



GIG
CYMRU
NHS
WALES

Bwrdd Iechyd Prifysgol
Cwm Taf Morgannwg
University Health Board

Supporting families

of children
with cerebral
palsy



Developed with support from local
families and healthcare professionals.



Introduction

This leaflet has been designed to provide information to families with a child recently diagnosed with cerebral palsy.

1

What is cerebral palsy?

2

How will this affect my child?

3

Who will support my child?

4

How can I support my child?

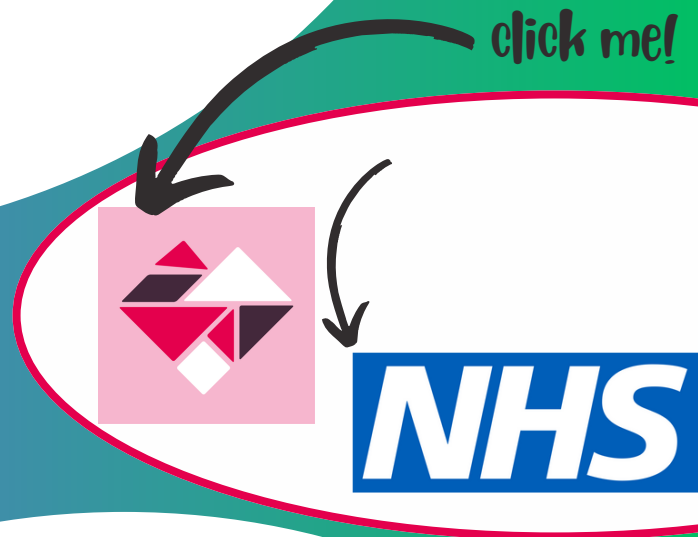
5

Where can I learn more?

Look out for this red box! It will have links to other sources of information!

What is cerebral palsy?

Cerebral palsy (CP) is the name for a **group of conditions that affect the brain** of a growing infant. Specifically, the messages sent from the brain to the muscles and back again. This causes difficulties **with movement**, posture and muscle control. It is the most common cause of physical disability in childhood in the UK.



What causes it?

CP is caused by **damage to the brain** during pregnancy, during birth or during the first two years of life. This can be from reduced oxygen supply, bleeding, infection or injury. Sometimes the cause is never found. The damage is **lifelong**, meaning there is no cure. Children might experience changes to their function as they grow but there are lots of ways to help your child.

How will this affect my child?

Cerebral palsy (CP) affects each child differently. It depends on the size and location of the brain damage. Some children may have other health or developmental difficulties like epilepsy, feeding difficulty or learning difficulties in addition to movement limitations.

Classification systems have been developed to help healthcare professionals describe the functional impact of CP upon your child. Below are two of these classification systems. There are others describing the impact on upper limb function and on speech.

CP Types

SPASTIC: 70-80%

Most common form.
Muscles appear stiff and tight.
Arises from Motor Cortex damage.

DYSKINETIC: 6%

Characterised by involuntary movements. Arises from Basal Ganglia damage.

ATAXIC: 6%

Characterised by shaky movements.
Affects balance and sense of positioning in space.
Arises from Cerebellum damage.

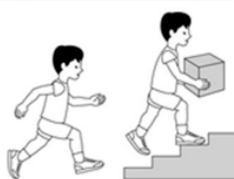
MIXED TYPES:
Combination damage.

click me!

GMFCS (Gross Motor Function Classification System)

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.



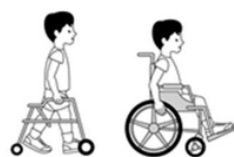
GMFCS Level II

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.



click me!

Parents often find **dealing with uncertainty** difficult when their child is first diagnosed with CP.

Taking it one day at a time can be a good way to manage this. **Reach out** to your family and friends, support organisations and other families .

Engaging with support services such as physiotherapy will **help your child reach their full potential**.



Who will support my child?

Some, or all, of these professionals might be involved (depending on your child's needs).

Doctors

These may be paediatricians, community paediatricians, neurologists and / or orthopaedic surgeons.

Occupational therapists (OT)

Work with your child on meaningful, functional goals to improve their play and living skills. Your child may also require adaptive equipment at home and school to support their independence.



