myCP Guide

Improving CP resources in Australia

My CP Guide is Australia's first online platform designed to provide trusted information about cerebral palsy (CP) across all stages of life. The information on My CP Guide comes from a range of local and international sources, and the team worked closely with people with CP, their families and carers to provide a selection of the most useful information.

Developed by a consortium of Australian organisations, led by Cerebral Palsy Australia and including Ability First Australia, Cerebral Palsy Alliance, and the Cerebral Palsy Support Network, My CP Guide is funded by the Australian Government Department of Social Services, through the Information Linkages and Capacity Building (ILC) program.

The My CP Guide team also worked in partnership with people with CP, medical experts, allied health practitioners, academic researchers and disability advocates, to develop new resources about different aspects of living with CP.

All the content available on the My CP Guide website has been assessed against our information governance framework to make sure it is current, reliable and from credible sources.

Who this resource is for

This document has been written for those with an interest in understanding the information needs and preferences of people with CP and their support networks. This could include mainstream health services, disability service providers, academic researchers, government departments and others.

Researching CP in Australia

In 2020, the My CP Guide team commissioned a large-scale research project that focused on the information needs of people with CP and their support networks. The research gathered input from parents and carers raising a child with CP, those growing up with CP and older adults living their lives with CP.

The research highlighted that the information needs of people with CP, their family and carers, vary greatly, with the age and life stage of the person with CP heavily influencing those needs. It also highlighted the challenges in finding reliable, useful and timely information about CP, as well as the difficulties that exist when seeking support.

The study gave the My CP Guide team a deeper understanding of what information was important, what was currently difficult to access, and in what formats it would be most useful. This evidence enabled the team to develop our platform, which now provides access to trusted information for people with CP and their support networks.

Summarising our research

The My CP Guide team believes it is important to release our research to the public, and to provide opportunity for talented professionals to work towards finding solutions to the problems raised in the research.

This summary document gives an overview of the information needs of the CP community in Australia. The information has been divided into life stages, as individual needs and preferences can vary significantly between them. It explains what the research has found about:

- the various types of information that people need at these different points of life
- what the key challenges are
- the most helpful ways in which information can be provided
- what the opportunities are for further information and resource development.

We encourage you to use this summary as a starting point, and warmly invite you to consider reviewing our complete research report, which is available on the My CP Guide website. Please also consider contacting the My CP Guide team before you start developing any specific content. As we are constantly building our content library and receiving feedback from the users of My CP Guide, we may be able to provide more information on the area you are interested in developing content for.

When a child with CP is aged 0 to 2 years

Families of newborns and very young children can be overwhelmed with a CP diagnosis. It can be a confusing and uncertain time. Information and resources developed for this group need to be clear and easy to understand.

> *Looking back on the diagnosis – [we wanted] some kind of resources to give a baseline of what we were [in for] – more of an idea of how differently it can impact children. Rather than a guessing game of 'Is my child going to walk? Is my child going to talk?'*
>
> Parent of a child aged 0-2 years

Key challenges

- Coming to terms with the CP diagnosis
- Absorbing relevant information while raising a child with CP
- Navigating the hospital system
- Finding appropriate peer support programs

Summary of the information needs for children with CP aged 0 to 2 years

Parents and carers want:

- easy to understand information that explains what CP is, the type of CP their child has, and the different ways in which it may affect their child
- access to websites where they can find out more about CP and learn about the possible therapies and interventions
- any conversations about their child's diagnosis to be private and respectful, with the opportunity to ask questions
- access to peer support, so parents and carers can share experiences, and get support from others who have been through similar experiences.

Preferred information sources and formats

- Private and respectful consultations with medical professionals
- Concise resources, both written (online and hardcopy) and video

Information development opportunities

- Researchers and academics could consider undertaking research that focuses on the social, health and economic impacts that the initial diagnosis of CP has on the family unit.
- Funded peer support programs can provide much-needed social, emotional, and practical support for parents and carers of children with CP.
- The mental health sector should consider producing tailored resources for parents and carers of children with CP, to improve their mental wellbeing.
- More research is needed about the best approach that medical professionals should use when delivering a diagnosis of CP to the family unit.
- Mainstream health professionals should consider providing accessible information for parents and carers of people with CP, particularly for those who are from culturally and linguistically diverse communities, and for those who identify as First Nations people.

Information on this page has been drawn from chapter 5 on page 20 in the full research report.

