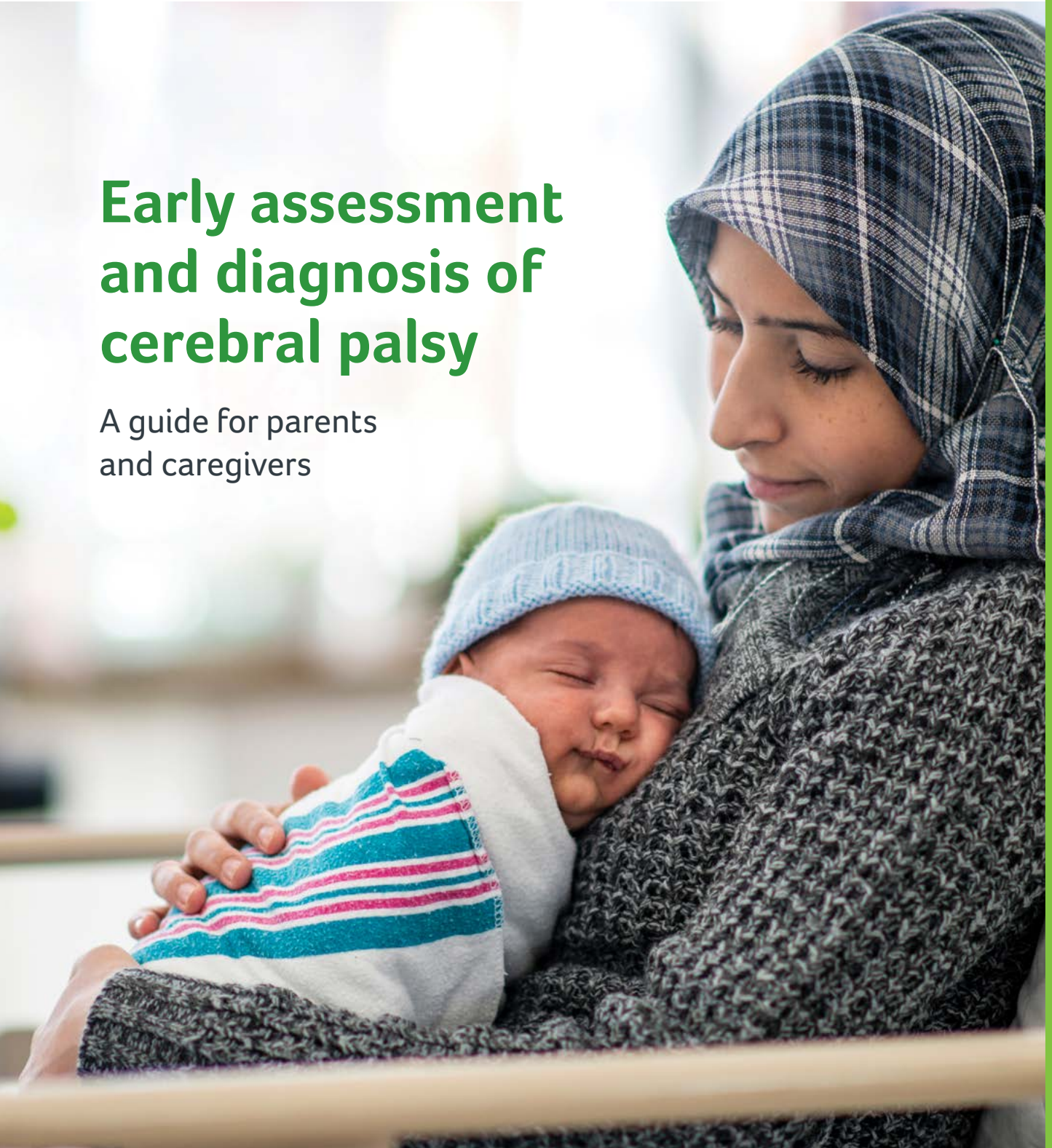




Cerebral Palsy
ALLIANCE

Early assessment and diagnosis of cerebral palsy

A guide for parents
and caregivers



Until recently, a diagnosis of cerebral palsy was often not made until a child was 12 to 18 months old. However, methods of diagnosis have improved greatly. Babies can now be diagnosed with cerebral palsy or at ‘high risk of cerebral palsy’ (where a baby is thought to have cerebral palsy but it is not yet certain), as early as three months old.

Receiving any type of diagnosis can be hard. For parents, hearing the diagnosis of ‘cerebral palsy’ for the first time can lead to a range of different thoughts, emotions and experiences. For some parents having the right words to describe the needs of their child is a relief. Something was not quite right and now with a diagnosis, they can seek the right help and support. For others though, a diagnosis of cerebral palsy is unexpected. It may be met with shock, sadness, an overload of information and fear of the unknown.

