

CEREBRAL PALSY - HŌKAI NUKURANGI

# The Early Years - Kete -



Cerebral Palsy Society  
*freedom & choice*

Starship  
Foundation

Supported by Starship Foundation and the Athlae Lyon Starship Research Trust



# Contents

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For more information about Cerebral Palsy and The Early Years toolkit, go to [www.cerebralpalsy.org.nz](http://www.cerebralpalsy.org.nz)





# Introduction

Nau mai, haere mai and welcome.

Congratulations, you have a beautiful new addition to your whānau.

This kete/toolkit is for whānau/families looking for health-related information and resources for their child living with cerebral palsy in Aotearoa New Zealand.

If you have recently found out your child has cerebral palsy, this kete is here to inform you about some of the health resources and services available to help you and your child thrive.

Cerebral palsy (often referred to as CP) affects children in different ways and their life journey may be different from what you had planned.

For many people, the medical terms you will start to hear associated with cerebral palsy are like a 'new language' - we hope this booklet helps you with this.

Focus on what your baby can do. Every child is unique and there is so much you can achieve together. You may experience many emotions, so look after yourself and your whānau.

## Acknowledgements

This kete is an outcome of work by the CaPTuRE project that explored the experiences of whānau who had received a CP diagnosis in Aotearoa New Zealand. Whānau with lived experience of cerebral palsy identified a range of different challenges and actions that may help others<sup>1</sup>.

Thank you to the Starship Foundation and the Athlae Lyon Starship Research Trust for the funding support, and for the additional funding support received by the Cerebral Palsy Society from the Sutherland Self Help Trust and Trillian Trust to support this document's presentation, translation and sharing with whānau.

We are very grateful to all the people who contributed to this work, including whānau and people with lived experience of CP; the Cerebral Palsy Society of New Zealand and health professionals across Aotearoa New Zealand.

1. Williams SA, Nakarada-Kordic I, Mackey AH, Reay S, Stott NS. Prioritized strategies to improve diagnosis and early management of cerebral palsy for both Māori and non-Māori families. *Dev Med Child Neurol.* 2024; 66: 1074-1083. <https://doi.org/10.1111/dmcn.15847>

## Te Whare Tapa Whā

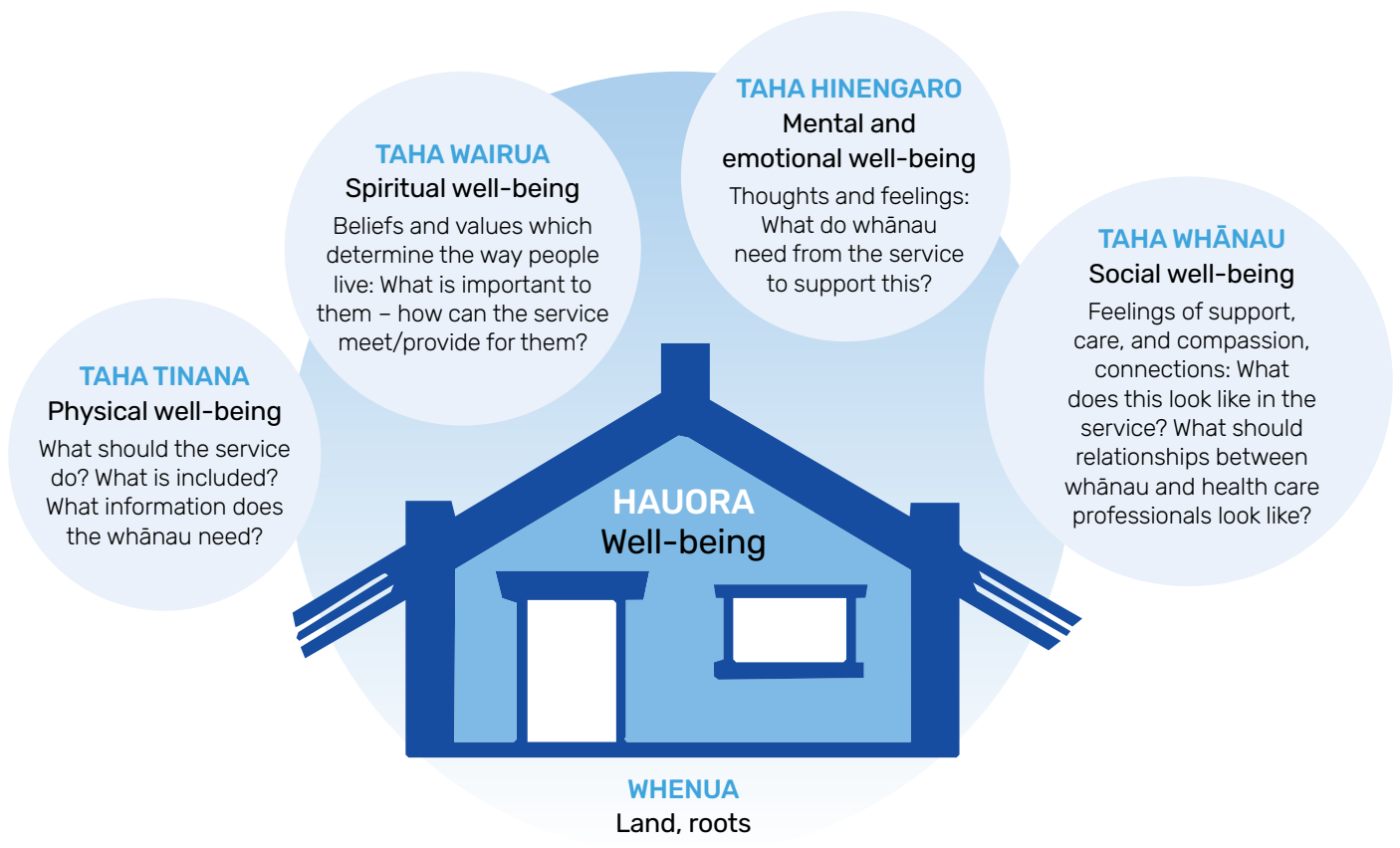
A well-known Māori model of health, Te Whare Tapa Whā described by Sir Mason Durie, considers all aspects of wellbeing and how they impact on hauora/health. Physical health or taha tinana is just one aspect of health and wellbeing.

