

Mental health and cerebral palsy

People with cerebral palsy are at greater risk of mental health concerns than the general population for a range of bio-psycho-social reasons. Healthcare practitioners are a vital link in assisting people with cerebral palsy and their families to build and support the development of good mental health.

Risk factors

People with cerebral palsy have a number of risk factors for developing mental health concerns:

- **Biological:** Just as the difference in brain development or injury to the developing brain increases the person's risk of epilepsy, so it also increases the person's vulnerability to mental health disorders. Neurodevelopmental brain differences, genetic risk, behavioural phenotype, epilepsy, sensory disorders, medications and family history of mental health disorders may all increase this risk. The presence of chronic medical conditions, including those causing chronic pain, also contribute to this risk.
- **Psychological:** The person's coping and defence mechanisms, emotional development, self-esteem, personality and experience of success or failure can increase either vulnerability or resilience. The impact of traumatic experiences (including abuse) can be an additional factor that affects a person's ability to deal with life experiences and associated thoughts and feelings.
- **Social:** Experiences perceived as marginalising, stigmatising, rejecting or isolating increase vulnerability. For young people, sharing with and learning from peers is critical to the development of the sense of self and a separate identity. Limited friendships and social networks therefore can increase vulnerability and undermine resilience. Family stress and coping, and parental mental illness can also increase risk. For people with cerebral palsy, a lack of social support, adverse life events (loss, separation, abuse or bereavement), a hostile and unsupportive environment or limited access to health and social services can likewise undermine the person's resilience.
- **Poverty:** Adults with cerebral palsy and families of children with cerebral palsy have reduced life opportunities in higher education and the work place. Parents often have to compromise their earning ability to fulfil their caring role. The resultant loss in earning can result in poverty. This can adversely affect the person's and families' mental health, physical health and well being.

Protective factors

Conversely the following factors build resilience and are protective for good mental health in us all, including people with cerebral palsy:

- **Biological:** good physical health, regular physical activity and a healthy, balanced diet, adequate rest and sleep.
- **Psychological:** secure attachment, social and communication skills, opportunities to develop mastery and competence, independence, opportunities to try new things and develop a sense of autonomy and self reliance.
- **Social:** belonging and being valued by the community with the opportunity to participate in and contribute; friends and other trusted relationships; social networks: connectedness; appropriate housing, transport, financial support, employment and social supports.

Transitions

Throughout the life course periods of transition are times when individuals and their families may require some extra support to maintain good mental health and manage any problems that arise. For children with cerebral palsy and their families some stressful periods may include:

- **Starting school.** The transition from infant to primary school. The gap between neurotypical children and children with a disability becomes more evident as the academic load increases and children's physical and social world enlarges.
- **Starting high school.** In high school children often have more physical challenges such as further to walk to classes and competitive sport, and more social challenges; the complex social world of adolescence. Young people with cerebral palsy may find it difficult to keep up physically with friends, limiting social opportunities. Those with cognitive difficulties may find the academic load at an inappropriate level for them.
- **Leaving school** and transitioning to adult life.

Young people with cerebral palsy need the same opportunities for independence, social engagement, education and employment as their peers.

Many find they have to navigate a range of physical, communication, sensory and social barriers to their independence, autonomy and participation in their communities. Many people consequently become very resourceful and develop great problem solving skills if given the encouragement and support they need.

These resources are designed to support healthcare practitioners in the care of their patients with cerebral palsy in Australia. They were developed in partnership by The Royal Children's Hospital; the Centre for Developmental Disability, Monash Health; and Murdoch Children's Research Institute. They have been amended for use by healthcare workers globally in partnership with IAACD. The initial project was funded by an Avant Quality Improvement Grant 2017.

Children with cerebral palsy

A motor impairment, alone or in combination with associated intellectual, sensory, or other health impairments, may exacerbate life's stressors and the challenges they pose to a person's mental well-being. Children with cerebral palsy may have reduced social opportunities, and this may impact on their social development and relationships.

Developing resilience in childhood is of vital importance. This is a crucial time for learning social skills. Some children with cerebral palsy face challenges with respect to their physical ability and communication difficulties. Despite school policies and best intentions, children with cerebral palsy are at risk of being bullied and may face disappointment about their lack of physical ability and associated reduced opportunities. Schools have a responsibility to adapt the curriculum to the needs of individual students, to support the child's social and emotional development and to address bullying issues if they arise.

Siblings of individuals with cerebral palsy

Having a child with cerebral palsy often changes the family dynamics with siblings taking on a partial carer role. Resentment can develop if siblings feel they are missing out or not receiving the same parental attention as their sibling with the disability. On the other hand, the experience may build a sensitivity to the needs of others, and a sense of social justice.