A diagnosis says what condition your child has. It is important for understanding how to care for your child in the best way and in order to receive the right services and supports. But a diagnosis does not define your child. It is just one part of who they are and will be. People with cerebral palsy go to preschool, school and university. They can go on to work in successful careers, have relationships and families and achieve their goals.



What is cerebral palsy?

Cerebral palsy (pronounced seh – ruh – bruhl pawl- zee) is the term for a group of physical disorders that affect movement and posture.

Cerebral palsy can arise from an injury to a baby's brain as it develops. This may be before, during or after birth. Or in some cases, it can happen because of genetic changes.

Cerebral palsy is a lifelong physical disability. Although there is no cure for cerebral palsy, there are many ways to support a child with cerebral palsy to lead a full and happy life and reach their potential.



Early diagnosis, early intervention

Cerebral palsy can now be accurately diagnosed as early as three months of age. With a diagnosis early intervention can begin. Early intervention refers to specialised supports and services that are introduced early in life to help a child develop and reach their full potential.

Early intervention can help with movement, cognition, communication, feeding, nutrition and growth, sleeping and family wellbeing. Research shows that starting intervention as early as possible will give any child, regardless of their condition or diagnosis, their best chance of learning.



Why is early intervention so critical?

Early intervention for babies and children with cerebral palsy is essential for developing cortical connections in the brain. The brain changes constantly in response to input that is received. This means the experiences and opportunities a baby has when it is very young shapes the way the brain develops. The ability for the brain to change itself in this way is called neuroplasticity.

Babies and children who receive cerebral palsy-specific early intervention will benefit from vital learning opportunities during this critical window of neuroplasticity. This is why it is so important for intervention to start early. The right diagnosis is often the first step to making this happen.



Who is Cerebral Palsy Alliance (CPA)?

CPA is a leading provider of evidence-based assessment, early intervention therapies, and services for babies and children with cerebral palsy and similar disabilities. They continue to support people living with CP of all ages, throughout their journey. Our research foundation supports the world's best and brightest researchers to identify and develop prevention, treatment, and cures for cerebral palsy.

What's in this guide?

This guide is for families of babies and young children with cerebral palsy or 'at high risk of cerebral palsy'. It will help parents and caregivers understand what cerebral palsy is, how it is diagnosed, and how to access treatment and services.

The guide includes information about:

- Common risk factors
- Early diagnosis
- Common tools and assessments
- Receiving a diagnosis
- Pathways of support for infants
- Early intervention.

This guide provides general information only. It is not intended to replace specific advice offered by your doctors or other health professionals. Please consult with your doctor or health team for advice personalised for you and your circumstances.

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Who is at risk of cerebral palsy?

Cerebral Palsy is the most common physical disability in childhood. In Australia, 1 in 700 babies is diagnosed with cerebral palsy. This means every 20 hours, an Australian child is born with cerebral palsy. As there is no pre-birth test for cerebral palsy, there is currently no way of knowing if a baby will be born with it.

We now know from research that there are certain risk factors for cerebral palsy. Risk factors may occur during a woman's pregnancy, as a baby is being born, or after they are born. Sometimes these risk factors cluster together to form a 'causal pathway'. A causal pathway is complex series of events that can cause or add to brain damage. This can lead to a diagnosis of cerebral palsy.



Risk factors associated with pregnancy history:

- Previous stillbirths or miscarriages
- IVF
- Maternal thyroid disease
- Pre-eclampsia
- Abnormalities of the placenta
- Bleeding
- Infection during pregnancy e.g. CMV, Rubella, Influenza
- Substance abuse
- Multiple births (twins/triplets/quadruplets), especially if the babies are born early or one baby dies during the pregnancy.



Risk factors associated with birth history:

- Born prematurely
- Admitted to a neonatal intensive care unit (NICU)
- Born with neonatal encephalopathy (involving seizures and resuscitation)
- Born with birth defects (of the brain, heart or limbs)
- Born with or admitted to hospital following a stroke
- Born too small (growth restriction during pregnancy)
- Low sugars (hypoglycemia) at birth
- Jaundice at or after birth
- Born with an infection or a brain infection shortly after birth
- Car accident or other accident during pregnancy or shortly after birth.

Babies with any of these risk factors, or groups of risk factors, should be screened for cerebral palsy as soon as possible.





What if my baby has no risk factors for cerebral palsy?

Some babies and children who go on to receive a diagnosis of cerebral palsy, will not show any risk factors.

If your baby doesn't have any of the known cerebral palsy risk factors but you are concerned something isn't right, you can speak with your family, community nurses or GP.

Don't be afraid to seek the information and support you need. This may come from family, friends, healthcare professionals and disability support services.