This kete has been created to include information on all aspects of wellbeing. Whānau have indicated to us that it is important to

consider all aspects of wellbeing to help you manage feelings that may arise.

Don't be afraid to reach out for support on this life journey.

See: [www.mentalhealth.org.nz/te-whare-tapa-wha](http://www.mentalhealth.org.nz/te-whare-tapa-wha)  
From: Durie M. Whaiora: Māori Health Development. 2nd ed. Oxford, UK: Oxford University Press; 1994.



## Hōkai Nukurangi

The te Reo Māori term for Cerebral Palsy is Hōkai Nukurangi – to achieve what is important to you.

The term was developed by linguist and educator Matua Keri Opai\*.

The essence of Hōkai Nukurangi is: Whether traversing (hōkai) the earth (nuku) in body or traversing the sky (rangī) in mind and spirit, a person adapts to different environments, utilising the means and abilities that are appropriate to them.

In Keri's discussions with Māori/non-Māori people and whānau with cerebral palsy, this was the most prominent, consistent, important theme – that each individual and each individual whānau had different wants, needs and goals that they desired out of a good, happy life. Keri's term expresses that concept.

For more information go to:  
[www.youtube.com/watch?v=9rVG9dySafw](https://www.youtube.com/watch?v=9rVG9dySafw)

\* Opai, K. (2022), Words have great power: Creating Māori concepts of disability. Dev Med Child Neurol, 64: 1182-1182. <https://doi.org/10.1111/dmcn.15266>



## Cerebral Palsy - Hōkai Nukurangi:

# What is CP?

### Key points:

- People with cerebral palsy (CP) can live happy and fulfilling lives.
- Your child with CP is unique.
- You can get support and information from other whānau with children with CP, organisations and health professionals.
- It can be very difficult waiting to find out how CP will impact your child's movement.
- People living with CP can have difficulty with general movements, such as rolling and harder activities such as walking or using their hands in everyday tasks.
- People living with CP may have other medical conditions, including epilepsy, and/or difficulties with seeing, learning, or talking.

### What is CP?

- CP is a lifelong condition and refers to a group of permanent conditions caused by a disturbance or insult to the brain during development.
- The way CP impacts your child's movement, and posture (how they sit and stand) is different and can depend on when the brain disturbance occurred, and which parts of the brain are affected.
- The disturbance or insult to the development of the infant brain mainly occurs during pregnancy, birth or very soon after birth (for approximately 9 out of 10 people with CP).
- The term CP also includes when the brain insult occurs later, after one month of age, up to two years of age (for approximately 1 out of 10 of people with CP).
- There is no one cause of all CP. There are many possible causes, risk factors and/or events that can lead to CP.

**"Don't place a ceiling to what the child might achieve - every child is unique." - FAMILY QUOTE**

- Sometimes the exact cause leading to CP is unknown.
- For all types of CP, the initial disturbance or insult to the brain often stays the same. The impact on your child's physical development can change over time as they grow.

