

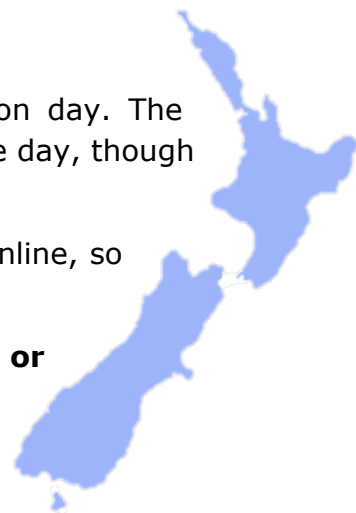
Cerebral Palsy in Aotearoa New Zealand: Early identification, surveillance and beyond

CP Education Day - July 9th, 2021

Thank you for joining us in our virtual cerebral palsy education day. The presenters have kindly agreed to share their slides with us for the day, though some yet to be published findings have been removed.

We will be working to make select session recordings available online, so keep an eye out for these to appear.

Click [here](#) if you would like to share feedback on the day, or thoughts for any future CP education days.



Presentation slides

Session 1: [Current practice on the identification, early management and hip surveillance for cerebral palsy](#)

Session 2: [Early diagnosis pathway](#)

Session 3: [Communication and reporting](#)

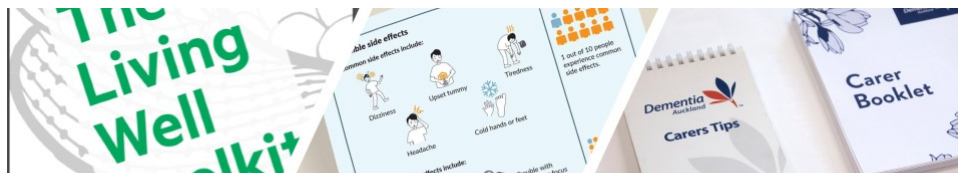
Session 3: [The NZCPR and engaging with Māori](#)

Session 4: [Respiratory Guidelines](#)

Session 4: [Australian 2020 Hip Surveillance Guidelines](#)

An information pack for whānau

Share your thoughts on what sort of information is needed in a Cerebral Palsy information Booklet for whānau – scan the QR code or click the image below.



What sort of information is needed in a Cerebral Palsy information Booklet for whānau?

Share your thoughts now!
<https://bit.ly/3hhFABm>



Download and use!

Poster summaries of cerebral palsy functional classification systems.

Understanding Cerebral Palsy and what the Functional Classification Systems mean for your child & your whānau.

Functional Classification Systems explained:

- GMFCS**
The Gross Motor Function Classification System (GMFCS) is the method for classifying the movement ability of children with cerebral palsy. This is based off their self-initiated movement including sitting, walking & stair climbing, but also includes skills such as running, jumping, speed & balance.
- MACS**
The Manual Ability Classification System (MACS) describes how children with cerebral palsy use their hands to handle objects, and if they need assistance or adaptations to do so. Some examples include using their hands to eat, dress, play, draw or write.
- CFCS**
The Communication Function Classification System (CFCS) is used to classify the everyday communication performance of children with cerebral palsy. This focuses on activity and participation levels using the communication model of a sender (transmits a message) and a receiver (understands the message) and how the CP child alternates between each.
- EDACS**
The Eating & Drinking Ability Classification System (EDACS) is used to classify the eating and drinking ability in everyday life of children with cerebral palsy. This includes functional activities such as sucking, biting, chewing, swallowing, and keeping food & fluid in the mouth.
- VFCS**
The Visual Function Classification System (VFCS) describes the degree that a child with cerebral palsy can use visual abilities and perform vision-related daily activities. This includes how children use vision to purposefully see, direct gaze, recognise and interact with the environment.

Cerebral Palsy Functional Classification Systems

Children 6-12 years

Starship Foundation

Classification Systems	Level I	Level II	Level III	Level IV	Level V
GMFCS Gross Motor Function	Walks and performs activities without limitations	Walks and performs activities with limitations	Walks with a hand-held mobility device	Self-mobility with limitations; may use powered mobility	Transported in a manual wheelchair
MACS Manual Ability	Handles objects easily and with success	Reduced speed/accuracy in object handling; may look for alternatives	Experiences difficulty; needs assistance for activities	Needs continuous support; handles a limited selection of objects	Does not handle objects; needs total assistance
CFCS Communication Function	Effective sender/receiver with unfamiliar/familiar partners	Slower but effective sender/receiver with unfamiliar/familiar partners	Effective sender and receiver with familiar partners	Inconsistent sender/receiver with familiar partners	Seldom effective sender/receiver even with familiar partners
EDACS Eating & Drinking Ability	Eats and drinks safely and efficiently	Eats and drinks safely but with some limitations to efficiency	Eats and drinks with some limitations to safety	Eats and drinks with significant limitations to safety	Unable to eat and drink safely - tube feeding considered
VFCS Visual Function	Uses visual function easily and successfully	Uses visual function successfully but needs compensatory strategies	Uses visual function but needs some adaptations	Uses visual function in very adapted environments	Does not use visual function even in very adapted environments

Click [here](#) to download the posters from the Starship website.