When a child with CP is aged 3 to 5 years

Families of children with CP aged between 3 and 5 years can be very busy incorporating therapies into their child's life. They may look for guidance from others in similar situations. Information resources need to be clear and easy to understand.

> *What would have been good would have been a children's book, having more children friendly resources. Perhaps they're out there, things to help them have a positive narrative.*
>
> Parent of a child aged 3-5 years with medium-level CP needs

Key challenges

- Finding books and stories for their child that explains CP
- Absorbing relevant information while raising their child
- Identifying and accessing funding options for therapies
- Making time for peer support groups

Summary of information needs for children with CP aged 3 to 5 years

Parents and carers want:

- concise information about the expected impact CP will have on their child's life, particularly during these early years
- accurate information about local health professionals with experience providing therapy for young children with CP
- more children's books that talk about CP in a clear and positive way.

Preferred information sources and formats

- Peer support (for parents/carers)
- Concise resources, both written (online and hardcopy) and video
- Children's books and other multimedia

Information development opportunities

- Researchers and academics could consider undertaking research that focuses on the social, health and economic impact of CP, as children enter the early childhood education system.
- Funded peer support programs can provide much-needed social, emotional and practical support for parents and carers of children with CP.
- The mental health sector could consider targeted outreach for parents and carers, to improve their mental wellbeing.
- More research is needed about the effects of positive representation of CP in education material (such as books and TV shows).
- Mainstream health professionals should consider providing accessible information for parents and carers of people with CP, particularly for those who are from culturally and linguistically diverse communities, and for those who identify as First Nations people.

Information on this page has been drawn from chapter 6 on page 29 in the full research report.

When a child with CP is aged 6 to 17 years

Families of children with CP aged between 6 and 17 years often have an increased need for targeted information and resources about the education and schooling options available for their child. They may also have concerns around their child making friends, and accessing appropriate support through the NDIS.

> *Watching interviews with people who have CP, kids and adults talking about their needs. They've been very useful, because it's about hearing their experience … (and) demonstrating certain things. How to sign up for myGov, how to find what you're looking for on Centrelink? How do I find a local therapist?*
>
> Parent of a child aged 6-17 years with medium-level CP needs

Key challenges

- Trying to absorb all the relevant information while looking after their child
- Understanding how CP may affect their child's education and schooling
- Understanding how the NDIS will fund support for their child
- Concerns about their child making and maintaining social connections
- Looking after the mental health of the child with CP, and the parent and carer

Summary of information needs for people with CP aged 6 to 17 years

Parents and carers of children and young people with CP want:

- detailed information about how CP changes the management of areas like diet, nutrition, weight and continence
- targeted information about how a CP diagnosis can interact with puberty and adolescence
- information to help them decide whether their child will be better off in a mainstream or special development school, and what support will be available
- to know what social groups are available - where their child can meet others with CP, and how they can connect with others who have similar experiences.

Preferred information sources and formats

- Peer and social support (for both parents/carers and teens with CP)
- Seminars or other group information sessions
- Short video resources, as well as written information (online and hardcopy)

Information development opportunities

- Researchers and academics could consider undertaking research that focuses on the social, health and economic impact of CP, as children and young people move through the school system.
- Funded peer support programs can provide much-needed social, emotional and practical support for people with CP aged 7 to 17, and their families.
- The mental health sector should consider targeted outreach for young people with CP, and their parents or carers, to improve their mental wellbeing.
- Research into the effects of mainstream schooling for young people with CP would help to improve education outcomes and increase socio-economic opportunities for them.
- Mainstream health professionals should consider providing accessible information for parents and carers of young people with CP, particularly for those who are from culturally and linguistically diverse communities, and for those who identify as First Nations people.

Information on this page has been drawn from chapter 7 on page 38 in the full research report.

When a person with CP is aged 18 to 45

The transition between adolescence and adulthood can be particularly difficult for people with CP and their families. Those with CP aged between 18 to 45 years need targeted information and resources for themselves, as well as for their older and ageing parents and carers.

> *A lot of young people (with CP) will say leaving school is like falling off a cliff. They don't naturally have the same pathways; school to uni, or school to work. Because of some of the challenges they might experience getting into the workforce, it can be a very isolating and stressful time. What do I do now? What are my options?*
>
> CP researcher

Key challenges

- Moving from pediatric to adult services
- Working out what to do after the school years
- Transitioning to independent living
- Making and maintaining both platonic and romantic relationships

Summary of information needs for people with CP aged 18 to 45

Young adults transitioning to adult services want:

- detailed information about their disability, including how to find appropriately skilled service providers and therapists with CP experience.