### Getting a diagnosis of CP – a pathway to diagnosis

- The pathway to receiving a diagnosis of CP is different for everyone and may be very challenging.
- For some whānau there may be factors that indicate early on that their baby is at a high chance of having CP, for example being born very early or having a very low birth weight.
- For other whānau, delays in development milestones can be a sign to talk with your child's health professionals.
- Whānau have told us that while they were waiting to get a diagnosis for their child, they felt a lot of different emotions including relief, stress, anger, grief and uncertainty.
- Currently in Aotearoa New Zealand most children get a diagnosis of CP before 2 years of age.
- Many whānau recognise much earlier that their child has different development needs.

### Cerebral Palsy in Aotearoa New Zealand

- CP is the most common physical disability in childhood, occurring in approximately 1 in every 500-600 babies born in Aotearoa New Zealand.
- It is estimated that there are up to 10,000 people living with CP in Aotearoa New Zealand.



## Key New Zealand sources of information on Cerebral Palsy

### Kidshealth NZ

Information for New Zealand whānau about the health and wellbeing of children/tamariki.

[www.kidshealth.org.nz/cerebral-palsy](http://www.kidshealth.org.nz/cerebral-palsy)

### Healthify – formerly Health Navigator

Service and resource information on living with CP in Aotearoa New Zealand – similar content to Kidshealth NZ.

[www.healthify.nz/health-a-z/c/cerebral-palsy](http://www.healthify.nz/health-a-z/c/cerebral-palsy)

### Cerebral Palsy Society of NZ

A member-based organisation that works to enhance the lives of people with CP, by providing programmes, support and advice.

[www.cerebralpalsy.org.nz](http://www.cerebralpalsy.org.nz)

### NZ Cerebral Palsy Register (NZCPR)

Te Rēhita a Hōkai Nukurangi Aotearoa

The register collates information on CP in Aotearoa New Zealand, used to assist advocacy, health planning and research. Participation is voluntary.

[www.starship.org.nz/health-professionals/cerebral-palsy-research](http://www.starship.org.nz/health-professionals/cerebral-palsy-research)

“You don't need to do or know everything at once.”

- FAMILY QUOTE

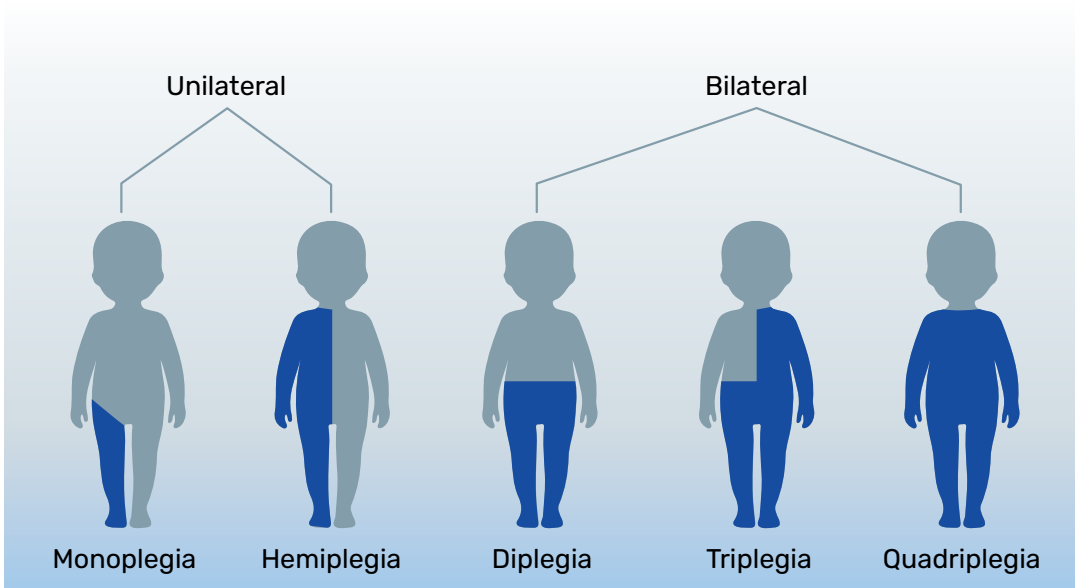
### How does CP impact movement?

Your child's CP can often be described in medical language by the parts of the body affected and the type of movement seen.

The focus at the time of diagnosis is also about looking at what your child can do in everyday activities, with the use of different functional classifications.