Or [here](#) for the Kids Health website

What are Functional Classification Systems?

Cerebral palsy can affect a person in many different ways. The term cerebral palsy does not help you understand what your child's health and support needs are for now and in the future. The 'functional classification systems' that health professionals often use can give you a better idea of your child's abilities in a range of everyday activities, such as moving around, seeing, eating, and communicating. This can also give you an idea of which activities or abilities may require more support than others.

If you would like to understand or have more information on what cerebral palsy is, please talk to your health professional or refer to the New Zealand KidzHealth webpage (<https://www.kidzhealth.org.nz/cerebral-palsy>).

Why are multiple Functional Classification Systems needed?

Cerebral palsy can affect a person's posture, balance, and ability to move, communicate, eat, sleep and learn. The different functional classifications systems relate to various areas of functioning, or the different 'systems' of the body and how they function.

What do these levels mean for my child?

As a parent or caregiver of a child with cerebral palsy, you can use these classification systems to help you and your health professional plan for your child's health and education needs. Each of the systems use the same scale: Level I to Level V. A child classified at level I will need less support and equipment. A child at level IV or V may need more support and involvement from health and school services to help them with their daily activities. Knowing the classification level of your child will also help you and your health professional plan for any regular appointments or investigations that need to take place to prevent complications. This may mean that if your child is classified at level III- V, they will need regular hip x-rays to make sure the hip joint remains in a good position.

Who can I go to if I need more information or assistance?

You can talk to your Paediatrician and/or your child's therapy team to get more information. These professionals can discuss what your child's particular classifications are, their subsequent needs and proper management for their systems. It is important to remember that there is support and services available for all types of cerebral palsy. These measures are an initial guide only.

Te whakaahuā i ngā nekehanga whānui a pēpi i te kāinga
He aratohu mā ngā whānau

ngā mātātahi āwharangi i te whakaahuā i te pēpi i ngā tūāwhiri, ā, he mō ngā "whānanga whānui" i te kāinga i te wā he mātātahi āwharangi i te kāinga. He aratohu mā ngā whānau i te tūāwhiri āwharangi i te kāinga i te wā he mātātahi āwharangi i te kāinga. He aratohu mā ngā whānau i te tūāwhiri āwharangi i te kāinga i te wā he mātātahi āwharangi i te kāinga.

Hipanga 1: Ko ngā mea e hiahiatia ana e koe

Te pēpi i te kāinga i te wā he mātātahi āwharangi i te kāinga. He aratohu mā ngā whānau i te tūāwhiri āwharangi i te kāinga i te wā he mātātahi āwharangi i te kāinga. He aratohu mā ngā whānau i te tūāwhiri āwharangi i te kāinga i te wā he mātātahi āwharangi i te kāinga.

Hipanga 2: Te whakarte whitiāhua

He aratohu mā ngā whānau i te tūāwhiri āwharangi i te kāinga i te wā he mātātahi āwharangi i te kāinga. He aratohu mā ngā whānau i te tūāwhiri āwharangi i te kāinga i te wā he mātātahi āwharangi i te kāinga. He aratohu mā ngā whānau i te tūāwhiri āwharangi i te kāinga i te wā he mātātahi āwharangi i te kāinga.

Hipanga 3: Whakaa huatanga

He aratohu mā ngā whānau i te tūāwhiri āwharangi i te kāinga i te wā he mātātahi āwharangi i te kāinga. He aratohu mā ngā whānau i te tūāwhiri āwharangi i te kāinga i te wā he mātātahi āwharangi i te kāinga. He aratohu mā ngā whānau i te tūāwhiri āwharangi i te kāinga i te wā he mātātahi āwharangi i te kāinga.

Hipanga 4: Te tuku i te ātaata ki te mātātahi hauora

He aratohu mā ngā whānau i te tūāwhiri āwharangi i te kāinga i te wā he mātātahi āwharangi i te kāinga. He aratohu mā ngā whānau i te tūāwhiri āwharangi i te kāinga i te wā he mātātahi āwharangi i te kāinga. He aratohu mā ngā whānau i te tūāwhiri āwharangi i te kāinga i te wā he mātātahi āwharangi i te kāinga.

