can call on (07) 3365 6499.

## Section 5

# Research and resources

# Research and resources

## Is there much cerebral palsy research?

Good quality scientific research has led to many important improvements in the diagnosis, assessment and management of children with cerebral palsy. It also provides us with information about how many children have cerebral palsy, important characteristics of children with cerebral palsy and the supports they might need to participate in everyday life in our communities.

### CP Register

The CP Register is a database of clinical information about CP. Information collected about each person with CP includes birth details, type and severity of cerebral palsy, other associated impairments and parent demographics. There are CP Registers in each state and territory, as well as an Australian CP Register which consolidates the information and provides a national picture of CP. People with CP and their families are asked to register with their state or territory CP Register. We can provide you with information about the CP Register and begin the registration process for your child.

The QPRS has been involved in a number of local and national research studies and continues to develop research studies and recruit for research studies being run by universities and other organisations. The doctors and therapists you see at clinics may speak to you or send out information about studies that you and your child may be eligible to participate in.

### Queensland Cerebral Palsy and Rehabilitation Research Centre

The Queensland Cerebral Palsy and Rehabilitation Research Centre is a part of the QPRS. Their mission is to lead research, innovation and education to advance the health of children with cerebral palsy, acquired brain injury and related disabilities, supporting them and their families across their lifespan. You may be provided with information about relevant studies your child could participate in by email, mail or at your appointments. You can also find out more about the current research studies and who can participate in them on their website qcprrc.centre.uq.edu.au

### Queensland Early Detection and Intervention Network – Cerebral Palsy (QEDIN-CP)

QEDIN-CP consists of health professionals who have a special interest and training in the identification and care of infants who may be at risk of having CP.

QEDIN-CP's vision: To improve the health and wellbeing of children with cerebral palsy and their families through early detection and early intervention.

QEDIN-CP's mission: All children impacted by CP in Queensland will be identified and provided with the earliest possible diagnosis to enable best practice early intervention and fast tracking into clinical trials as part of a national strategy for CP.

QEDIN-CP's aims:

- To increase the early detection of infants at high risk or with CP to enable entry into interventions earlier at a time of maximum brain development.
- To provide information on support for families of infants identified early as being at high risk or of having CP.
- To increase the early diagnosis of those infants who are not currently identified as being at high risk for CP but have a medical history that indicates that they could potentially be at risk (50% of CP cases).
- To provide support for clinicians involved in the identification/diagnosis of infants who may have CP.
- To provide education and training on early detection and early interventions for infants at risk of CP, and the ongoing maintenance of clinical skills for early detection.

For more information, visit the QEDIN-CP website qcprrc.centre.uq.edu.au/qedin-cp

## Other useful websites/resources

**CanChild**: A research centre dedicated to generating knowledge and transforming lives of children and youth with developmental conditions. This site includes useful resources around all aspects of CP. www.canchild.ca

**Cerebral Palsy (CP) Alliance** www.cerebralpalsy.org.au
*Follow Your Instincts, Early Intervention Therapy* (0-2 guide)

**Cerebral Palsy Australia** cpaustralia.com.au

**Cerebral Palsy Support Network** www.cpsn.org.au

**Cerebral Palsy Guide:** Provides free educational materials, financial options and emotional support for those affected by cerebral palsy: www.cerebralpalsyguide.com

**Mable:** Find NDIS approved services www.mable.com.au

**Raising Children Network** raisingchildren.net.au

**National Disability Insurance Scheme** www.ndis.gov.au

**Novita Children's Services** www.novita.org.au

**Pathways** www.pathways.org

**Queenslander with a Disability Network** www.qdn.org.au

**Queensland Cerebral Palsy Register** www.qcpr.org.au

**Speaking Promotes Education and Knowledge** Free resources for speech and language development. deta.qld.gov.au/about/app/speak.html

**Siblings Australia** www.siblingsaustralia.org.au

***There's no such thing as a silly question***: A practical guide for families living with a child with chronic illness, disability, mental illness or a life-threatening condition www.sa.gov.au/__data/assets/pdf.../TheresNoSillyQuestion_SA_Edition.pdf