Adults with CP want:

- a plain English guide that explains how to navigate the NDIS
- a factsheet or webpage that explains CP to therapists, educators, driving instructors or employers
- information and advice on all the functional aspects of living independently, from cutting up food to becoming a new parent
- information about mental health support to be available both in-person and online
- information on socialising, mentoring, dating and intimacy.

Preferred information sources and formats

- Peer and social support (for people with CP)
- Parent/carer peer support groups
- Online chat groups
- Written (online and hardcopy) information and detailed video resources

Information development opportunities

- Researchers and academics could consider undertaking research that focuses on the social, health and economic impact of CP, as people transition from adolescence to adulthood.
- Funded peer support programs can provide much-needed social, emotional and practical support for people with CP aged 18 to 45, as well as their families.
- The mental health sector should consider targeted outreach for both young adults and older people with CP, to improve their mental wellbeing.
- More information about employment options for people with CP would help to reduce unemployment and increase socioeconomic opportunities for them.
- Mainstream health professionals should consider providing accessible information for people with CP, particularly those who may have complex communication requirements, are from culturally and linguistically diverse communities, and those who identify as First Nations people.

Information on this page has been drawn from chapter 8 on page 60 in the full research report.

When a person with CP is aged over 45

While much of the existing information about CP focuses on children, people with CP over the age of 45 also have a need for targeted resources. This age group desires information about ageing well with CP, with peer support highly valued.

> *... older people with CP and their families had concerns about aging and what the future would look like as both them and their support network became frailer and encountered health issues associated with getting old. Fear of isolation, especially contemplating the likelihood of families changing, and older family members dying, was top of mind for older participants.*
>
> CP researcher

Key challenges

- Ageing and physical decline
- Reduced therapies due to financial pressures
- Isolation, social networks and lack of independent friendships
- Transition of support, care and responsibility

Summary of information needs for people with CP aged over 45

Older people with CP want:

- information that explains the impact of their diagnosis on the ageing process, and what they can do to best manage their health
- advice on keeping active and sustaining their health through exercise and therapies
- clear, consistent information on navigating the NDIS
- to meet and chat with others with CP
- information for family and carers on the legal steps they should take to protect their family member with CP, in the event of the death of the family member or carer
- educational materials for the community to better understand CP.

Preferred information sources and formats

- Peer and social support (for people with CP)
- Written information (online and hardcopy)

Information development opportunities

- Researchers and academics could consider undertaking research that focuses on the social, health and economic impact of CP as people age.
- Funded peer support programs can provide much-needed social, emotional and practical support for people with CP of all ages and their families. Peer support programs recognise that people may experience times of stress where they sometimes need the support of a friend or peer with shared experiences.
- Mainstream health professionals should consider providing accessible information for people with CP, particularly those who may have complex communication requirements, are from culturally and linguistically diverse communities, and for those who identify as First Nations people.
- The aged care sector should consider targeted outreach for older people with CP and their families, to improve any transitions to aged care settings.
- Law firms and associated organisations could consider creating targeted information about planning for the future, specifically for older people with CP and their families.

Information on this page has been drawn from chapter 9 on page 79 in the full research report.

Conclusion and next steps

Information and resources rated by people with CP, their parents and carers, as being useful and accurate, is seen as a very important factor when measuring their quality. However, our research has demonstrated there is a real deficit of timely and insightful information available - especially resources that have been written in plain English or are available in preferred formats. Further, the quality of the information currently available varies considerably, and is largely dependent on the knowledge of the individual health and support professionals encountered. As a result, much of the burden of finding high-quality information about CP currently rests with the person with CP themselves, as well as their families or carers.

The My CP Guide platform already works to locate and deliver high-quality information about CP for those across all stages of life, making it readily available to all who would benefit from it. However, we know there is more work to be done.

The My CP Guide team believes that by addressing these information gaps, we will positively contribute to:

- enabling people with CP to be better informed about how their life may change, and what others have done to improve the quality and enjoyment of their lives
- providing reassurance and informing parents about the key challenges in the early years of their child's life
- making the search for quality information much easier and faster
- helping people with CP and their families to more easily make informed choices about their lives.

We invite all of Australia, from academic researchers, advocacy organisations, disability service providers, schools and hospitals to work with us to improve the lives of people with CP and their support networks.

If you would like more information or believe you could contribute to My CP Guide, **please get in touch with us by email at: info@cerebralpalsyaustralia.com**