Adolescents with cerebral palsy

A key part of adolescent development is identity formation. This can be challenging for those with physical, communication, cognitive, hearing and/or vision impairments. Pubertal changes, self-esteem, body image and sexuality are all relevant.

Adolescents often feel frustration, anger, anxiety or despair and are at risk of depression and anxiety, and so it is important to be vigilant about monitoring mental health and providing information, support, counselling and referral as required.

Optimising the person's ability to communicate is of fundamental importance and a communication review by an experienced speech pathologist may be helpful.

Adults with cerebral palsy

Young adults with cerebral palsy need to find their place in the world.

Those who are able to work may need support and encouragement to apply for jobs and to cope with the frustration and disappointment that are often features of that journey. There is both increasing awareness of the benefits of diversity in businesses of all kinds, and more support available for employment for people with disability. Success in the search for employment will hopefully become easier to achieve.

The community has an obligation to support and include all citizens. Reasonable adjustments of educational and employment settings are required to enable the participation and contribution of people with disabilities in these environments under Disability Discrimination and Equal Opportunity legislation.

www.humanrightscommission.vic.gov.au/discrimination/exceptions-exemptions-and-special-measures/reasonable-adjustments

<https://www.un.org/en/about-us/universal-declaration-of-human-rights>

https://ncpedp.org/?RPWDact2016_%28Rights_of_Persons_with_Disabilities_Act_2016%29

For those not able to work in paid employment, meaningful activities can be found through volunteering, educational and social activities, hobbies and interests, and participation in their local community.

Relationships are important to everyone, and counselling may be helpful for some people who are finding it difficult to find or maintain friends and/or romantic partners.

The rate of depression is reported to be three or four times higher in adults with cerebral palsy.^{1,2} The risk of developing depression may not be related so much to the severity of the disability but to life experiences

and opportunities, the amount of emotional and practical support that is available and the strategies adults have in place to cope with disappointment and stress.

Assessment and management

Mental health concerns can be easily overlooked and remain untreated, particularly in people who have difficulty describing and communicating their symptoms. This can lead to suboptimal performance at school or at work, social withdrawal and isolation, and an impaired quality of life.

These feelings may result from:

- Communication difficulties.
- Limited independence and reliance on parents over and above the usual age.
- Reduced functional ability.
- Chronic pain and poor physical health.
- Social isolation and limited social opportunities.
- Concerns about body image and sexuality.
- Mental health concerns in people who have difficulty communicating their experience may manifest as changes in behaviour, for example, tearfulness, irritability, aggressive behaviour, social withdrawal, change in appetite or sleep disturbance. Anti-seizure medication and drug interactions may also lead to behavioural change. Risk of deliberate self-harm and suicide should be assessed as with any other person.

It is important to review the person's current life circumstances, relationships, opportunities and supports. Referral to a psychologist (for treatment of mental health disorders, counselling, psychometric testing and/or managing challenging behaviours) or a psychiatrist may be helpful.

There may be local or national mental health support available. For example, in Australia, preparing a Mental Health Care Plan improves the patient's access to, and the affordability, of a psychologist.

Remember that:

- For people without cognitive or communication difficulty the diagnosis and management will be the same as in the general population.
- For people who have communication difficulties, the use of the person's preferred communication method is essential in facilitating their ability to express their mood, feelings and experiences.
- For those that are not able to express themselves, response to therapy will need to be carefully noted by careful questioning of the caregiver about improvements in mood and behaviour. For instance, thinking about depression: Has the person's mood changed? Are they laughing and joking as before? What have they enjoyed in the past? Are they still enjoying things to the same degree? Are they as socially engaged as they were before? Are there changes in sleep and/or interest in food?

For more information, see:

Department of Developmental Disability Neuropsychiatry (2014). *Accessible Mental Health Services for People with an Intellectual Disability: A Guide for Providers*. Department of Developmental Disability Neuropsychiatry. ISBN 978-0-7334-3431-0. <https://bit.ly/2KsWxGK>

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1. Linhares D, Hung C, Matsumoto H, Kung J, Callego F, Kim H, Hyman J, Roye D, Dutlowsky J. The 'true' prevalence and risk factors of depression in adults with cerebral palsy. *Dev Med Child Neurol* 2017 59(53):120.
2. Cooper, S.A., et al., Mental ill-health in adults with intellectual disabilities: prevalence and associated factors. *The British Journal of Psychiatry*, 2007. 190(1): p. 27-35. http://doi.org/10.1111/dmcn.67_13512.