***The Brain That Changes Itself*** by Norman Doidge: insightful true stories about neuroplasticity.

**World CP Day** www.worldcpday.org

**Facebook groups (recommended by our caregiver feedback group)**

- Autism Parents Australia
- Cerebral Palsy parents Australia
- Cerebral Palsy parents information group
- HemiHelp
- Hope for HIE Australia
- Mild CP Support Group – Australia and New Zealand
- Brisbane Cerebral Palsy parents
- Parents for special needs kids – Brisbane
- QCH (special needs kids) Parents Connect
- NDIS self-managing participants and their families
- NDIS grassroots discussion

## Section 6

# Appendix

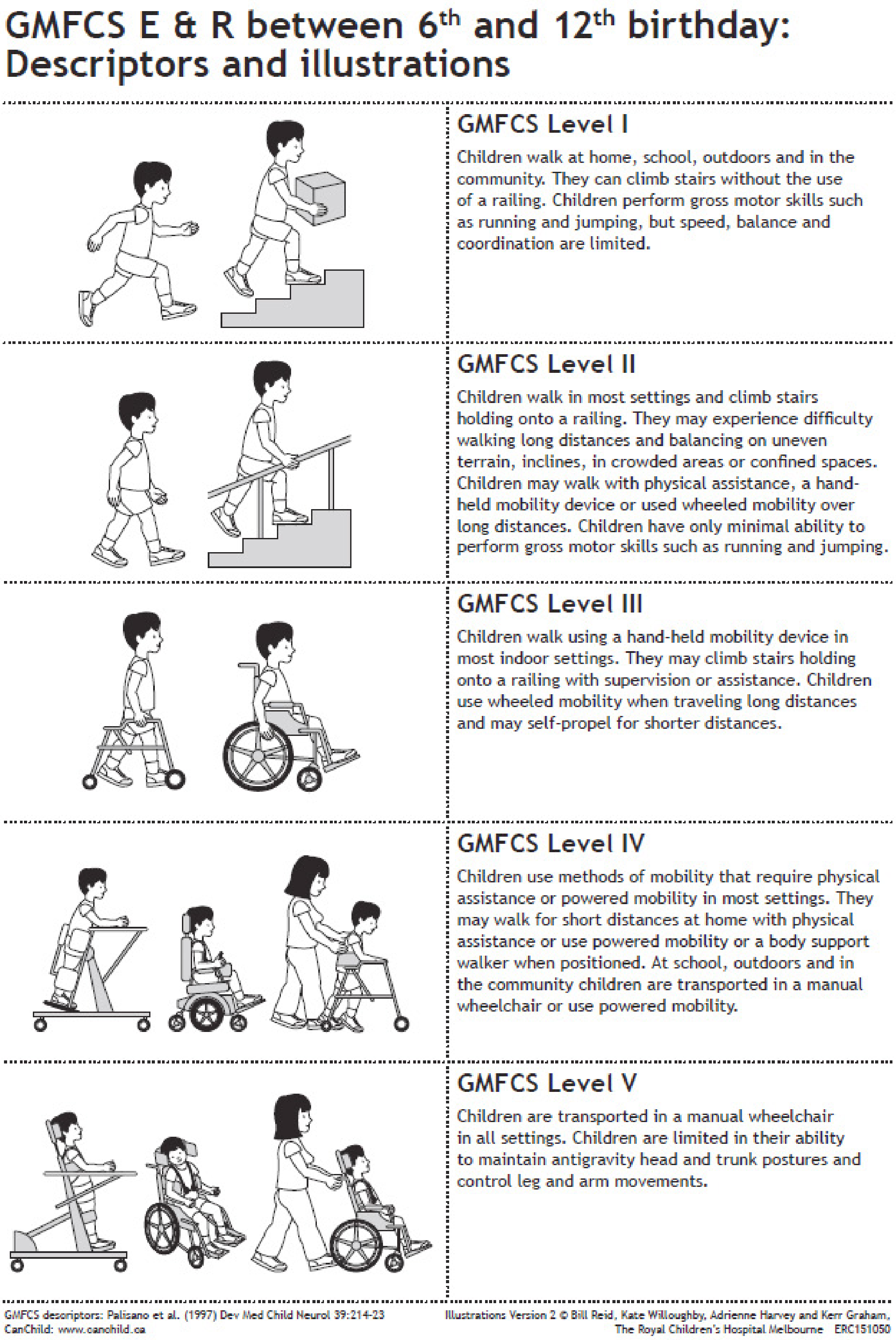
# Appendix 1:

## Classification: How is the severity of cerebral palsy described?

Before 2 years of age it is difficult to predict how much your child will be affected by cerebral palsy. Once the brain is fully matured your treating team will be able to talk you through the functional impact that cerebral palsy may have on your child. There are a few classification tools that are used within the cerebral palsy population so we have included the most common ones below:

### a. Gross Motor Functional Classification System (GMFCS- E&R):

The GMFCS-E&R classifies a child's gross motor functional ability according to five levels from Level I (able to walk independently with limitations in higher gross motor skills) to Level V (unable to sit alone) within the age group bands of 2-6 years, 6-12 years and 12-18 years. An example of the 6-12 years has been included below:



## GMFCS E & R between 6th and 12th birthday: Descriptors and illustrations

### GMFCS Level I

Children walk at home, school, outdoors and in the community. They can climb stairs without the use of a railing. Children perform gross motor skills such as running and jumping, but speed, balance and coordination are limited.

### GMFCS Level II

Children walk in most settings and climb stairs holding onto a railing. They may experience difficulty walking long distances and balancing on uneven terrain, inclines, in crowded areas or confined spaces. Children may walk with physical assistance, a hand-held mobility device or used wheeled mobility over long distances. Children have only minimal ability to perform gross motor skills such as running and jumping.

### GMFCS Level III

Children walk using a hand-held mobility device in most indoor settings. They may climb stairs holding onto a railing with supervision or assistance. Children use wheeled mobility when traveling long distances and may self-propel for shorter distances.

### GMFCS Level IV

Children use methods of mobility that require physical assistance or powered mobility in most settings. They may walk for short distances at home with physical assistance or use powered mobility or a body support walker when positioned. At school, outdoors and in the community children are transported in a manual wheelchair or use powered mobility.

### GMFCS Level V

Children are transported in a manual wheelchair in all settings. Children are limited in their ability to maintain antigravity head and trunk postures and control leg and arm movements.

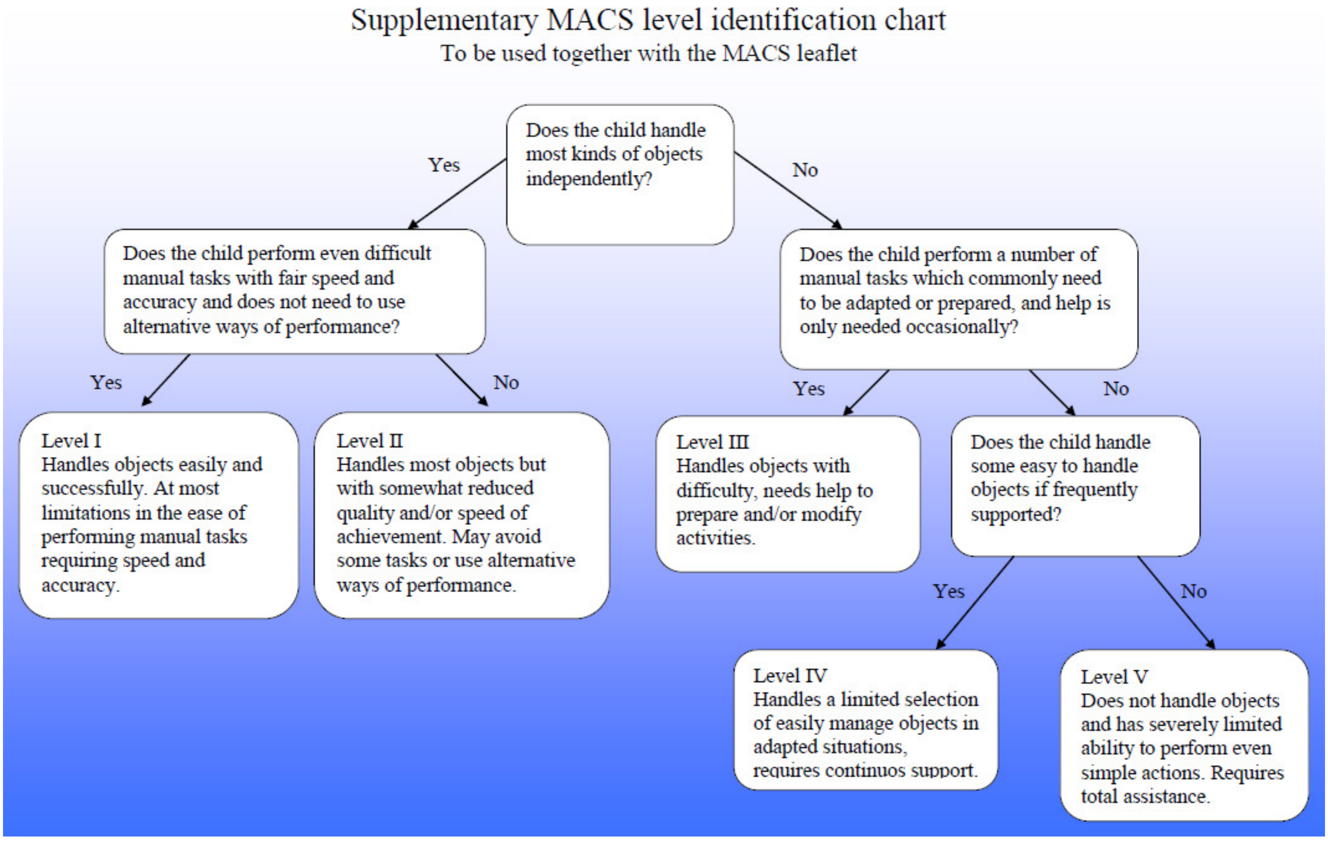
GMFCS descriptors: Palisano et al. (1997) Dev Med Child Neurol 39:214-23
CanChild: www.canchild.ca