## Medical terms to describe Cerebral Palsy

Terms for parts of the body affected		Meaning
Unilateral Cerebral Palsy	Monoplegia (one limb) Hemiplegia (one side)	Affecting one limb or one side of the body (arm, trunk and leg)
Bilateral Cerebral Palsy	Diplegia (two limbs)	Affecting both legs
Bilateral Cerebral Palsy	Triplegia (three) Quadriplegia (four)	Affecting three or all four limbs



Terms for type of movement	Meaning
Spastic or Spasticity	Increased muscle tightness, stiffness, and muscle weakness
Dyskinetic Dystonia or Dystonic	Changing muscle contractions causing twisting or repetitive movement
Athetosis or Athetoid	Uncontrolled movements
Ataxic	Shaky movements, affecting a person's balance and coordination



## Function

- Functional classifications are used by health professionals to describe what your child can do and what they might find more challenging.
- These functions are described in a range of classification systems for moving, hand use, seeing, eating, communicating. All classifications use a Level I – V (1 – 5) scale where Level I means greater functional ability and Level V means less functional ability.
- The classifications can help plan for your child's health and education needs.

Examples include:

- The Gross Motor Functional Classification System (GMFCS) which looks at large movements, like rolling, crawling or walking.
- The Manual Ability Classification System (MACS) which looks at fine motor movements of the hands and arms, like handling toys.

More information on each of these can be found by talking to your health provider or at: [www.starship.org.nz/guidelines/classification-systems-for-cerebral-palsy](http://www.starship.org.nz/guidelines/classification-systems-for-cerebral-palsy)

## Overseas sites with CP information

### My CP Guide (Australia)

For people with lived experience of CP.

[www.mycpguide.org.au](http://www.mycpguide.org.au)

### CP Alliance (Australia)

An organisation that provides therapy and supports research related to CP.

[www.cerebralpalsy.org.au/cerebral-palsy](http://www.cerebralpalsy.org.au/cerebral-palsy)

### Canchild (Canada)

An organisation that supports research and innovation on CP.

[www.canchild.ca/en/diagnoses/cerebral-palsy](http://www.canchild.ca/en/diagnoses/cerebral-palsy)

### CP Foundation (USA)

Information for families, and health professionals.

[www.yourcpf.org](http://www.yourcpf.org)



“Your child will grow and their needs change over time. It may look different in five years’ time than it does now.”

- FAMILY QUOTE





## Health and *Disability Services*

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### Key points:

- There can be many health services and people involved with your child's care. This can be overwhelming, making it difficult to know where to start and the best person or place to get information from.
- Public health and disability services are provided by Health NZ, Te Whatu Ora. See: [www.disabilitysupport.govt.nz](http://www.disabilitysupport.govt.nz)
- For some people with cerebral palsy (dependent on the cause) services are also provided by the Accident Compensation Corporation (ACC). See: [www.acc.co.nz/im-injured/what-we-cover/injuries-we-cover](http://www.acc.co.nz/im-injured/what-we-cover/injuries-we-cover)
- Knowing where to go for support and understanding what help and services you can access can be challenging. Talk to members of your health team so they can support you.

### For more information

#### Healthify NZ

Overview of disability services in NZ and links to other information.

[www.healthify.nz/hauora-wellbeing/d/disability-services](http://www.healthify.nz/hauora-wellbeing/d/disability-services)

#### Firstport

Disability information for all of NZ.

[www.firstport.co.nz](http://www.firstport.co.nz)

## Understanding Child Disability Allowance and Needs Assessment

Have a conversation early with your Paediatrician or a Social Worker about accessing these important services.

### Child Disability Allowance

The Child Disability Allowance is not income or asset tested and is a non-taxable allowance. This means if your child meets the medical criteria than you will get the allowance no matter how much you earn or how many assets you have. Anyone who cares for a child who meets the medical criteria can consider applying.

See: [www.workandincome.govt.nz/products/a-z-benefits/child-disability-allowance.html](http://www.workandincome.govt.nz/products/a-z-benefits/child-disability-allowance.html)

### Disability Allowance

The Disability Allowance is different from the Child Disability Allowance. The Disability Allowance is paid to reimburse on-going disability-related expenses and is income tested (based on what you earn).

See: [www.workandincome.govt.nz/products/a-z-benefits/disability-allowance.html](http://www.workandincome.govt.nz/products/a-z-benefits/disability-allowance.html)

## More information on financial help

### Kidshealth NZ

Information about accessing financial help for your child.

[www.kidshealth.org.nz/financial-help-when-your-child-has-disability-or-chronic-condition](http://www.kidshealth.org.nz/financial-help-when-your-child-has-disability-or-chronic-condition)

### Parent to Parent

Help and information on accessing and navigating the health system.

[www.parent2parent.org.nz](http://www.parent2parent.org.nz)

## Needs Assessment Service Coordination (NASC)

(Usually called NASC for short – pronounced nas-k)

This is a first step to see what disability support services you and your family can access.

A Needs Assessment agency works with you to determine what your child's needs are and provide information about disability services available to you. You can self-refer to NASC or be referred through your health team.