It's important to trust your instincts about what is right for your child and keep asking for help.

What signs should I look for?

Babies born very early (prematurely) are usually monitored carefully in hospital and after they go home to look for any signs of cerebral palsy. So are babies who are known to have had a brain injury (neonatal encephalopathy or stroke). But often it is parents, GPs, community nurses or other health professionals who notice something may be different about a baby's development.

If your baby has any of the following six signs, consider taking them to a Paediatrician or Neurologist to be tested for cerebral palsy:



Your baby seems to prefer using one hand more than the other (this happens before they are 12 months of age).



Your baby makes tight fists with their hands (this continues past 4 months of age).



Your baby's legs feel stiff or tight. They may not be able to bring their toes to their mouth during nappy changes (this happens between 6-12 months of age).



Your baby is unable to hold their head up without help (this continues past 4 months of age).



Your baby is unable to sit up by themselves (this continues past 9 months of age).



Your baby seems to prefer to use one side of their body or they lean to one side (this happens when they are moving and also when they are still).

If you see any of these signs it does not mean your baby definitely has cerebral palsy. But it is a good idea to talk with your health practitioner as more tests may be needed.



It is also important to speak with your doctor as early as possible if your baby:

- Finds it hard to eat, drink or swallow. For example, they may make gurgly sounds, take a long time to feed, choke or cough on solids, or get sick with repeated chest infections
- Is slow to develop communication skills. For example, they do not make babbling sounds, they do not make gestures with their hands, or they do not show interest in objects or people
- Has poor sleep patterns
- Has pain in their body. It can be hard to know if a baby is in pain but they may cry, fuss, squirm and move their body, or scrunch up their face
- Finds it hard to see or hear.

If your baby has any of these symptoms, there are things that you can do. Your health team can connect you with the right supports.

When is cerebral palsy diagnosed?

The diagnosis of cerebral palsy can and should be made as early as possible for parents and their babies. This is so the right help can be sought. The diagnosis can often be made at three months of age. However, if pregnancy was normal, delivery was on-time and the baby was healthy at birth, signs may not arise until later in a baby's development.

Doctors may suspect cerebral palsy if a baby is delayed in their movements, has tight or floppy muscles, or displays unusual postures like prolonged fistled hands or an early hand dominance. However, in most cases more information than this will be needed to make a diagnosis. This could include a brain scan, a neurological assessment, or genetic tests.

Until they are sure of a diagnosis, your doctor may use the words "high risk of cerebral palsy". This is so your baby will be able to access cerebral palsy specific treatments instead of general care.



How is cerebral palsy diagnosed?



Cerebral palsy is a complex condition. Making a diagnosis is not always straightforward. However it is becoming clearer which tests to conduct and what information needs to be considered.

The international research community agrees that early diagnosis of cerebral palsy is

98% accurate

when three specific tests show that cerebral palsy is likely. Along with these tests, your baby's medical history will also be considered.



Movement Assessment

A test of your baby's movements is done when they are between 8 weeks old and 20 weeks old (or 8-20 weeks after their due date if they were born premature). This test is called the General Movements Assessment (GMs).

A video is taken of your baby when they are lying comfortably on their back. The movements your baby makes are recorded. You can take this video yourself. Or you can ask a health professional to do this for you. The video is uploaded to a secure app. A trained scorer then looks at the type and quality of the movements your baby is making. They can work out your baby's risk of cerebral palsy from their movements.



Brain Scan

Medical Resonance Imaging (MRI) is the best type of brain scan for a baby who is thought to have cerebral palsy. The doctor looks at the scans to see if there is any damage in the movement parts of the brain.

If your baby was premature they may have had a head ultrasound while they were in the Neonatal Intensive Care Unit. Head ultrasounds are good when a problem in the brain is quite large. But they can miss the type of damage that is seen when cerebral palsy is mild.

This is why your baby may also need to have a MRI. If your baby is older than 3 months they may move quite a bit. They may need anesthetic to stay still. This is why an MRI is sometimes left until your baby is older.



Neurological Assessment

Cerebral palsy is caused by an injury to the brain. The brain and the nerves in the body make up the nervous system. The word 'neurological' refers to the nervous system and what it does.

Therefore, if your baby is thought to have cerebral palsy they will need a neurological test. The Hammersmith Infant Neurological Examination (HINE) is a test of neurological function (how well your baby's nervous system works). It tests your baby's reflexes, posture and movement. It also tests their nerve function, how alert they are and their attention. A low score on the HINE means higher risk of cerebral palsy.

What information is included in a diagnosis of cerebral palsy?

It is possible to diagnose cerebral palsy early. But, for a child under two years of age it can be hard to know:

- The type of cerebral palsy
- Which parts of the body may be affected
- How movements may be affected
- How severe the cerebral palsy may be.