Illustrations Version 2 © Bill Reid, Kate Willoughby, Adrienne Harvey and Kerr Graham,
The Royal Children's Hospital Melbourne ERC151050

### b. Manual Ability Classification Scale (MACS):

The MACS is a scale which describes a child's ability to handle objects and ranges from Level I (handles objects easily and successfully) to Level V (does not handle objects and has severely limited ability to perform even simple actions). It is used for children aged 4-18 years.

*Source: Eliasson et al, 2005 (updated 2010)*



Supplementary MACS level identification chart

To be used together with the MACS leaflet

Does the child handle most kinds of objects independently?

Does the child perform even difficult manual tasks with fair speed and accuracy and does not need to use alternative ways of performance?

Does the child perform a number of manual tasks which commonly need to be adapted or prepared, and help is only needed occasionally?

Level I
Handles objects easily and successfully. At most limitations in the ease of performing manual tasks requiring speed and accuracy.

Level II
Handles most objects but with somewhat reduced quality and/or speed of achievement. May avoid some tasks or use alternative ways of performance.

Level III
Handles objects with difficulty, needs help to prepare and/or modify activities.

Does the child handle some easy to handle objects if frequently supported?

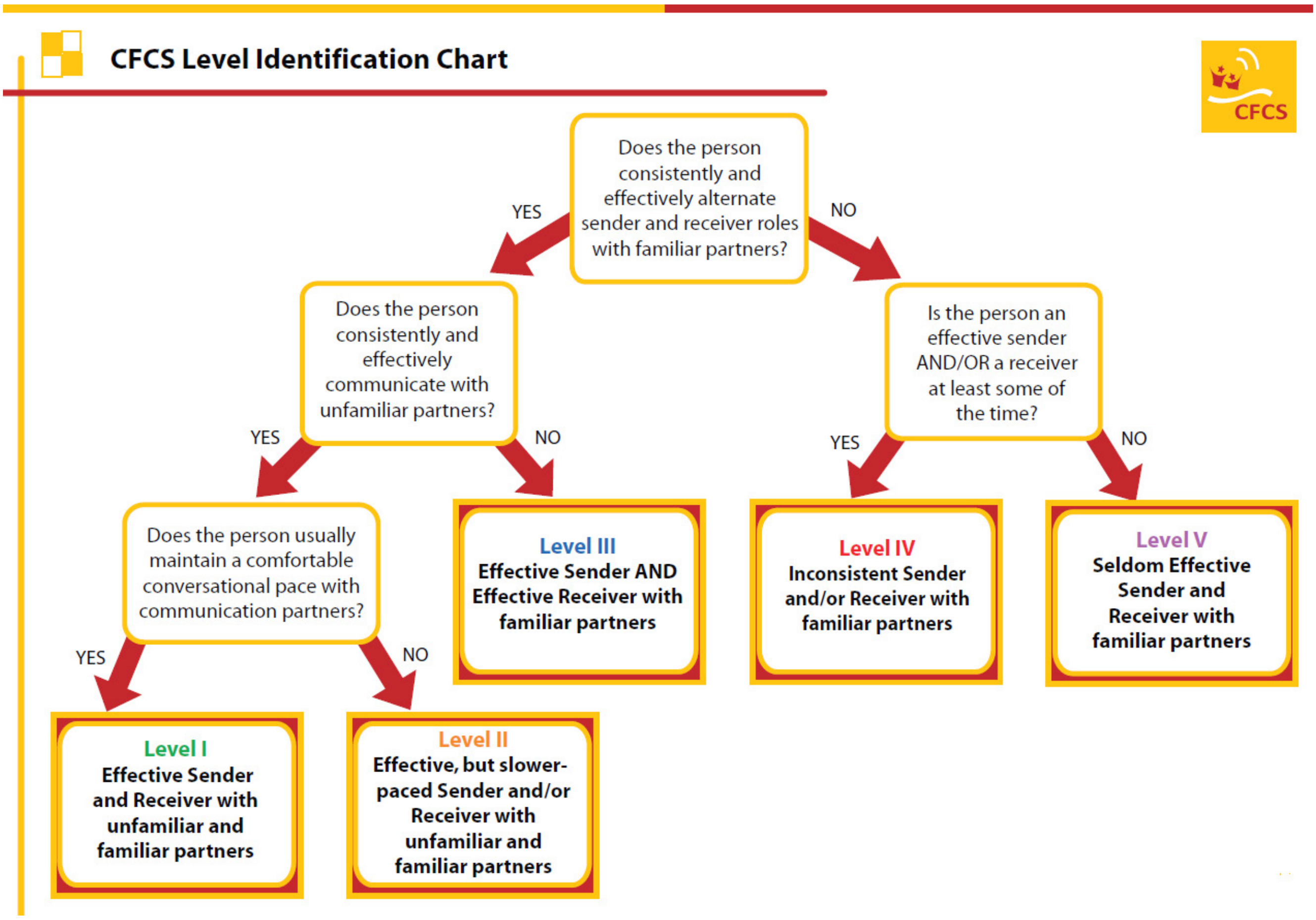
Level IV
Handles a limited selection of easily manage objects in adapted situations, requires continuos support.

Level V
Does not handle objects and has severely limited ability to perform even simple actions. Requires total assistance.

### c. Communication Functional Classification Scale (CFCS):

The CFCS classifies communication function and ranges from Level I (effective sender and receiver with unfamiliar and familiar partners) to Level V (seldom effective sender and receiver even with familiar partners).

*Source: Hidecker et al, 2011.*