Physiotherapists (PT)

support with advice and exercises based around everyday activities to help increase muscle strength and control, improve balance, improve movement and support the development of functional skills and independence

Speech and Language Therapy (SLT)

Support your child with communication. This may require communication aids. Assess and advise on swallowing as difficulties with this are a risk for aspiration.

Health Visitor

Work with you and your family to identify any health / developmental needs. They are a great first point of contact, advice and can refer you to local services.

Dietitian

Support you and your child to achieve optimum nutrition to aid growth, daily functioning and wellbeing. This may be through a range of feeding techniques and could involve specialist nutrition products.

click me!



Charities and organisations

Some local support organisations are discussed later.

How can I support my child?

- **Develop goals with you child and the health care team.**

As one goal is achieved, develop the next one.

- **Encourage their ambitions and talents.**

There are numerous activities available which are safe and adapted for children with CP.

- **Provide a safe, patient and nurturing environment for them to learn and grow.**

As with all children, children with CP require love, patience, safety and security to thrive to the best of their ability.



Raising a child with a disability takes time, effort, empathy and patience. *You got this!*



click me!



- **Engage with therapy at home.**

Your physiotherapists and other therapists will offer you guidance during your appointments. Following this advice at home will help your child's health and development.

- **Look after yourself.**

Develop a support network . There will be good and bad days. Developing healthy coping mechanisms to manage this will benefit yourself, your family and your child in the long term.

- **Seek support when you need it.**

Don't be afraid to ask for help. Reaching out to other parents, your health care team or other support organisations may be beneficial. Learning about CP can be a great way to feel in control. Just make sure the information is from appropriate sources (there are loads to start with in this leaflet!).

The Six F-Words for Child Development

1



FUNCTION

I might do things differently but I CAN do them. How I do it is not important. Please let me try!



2

FAMILY

They know me best and I trust them to do what's best for me. Listen to them. Talk to them. Hear them. Respect them.

3



FITNESS

Everyone needs to stay fit and healthy, including me. Help me find ways to keep fit.



4

FRIENDS

Having childhood friends is important. Please give me opportunities to make friends with my peers.

5



FUN

Childhood is about fun and play. This is how I learn and grow. Please help me do the activities that I find the most fun.



6

FUTURE

I will grow up one day, so please find ways for me to develop independence and be included in my community.

Where can I learn more?

There are lots of charities/ support organisations that work to support children with CP. Their websites often have tonnes of useful information. Below are just a few that you could consider.

click me! 

The logos on the right all have links to websites!



CP Cymru

Locally, lots of families are referred to CP Cymru. If your baby is under the age of 2 years old you can self-refer to the Better Start Better Future early intervention service.

This service comes highly recommended by many families

They also have tonnes of information on their website and their family support service can be a good way to meet other families.

Scope

A charity campaigning for disability equality in England and Wales. They provide practical information and emotional support.



Whizz-Kidz

Work with young wheelchair users and families to provide the right wheelchair and equipment for them. They also provide programs to help your child get the most out of their equipment.



Cerebra

Cerebra are a charity that support children with brain conditions. They have loads of information including Parent Guides and Factsheets, a sleep advice service and a legal rights service.





Books, magazines, podcasts

Cerebral Palsy Guide and Cerebral Palsy Foundation have lists of useful resources such as books, podcasts etc. This includes children's books.

Other leaflets similar to this one

Other health boards have developed information leaflets about CP similar to this one. The University College London Hospitals website in particular has lots of information on other aspects like 'bowel and bladder dysfunction', 'activities of daily living' and 'fatigue management'. The Cambridgeshire Community Services has information on hip and spine surveillance.

The logos all have links to the relevant websites.



Other sources of information

SNAP Cymru

A charity in Wales that offers advice and support with your child's educational needs.



GOV.uk

Has advice and information regarding disability living allowance and special educational needs.



Disability Sport Wales

Offers thousands of disability inclusive sport opportunities throughout Wales.



GIG
CYMRU
NHS
WALES

Bwrdd Iechyd Prifysgol
Cwm Taf Morgannwg
University Health Board

This leaflet was made with support and feedback from local families and healthcare professionals. We would like to thank them for giving up their time. Their contribution is invaluable. If you have any feedback for our service, please don't hesitate to get in touch.