Click here to download instructions for taking a GMs video in Te Reo Māori

With thanks to the Friedlander Foundation, Dr Angus McMorland and colleagues from the University of Auckland

Coming soon on the Starship website

The screenshot shows the Starship website interface. At the top, there is a navigation bar with 'Starship' logo and links for 'CLINICAL SERVICES', 'WORK AT STARSHIP', and 'CONTACTS'. Below this is a search bar and a 'Donate' button. The main content area features a document titled 'Early diagnosis of cerebral palsy (CP), intervention and surveillance'. The document includes an introduction, a table of contents, and a list of key points. The text is partially obscured by a large 'DRAFT' watermark.

Key websites and links

[CaPTuRE study website](#)

[NZ CP Register](#)

[CP Research at Starship](#)

[Update on the NZ CP Clinician Network](#)

[HINE instruction website](#)

[GMs training courses](#)

[CP Alliance resources for early diagnosis](#)

[Australian Hip Surveillance guidelines](#)

[Australasian Academy of cerebral palsy and developmental medicine \(AusACPDM\)](#)

['Better Together 2022' AusACPDM / IAACD conference website](#)

NZ Child and Youth Clinical Networks
Cerebral Palsy Network

Bookmark this page – updates coming in 2021

<https://www.starship.org.nz/health-professionals/cerebral-palsy-clinical-network>

Current Workstreams:

- Best Practice
- Voices
- Transition
- Education & Network
- Interventions
- NZ CP Register
- Participation

Key Papers discussed across the day

Novak et al. [Early, Accurate Diagnosis and Early Intervention in Cerebral Palsy: Advances in Diagnosis and Treatment](#). *JAMA Pediatr.* 2017;171(9):897–907.

Morgan et al. [Early Intervention for Children Aged 0 to 2 Years With or at High Risk of Cerebral Palsy: International Clinical Practice Guideline Based on Systematic Reviews](#). *JAMA Pediatr.* 2021.

Appleton RE, Gupta R. [Cerebral palsy: not always what it seems](#). *Arch Dis Child.* 2019 Aug;104(8):809-814.

Morgan et al. [The Pooled Diagnostic Accuracy of Neuroimaging, General Movements, and Neurological Examination for Diagnosing Cerebral Palsy Early in High-Risk Infants: A Case Control Study](#). *J Clin Med.* 2019;8(11):1879.

[RACP 2020 statement Indigenous child health in Australia and Aotearoa New Zealand](#)

Williams et al. ["It Should Have Been Given Sooner, and We Should Not Have to Fight for It": A Mixed-Methods Study of the Experience of Diagnosis and Early Management of Cerebral Palsy](#). *J Clin Med.* 2021; 10(7):1398.

Williams et al. [Clinical practice of health professionals working in early detection for infants with or at risk of cerebral palsy across New Zealand](#). 2020. *J Paediatr Child Health*, 57: 541-547.

Novak, Morgan, McNamara, A et Veld. [Best practice guidelines for communicating to parents the diagnosis of disability](#). *Early Human Development.* 2019.

Lacey et al., [The Hui Process: A framework to enhance the doctor-patient relationship with Māori](#). *The New Zealand medical journal.* 2011. 124(1347):72-8

Gibson et al., [Prevention and management of respiratory disease in young people with cerebral palsy: consensus statement](#). *Dev Med Child Neurol*, 2020 63: 172-182

Latest Australian CP Register reports:

- https://cpregister.com/wp-content/uploads/2020/10/ACPR-Report-2020-Bulletin_s_Ir.pdf
- <https://cpregister.com/wp-content/uploads/2019/02/Report-of-the-Australian-Cerebral-Palsy-Register-Birth-Years-1995-2012.pdf>



New Zealand Cerebral Palsy Register
(NZCPR)

<https://www.starship.org.nz/health-professionals/cerebral-palsy-research/>



A confidential dataset of health information about CP (HDEC 13/NTA/130)



Work together with whānau & people with lived experience of CP



Health professionals can help by sharing information with whānau about the NZCPR and notify us, so we can work with whānau



Identify health inequity



Open to all people in Aotearoa NZ with CP



Understand prevalence of CP



Promote research and new interventions

Contact: nzcpregister@adhb.govt.nz



With many thanks to our collaborators and support



Athlæ Lyon Starship
Clinical Research Award