CFCS Level Identification Chart

### d. Eating and Drinking Ability Classification System (EDACS):

The EDACS describes a child's ability to eat and drink and ranges from Level I (eats and drinks safely and efficiently) to Level V (unable to eat or drink safely). This is simplified below:

**Eating and drinking ability classification system**

| | |
|---|---|
| **Level I** | Eats and drinks safely and efficiently |
| **Level II** | Eats and drinks safely but with some limitations to efficiency |
| **Level III** | Eats and drinks with some limitations to safety; there may be limitations to efficiency |
| **Level IV** | Eats and drinks with significant limitations to safety |
| **Level V** | Unable to eat or drink safely – tube feeding may be considered to provide nutrition |

*Source: © Chailey Heritage Clinical Services 2013*

Historical evidence suggests that after two years of age, children generally (but not always) stay within the same classification bands. It is important to ask questions and discuss your child's classification with your treating team to have a better understanding of what this means for their functional progress and prognosis.

## Appendix 2

**Other QPRS fact sheets:**

- *About QPRS*
- *Ankle Foot Orthoses*
- *Common nutritional concerns for children with cerebral palsy*
- *Fluid needs of children with cerebral palsy*
- *How to help your child with cerebral palsy gain weight*
- *Management of constipation in children with cerebral palsy*
- *Minced and moist food textures*
- *Smooth, pureed food textures*
- *Social Work Services at QPRS*
- *Soft food textures*
- *Statewide Hip Surveillance Program*
- *Weight management for children with cerebral palsy*

Please ask one of our team members at your child's next appointment if you would like a copy of any of these.

### Notes

AUDAX AT FIDELIS

Queensland
Government

www.childrens.health.qld.gov.au

childrenshealthqld  @childhealthqld  queenslandchildrenshospital