Types of cerebral palsy



- **Spastic:** the most common form of cerebral palsy characterised by muscles that feel stiff and tight.
- **Dyskinetic:** characterised by involuntary movements (i.e. out of a person's control).
- **Ataxic:** characterised by shaky movements, also affects balance and sense of positioning in space.

Mixed: a combination of types.

Parts of the body and movements affected



Quadriplegia

Both arms and legs are affected. The muscles of the trunk, face and mouth are often also affected.



Diplegia

Both legs are affected. The arms may be affected to a lesser extent.



Hemiplegia

One side of the body (one arm and one leg) is affected.

Severity

Cerebral palsy can vary in level of severity. The severity of cerebral palsy is classified according to **gross motor function**, **hand function** and **communication function**.

A classification system is a way to describe different levels of ability in individuals with cerebral palsy using common language. Classification systems used to describe cerebral palsy, such as the Gross Motor Function Classification System (GMFCS), are described in more detail in the Cerebral Palsy Alliance Early Intervention Guide (0-2 Years) available to download at www.cerebralpalsy.org.au.

Getting started with early intervention

Early intervention improves physical and cognitive outcomes for children with cerebral palsy or at 'high risk of cerebral palsy'. It is important that intervention, or 'therapy', starts as soon as possible in order to support your child to achieve their best possible outcomes.

There are many interventions available for children with cerebral palsy. There are also lots of different providers offering therapy and support. You may be thinking, "How do I know which interventions we should do, and which ones we shouldn't?" A team of therapists, each with different knowledge and skills, will support your child's unique needs and your family's. They will recommend interventions supported by high quality research to support your child's development across all areas.



Your child deserves the best evidence-based care and support available. Through the work we conduct at the Cerebral Palsy Alliance Research Institute, we have access to a growing library of research that identifies which therapies work, which ones don't, and how much of the right therapy is needed to really make a difference. Our therapists use this research to guide their decision-making and ensure you are receiving the right supports.



We have also used this information to create a series of downloadable tools to help the families of babies and children living with cerebral palsy find information about interventions that will deliver the best outcomes. To download these resources and other information go to our website at www.cerebralpalsy.org.au



Guides for parents

If you would like to read more information about early intervention for cerebral palsy there are a number of resources on the Cerebral Palsy Alliance website. Our guides, *Early Intervention Therapy - A guide for parents of babies and children 0-2 with cerebral palsy* and *Identifying the right intervention for your child* include helpful information about which interventions may be right for your child's needs.

Visit www.cerebralpalsy.org.au to download those resources and find more information about CPA services and support.

Support for parents and families

It can be frustrating, stressful and concerning when diagnosis takes a long time. You may feel unsure or confused about the information you are hearing. It is also common to experience feelings of grief and loss at the time of receiving a diagnosis of cerebral palsy or high risk of cerebral palsy. Parents and families tell us it is important to identify the people in your life who can support you.

For example, family and friends can offer much needed emotional and practical assistance. Your healthcare team can help you by providing information personalised to you, your child and your family. They can also help connect you with other parents who may be experiencing something similar. You may find that linking in with informal community groups on social media (e.g. Facebook), can help you feel connected to others going through a similar experience.

Take the time to be kind to yourself. You will have more questions than answers. With time, information and experience, understanding and accepting a diagnosis of cerebral palsy helps families to move forward and be the best family they can be.

If you need support or would like to talk to a trained professional about your experience, you can contact the following services.

Carers Australia

Short-term counselling and emotional and psychological support services for carers and their families.

1800 242 636

www.carersaustralia.com.au

Family Relationship Advice Line

A national phone service that helps families affected by relationship or separation issues.

1800 050 321

Lifeline

24-hour crisis support telephone service.

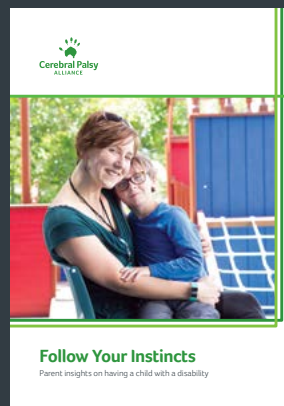
131 114

www.lifeline.org.au/about/our-services/

Raising Children Network

List of parent helplines and hot lines across Australia.

raisingchildren.net.au/grown-ups/services-support/about-services-support/helplines#general-helplines-australia-wide-nav-title



Follow your instincts – A Parent Guide

Many families have said hearing from other parents about their experiences provided great support, encouragement and strength as they navigated a pathway for their child's wellbeing and future opportunities. We are grateful to all the families who kindly shared their experiences so that others may benefit. To download this resource and other information go to our website: www.cerebralpalsy.org.au

References

This guide was adapted with permission from:

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