## More information about NASC

### Disability Support

To find a NASC provider in your region go to:

[www.disabilitysupport.govt.nz/disabled-people/assessment-and-funding/needs-assessment-services](http://www.disabilitysupport.govt.nz/disabled-people/assessment-and-funding/needs-assessment-services)

### Kidshealth NZ

Helpful summary information on NASC.

[www.kidshealth.org.nz/needs-assessment-service-coordination-nasc](http://www.kidshealth.org.nz/needs-assessment-service-coordination-nasc)





# Health connections

CP is a lifelong condition, and the impact of some of the physical conditions can change as your child grows. Health services will help monitor any changes as your child develops.

## Key points:

- Your child's CP will affect different parts of their body and can change as they grow and develop.
- Building connections with health and education services is important as everyone will need to be involved to monitor changes over time.
- Connections with health and education services will be different for everyone and depends on factors such as your whānau and child's needs and priorities, and where you live.
- The first connections are with your GP and Well Child Tamariki Ora provider.

**“Your focus will shift,  
so just concentrate on what is  
important to you right now.”**

- FAMILY QUOTE





## Connecting to health services:

Here is a list of some of the health specialists who might work with you and your child depending on your child's needs.

Medical specialists	Description of role
<b>General Paediatrician</b>	Provides paediatric medical assessment and management for children and young people, generally seen at hospital. Key person to confirm CP diagnosis and make initial connections to other services depending on needs.
<b>Developmental Paediatrician</b> (Not in all regions of NZ)	Provides assessment and management of children with significant developmental concerns.
<b>Neonatologist</b>	Provides care for newborns who were born early or have medical problems.
<b>Neurologist</b>	Specialises in diagnosing and treating diseases of the brain, spinal cord and nerves. Including management of epilepsy/seizures.
<b>Orthopaedic Surgeon</b>	Assessment, treatment and monitoring of a child's bones and muscles as they grow.
<b>Paediatric Rehabilitation Specialist</b> (Not in all regions of NZ)	Works with a child if they have functional challenges due to injury and/or illness and supports them to take part in everyday activities.

Child development services	Description of role
<b>Visiting Neurodevelopmental Therapist</b>	This may be a physiotherapist, occupational or speech therapist who works with young infants. The age ranges that they work with may be different for each region in NZ.
<b>Physiotherapist (PT)</b>	Develops a child's physical function, promotes activity and doing everyday activities.
<b>Occupational Therapist (OT)</b>	Focuses on a child's abilities in everyday life e.g. dressing, bathing, hand use and play.
<b>Speech Language Therapist (SLT)</b>	Works with children with communication and/or feeding difficulties.
<b>Dietitian</b>	Experts in food and nutrition and will help with a child's nutrition.
<b>Social Worker</b>	Assesses and advises on the social needs of children and their whānau and provides support.

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<b>Kaimahi Hauora Māori - Māori Health Support Worker</b>	Offers cultural and other support for your pēpi, whānau and staff working with you.
<b>Cultural case workers</b>	Offers cultural support for all whānau.
<b>Psychologists</b>	To support the social, emotional and behavioural needs of a child and their whānau.

## Connections to other key health services:

Your child's paediatrician will connect your child to other services depending on their needs.

Concern	Services involved	Details
<b>Eyesight</b>	<ul style="list-style-type: none"> <li>Well Child Tamariki Ora assessments</li> <li>Ophthalmologist – eye specialist</li> </ul>	Additional vision tests may be needed, particularly for infants born early. <a href="http://www.kidshealth.org.nz/hearing-vision-checks-preschool-children">www.kidshealth.org.nz/hearing-vision-checks-preschool-children</a>
<b>Hearing</b>	<ul style="list-style-type: none"> <li>Newborn hearing tests</li> <li>Well Child Tamariki Ora assessments</li> <li>Audiologist</li> </ul>	Additional hearing tests may be needed, particularly for children born early. An audiologist can test people for hearing loss and help with hearing aids and cochlear implants.
<b>Dental services</b>	<p>When age appropriate:</p> <ul style="list-style-type: none"> <li>Hygienist</li> <li>Dentist</li> </ul> <p>For free children's dental care, contact, 0800 TALK TEETH (0800 825 583).</p>	CP can impact eating, drinking and swallowing and the muscles that open the mouth. This can make teeth cleaning and oral hygiene difficult.



## Ongoing health monitoring:

Monitoring	Details
Hip joints	CP can impact the development of the hip joint bones. All children with CP need to have an x-ray from around 12 months of age to check their hip position. Many children need ongoing monitoring as they grow. This will be done by their Orthopaedic or Paediatric doctor.
Muscle tone and tightness	CP can result in tight and spastic muscles. Your child will be monitored for this over time to make sure they grow, play and function the best they can.
Feeding and eating	CP can impact your child's ability to eat, drink and swallow. Your child will be monitored over time, as feeding needs change in the first 5 years. The positioning of your child and equipment may assist feeding.
Orthotics (Splints/ devices to assist movement and position)	Orthotic splints for different areas of your child's body (if needed) can help maintain muscle length and posture. Orthotics can improve walking, moving and play as your child grows.
Wheelchair and seating	Specialist seating therapists provide wheelchair and seating assessments and equipment.
Assistive equipment	Assistive equipment can help promote play, learning and moving. Equipment can help with eating, drinking, toileting, bathing, sleeping, seating, standing and walking.
Technology	Technology can help with communication, learning, play and preparing for early education.



**"If it is your first appointment with a service it's good to bring a support person with you."**

- FAMILY QUOTE



# Who is in your child's health team?

Role	Name	Date	Contact details
GP			
Well Child Tamariki Ora Provider e.g Plunket			



# Early interventions

- Early interventions assist with your child's development, if there are delays or concerns about how they are progressing.
- Early health and education intervention services may work together.
- There are choices of early intervention providers, dependent on which region you live in (see examples in the table below).

## Child Development Services across NZ

- Health NZ, Te Whatu Ora provides early health interventions across NZ through Child Development Services. Information on services in each region are found at: [www.healthpoint.co.nz](http://www.healthpoint.co.nz)
- Child Development Services offer a range of assessment and intervention services, depending on the needs of your child and whānau. The age range for services is different for each region in NZ.
- The Child Development team will work alongside your whānau to improve your child's independence in everyday activities.
- Team members generally visit your home to see you and your child, or they could see you at the hospital or clinic.
- Your child can be referred through your GP, other health professionals and health providers such as Well Child.

## The Child Development Service will work with you and your child:

- to understand your child's and whānau needs
- to support you with early learning and activity opportunities
- to help plan how activities can be included in everyday life for your whānau.

## Key points when looking for interventions:

- Interventions help your child and whānau work towards a goal or focus.
- Interventions should be centred around your child and whānau.
- Interventions should be about fun, play, moving, exploring and learning.
- Interventions encourage your child to take part in everyday life activities suitable for your child's age and stage.
- Interventions need to become more challenging as your child develops skills.

Above photo courtesy of Cubro

## Examples of early intervention health and education services

Early interventions can come from a variety of sources. Some examples are listed below. There are variations in what is offered across the country. Private providers offer further therapy options, which whānau pay for.

Name	Description and details
<b>Ministry of Education – Early Learning/ Learning Support</b>	Describes the process of how to access Learning Support. <a href="http://www.education.govt.nz/parents-and-caregivers/early-learning/learning-support">www.education.govt.nz/parents-and-caregivers/early-learning/learning-support</a>
<b>BLENNZ: The Blind and Low Vision Education Network NZ Early Learning Services</b>	A national network of educational services for ākonga (students) who are blind, deaf and blind or have low vision. There are Visual Resource Centres nationwide. There is an Early Childhood Centre and school at Homai, South Auckland, and several satellite school classes around Auckland. <a href="http://www.blennz.school.nz/school-centres-and-services/locations">www.blennz.school.nz/school-centres-and-services/locations</a>
<b>Kōhanga Reo</b> (There are more than 400 throughout Aotearoa New Zealand)	Kōhanga Reo are education services that build young children's and whānau knowledge of te reo Māori (language) and tikanga (culture). <a href="http://www.kohanga.ac.nz">www.kohanga.ac.nz</a>
<b>Conductive Education</b> (Auckland, Hamilton, Taranaki, Wellington, Christchurch and Invercargill)	Early education provider for children with disabilities. <a href="http://www.nzfce.org.nz/our-services">www.nzfce.org.nz/our-services</a>
<b>Ohomairangi Trust</b> (Auckland)	Ohomairangi Trust is a Māori Early Intervention Service, offering Maori whānau and others, community-based services for children with special needs. <a href="http://www.ohomairangi.co.nz/early-intervention-service">www.ohomairangi.co.nz/early-intervention-service</a>
<b>McKenzie Centre</b> (Hamilton)	Early pre-school intervention for children with special needs. <a href="http://www.mckenziecentre.org.nz">www.mckenziecentre.org.nz</a>
<b>Wellington Early Intervention Trust</b>	Provides early intervention services to preschool children with developmental delays. <a href="http://www.weit.org.nz">www.weit.org.nz</a>
<b>Champion Centre</b> (Canterbury)	Provides early intervention services to babies and young children with disabilities and their families. <a href="http://www.championcentre.org.nz">www.championcentre.org.nz</a>
<b>Raukatauri Music Therapy Centre</b> (Based in Auckland with centres in Bay of Plenty, Hawkes Bay and Northland)	Offers quality, accessible music therapy service to all people, whatever their needs. <a href="http://www.rmtc.org.nz">www.rmtc.org.nz</a>





# Education resources

## for starting school

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Both the Ministry of Education and Kidshealth NZ websites have extra information on services to support students with additional learning needs. See:

- [www.education.govt.nz/parents-and-caregivers/schools-year-0-13/learning-support](http://www.education.govt.nz/parents-and-caregivers/schools-year-0-13/learning-support)
- [www.kidshealth.org.nz/learning-support-what](http://www.kidshealth.org.nz/learning-support-what)

### Attending your local school:

Most children who have CP or any extra education needs will go to the usual classes at their local school and if needed, support can be provided through the school.

Parents can contact a Ministry of Education Learning Support, Service Manager for more information about local services. See:

- [www.education.govt.nz/our-work/our-role-and-our-people/contact-us/regional-ministry-contacts/learning-support-services](http://www.education.govt.nz/our-work/our-role-and-our-people/contact-us/regional-ministry-contacts/learning-support-services)

### Attending a special school, satellite classes, and special units within local schools:

If your child has high needs, they may attend a specialist school or satellite class, or a unit based within a local school. Ongoing Resource Scheme (ORS) funding is needed for this.

[www.education.govt.nz/school/student-support/special-education/ors/criteria-for-ors](http://www.education.govt.nz/school/student-support/special-education/ors/criteria-for-ors)

## Terms related to education support:

Term or service	Description and details
Special Education Needs Coordinator (SENCO) Learning Support Coordinator (LSC)	Many (but not all) schools and kura have a SENCO and/or a LSC who manage all the learning support needs programmes in the school or kura.
Physical disability support	Physical disability support is for students at school who have a physical disability that prevents them from participating fully in learning.  <a href="http://www.education.govt.nz/education-professionals/schools-year-0-13/learning-support/physical-disability-support">www.education.govt.nz/education-professionals/schools-year-0-13/learning-support/physical-disability-support</a>
Ongoing Resourcing Scheme (ORS)	Extra specialist support for a small number of children with the highest needs. The terms 'high' or 'very high' needs are special education terms. These words are used to describe how much help your child will need to join in learning alongside the children in their class.  <a href="http://www.kidshealth.org.nz/learning-support-when-your-child-has-significant-needs">www.kidshealth.org.nz/learning-support-when-your-child-has-significant-needs</a>  <a href="http://www.education.govt.nz/school/student-support/special-education/ors/criteria-for-ors">www.education.govt.nz/school/student-support/special-education/ors/criteria-for-ors</a>
Resource Teacher of Learning and Behaviour (RTL B)	Teachers with specialist training who work alongside you and your child's school to plan and put in place support for learning and wellbeing.
Individualised Education Plan (IEP) or Individualised Plan (IP)	These plans support your child's learning. The plan helps to identify goals that can support your child's development.
Specialised School Transport Assistance (SESTA)	Ministry of Education transport service that supports children who have safety or mobility needs to travel to and from school.  <a href="http://www.education.govt.nz/school/property-and-transport/transport/sesta">www.education.govt.nz/school/property-and-transport/transport/sesta</a>
Regional Health Schools	There are three regional Health Schools in NZ that can assist if your child is in hospital or home unwell for a long period of time.  <a href="http://www.kidshealth.org.nz/education-when-your-child-hospital">www.kidshealth.org.nz/education-when-your-child-hospital</a>

**“Remember you know your child best – fun activities that work well for your family, are important.”**

- FAMILY QUOTE

## Assistive technology for communication

Organisation	Description and details
Ministry of Education	Information about what assistive technology is and the process for applying.  <a href="http://www.education.govt.nz/school/student-support/special-education/assistive-technology">www.education.govt.nz/school/student-support/special-education/assistive-technology</a>
TalkLink Trust	Works with communication assistive technology and Augmentative and Alternative Communication (AAC).  <a href="http://www.talklink.org.nz">www.talklink.org.nz</a>

“People are ready to hear information at different times about the future, do what works for your family.”

- FAMILY QUOTE





## Whānau resources

- Many whānau with lived experience of CP find it helpful to connect with other families with similar experience.
- Below is a list of some resources that may help your whānau.

Resource	Information and website
Māori and Pacific Disability Support Services	A NZ Government site with a list of resources. <a href="http://www.disabilitysupport.govt.nz/disabled-people/support-and-services/maori-and-pacific">www.disabilitysupport.govt.nz/disabled-people/support-and-services/maori-and-pacific</a>
Vaka Tautua	A national Pacific health and social services provider with a presence across Auckland, Wellington, Canterbury and Otago regions. <a href="http://www.vakatautua.co.nz">www.vakatautua.co.nz</a> Disability Services: <a href="http://www.vakatautua.co.nz/tagata-sailimalo">www.vakatautua.co.nz/tagata-sailimalo</a>
CCS Disability Action	Largest disability and support service in NZ. Includes mobility parking. <a href="http://www.ccsdisabilityaction.org.nz">www.ccsdisabilityaction.org.nz</a>

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Parent 2 Parent	National organisation for the parents and whānau of disabled Kiwis. <a href="http://www.parent2parent.org.nz">www.parent2parent.org.nz</a>
Complimentary vs Alternative treatments	Information and advice about complementary and alternative medicine. <a href="http://www.kidshealth.org.nz/advice-parents-about-complementary-alternative-medicine">www.kidshealth.org.nz/advice-parents-about-complementary-alternative-medicine</a>
Community Law	Free legal help from lawyers and resources. <a href="http://www.communitylaw.org.nz">www.communitylaw.org.nz</a>
Citizens Advice Bureau	Provides people with free, confidential, independent information and advice face-to-face or via freephone about their rights and how to access services they need. <a href="http://www.cab.org.nz">www.cab.org.nz</a>
Incredible Years	Programmes for parents of children aged 3-8 years, providing them with skills to better support their child in a positive home environment. <a href="http://www.pb4l.tki.org.nz/Incredible-Years-Parent">www.pb4l.tki.org.nz/Incredible-Years-Parent</a>
Triple P - Stepping Stones	Stepping Stones is based on Triple P's positive parenting strategies. It helps whānau manage problem behaviour and developmental issues common in children with disability. <a href="http://www.triplep-parenting.net.nz/nz/parenting-courses">www.triplep-parenting.net.nz/nz/parenting-courses</a>

"Being connected to others with similar experiences was really valuable to us."

- FAMILY QUOTE





## Looking after *your wellbeing*

- When you and your whānau found out your child has cerebral palsy, there likely would have been a lot of different feelings and emotions. You may have felt shock, anger, denial, fear, guilt, sadness and helplessness. All these feelings are normal.
- Living with a child with special needs can bring great joy and a lot of stress as you and your whānau manage all the things that are needed to keep your child happy and healthy.

### Examples of wellbeing resources

Useful websites	
Health NZ – wellbeing support	A clear helpful site with a range of wellbeing resources. <a href="http://www.wellbeingsupport.health.nz/available-wellbeing-support">www.wellbeingsupport.health.nz/available-wellbeing-support</a> <a href="http://www.wellbeingsupport.health.nz/wellbeing-resources">www.wellbeingsupport.health.nz/wellbeing-resources</a>
Healthify App Library	Contains a large collection of health-related apps. <a href="http://www.healthify.nz/app-library">www.healthify.nz/app-library</a>

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<b>Sparklers</b>	A great collection of NZ based resources for schools and whānau for growing tamariki wellbeing and emotional literacy. <a href="http://www.sparklers.org.nz">www.sparklers.org.nz</a>
<b>Mental Health Foundation</b>	Works towards creating positive mental health and wellbeing. Provides information, advice and resources. <a href="http://www.mentalhealth.org.nz">www.mentalhealth.org.nz</a>
<b>Family Services Directory</b>	A searchable online directory of family support organisations and the services they offer. Operated by the Ministry of Social Development. <a href="http://www.familyservices.govt.nz/directory">www.familyservices.govt.nz/directory</a>
<b>Whakarongorau Aotearoa</b>	The National Telehealth Service delivers free 24/7 health, mental health and social services advice and support. <a href="http://www.whakarongorau.nz/telehealth-services">www.whakarongorau.nz/telehealth-services</a>





## Karakia

This Karakia can be used as a form of meditation, to bring a sense of calm. The Karakia was developed and gifted by Meria Rokx, initially for tamariki at kohanga reo to help regulate feelings.

Hā ki roto

Breathe in

Hā ki waho

Breathe Out

Kia tau te mauri e kokiri nei

Settle the mauri that stirs inside of me

I nga piki me ngā heke

Through the ups and downs

Ko te Rangimarie tāku e rapu nei

It is the peace that I seek

Tihei mauri ora

Ngā mihi nui, Thank you

**"[It's important to] recognise it is not only the child with CP that is involved, but the whole family is and every decision impacts all that are involved."**

- FAMILY QUOTE





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Hōkai Nukurangi

– to achieve what is important to you.

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[www.cerebralpalsy.org.nz](http://www.cerebralpalsy.org.nz)