

Referral pathways

Everyone with cerebral palsy is a unique individual with particular interests, preferences and relationships and a unique pattern of medical, therapy, equipment, educational, psychological, social and financial needs. While there is no single management pathway, some general guidelines about the contribution of various members of the multidisciplinary team are described below.

The healthcare practitioner has a central role in regularly reviewing the person with cerebral palsy and ensuring the person's health needs are identified and addressed. Usually a medical practitioner has this central role. This is often a paediatrician for children, but in some parts of the world, it could be a general practitioner or other healthcare professional. Healthcare for both children and adults with cerebral palsy is multidisciplinary with no one health professional able to meet all health needs.

The healthcare practitioner plays a central role in oversight and coordination of care, management of acute medical issues, and paying attention to health promotion (including diet, exercise and weight management) and disease prevention (including immunisation and cancer screening for adults).

The healthcare practitioner also has a valuable role in consideration of the impact of the disability on other family members. The family member with cerebral palsy brings new dimensions and experiences to family life,

and most families feel that their life has been enriched through sharing their life journey with someone with cerebral palsy. There are also often challenges and stresses experienced by all involved that relate to a whole range of health, social, access, communication, service availability and provision, time, financial and support related issues. Parents of people with cerebral palsy, particularly mothers, have been identified as having higher rates of mental health disorders such as depression and anxiety.¹ Siblings require focus to ensure their physical, psychological and social needs are addressed. Extended family members may also be significantly impacted by the effect of the child's disability on family identify, dynamics and functioning.

An example of a clinical pathway for the management of cerebral palsy can be found at

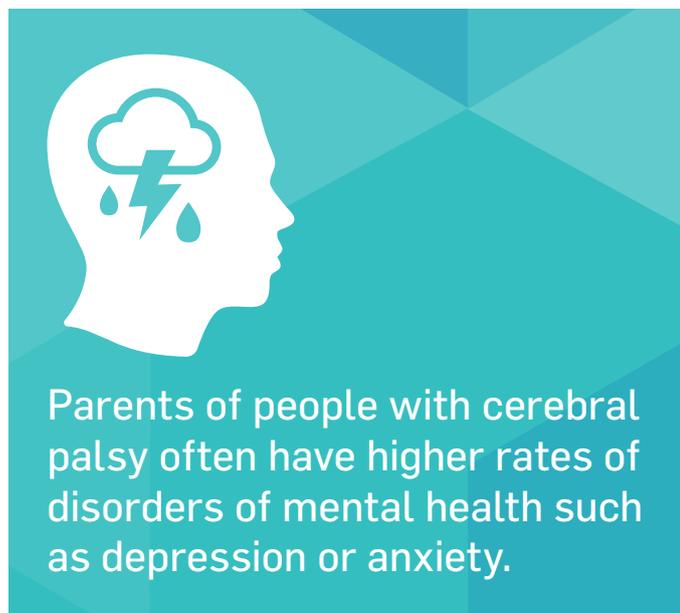
<https://www.nice.org.uk/guidance/ng62>

Other health professionals may also play an important role in the healthcare of people with cerebral palsy:

Developmental or general paediatrician

For children with cerebral palsy the paediatrician plays a role in ensuring the child and family have access to specialist expertise around development, monitoring of known health risks and linking to appropriate services.

For adults with cerebral palsy there is often no medical specialist in this area. The healthcare practitioner therefore plays the central medical role in monitoring health status, providing healthcare and coordinating the contribution of other health professionals. Some countries have specific support networks available. In addition, a number of countries and regions have academies of childhood disability or similar professional networks. There is also the International Alliance of Academies of Childhood Disability which has a community of multi-disciplinary practitioners, and resources for a global audience.



Parents of people with cerebral palsy often have higher rates of disorders of mental health such as depression or anxiety.

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.

Neurologist

For children a paediatric neurologist investigates the underlying cause of the cerebral palsy and contributes to the management of seizures and movement disorders.

For adults a neurologist usually manages seizures and movement disorders and can also contribute to identifying the underlying cause of the cerebral palsy.

Gastroenterologist

For children and adults paediatric and adult gastroenterologists provide assessment and advice on the management of gastro-oesophageal reflux, nutrition and/or chronic constipation.

Geneticist

For children and adults genetics is a field that is developing so rapidly that the underlying genetic cause of disability for people of all ages is being increasingly identified. However, genetic services can be limited in many countries. In better resourced countries, genetic review every five years is recommended for people with cerebral palsy of any age for whom a cause of disability has not previously been identified.

Rehabilitation specialist

For children and adults paediatric and adult rehabilitation specialists can assess, advise on and manage contractures and spasticity, work with the person to optimise function and in conjunction with allied health colleagues may suggest specific exercise programs to improve strength.

Orthopaedic surgeon with expertise in working with people with cerebral palsy

For children most of the orthopaedic issues requiring intervention for people with cerebral palsy arise and are managed in childhood. There are a number of orthopaedic surgeons with expertise in this area, generally associated with major children's hospitals. Their role is the care and management of spasticity, contractures, and joint and bone deformity. They also play a central role in hip surveillance to facilitate the management of subluxation or dislocation.

For adults there are few orthopaedic surgeons with a special interest and expertise in this area and awareness of the needs of this group is growing.

Ophthalmologist

Children and adults with cerebral palsy are at increased risk of visual impairment and those with communication difficulties may not be able to report or describe their difficulty. Regular assessment and advice on eye health and visual function is therefore important from the neonatal period and throughout life.

Audiologist

Children and adults with cerebral palsy are at increased risk of hearing impairment and those with communication difficulties may not be able to report or describe their difficulty. Regular assessment and advice on hearing is therefore important from the neonatal period and throughout life.

Dental services

Children and adults with cerebral palsy have an increased risk of poor oral health and orthodontic issues. Regular dental and oral health surveillance is an important part of healthcare throughout life.

Allied health

People with cerebral palsy benefit from the expertise of allied health professionals with a specialist focus on assessment and management of people with cerebral palsy.

- **Physiotherapist:** For the assessment, monitoring and management of movement disorders to improve function, activity and participation; and advice on, prescription of, and support for appropriate mobility aids including walking frames and wheelchairs.
- **Occupational therapist:** For the assessment, monitoring and management of functional impairments of upper limb function; advice and support for strategies, aids and equipment to optimise independence in activities of daily living; for advice on, prescription of and support for seating solutions including wheelchair prescription for people with complex needs. Occupational therapists can also play a valuable role in understanding and establishing activities that address the sensory needs of people with severe disability.
- **Speech pathologist:** For assessment and advice on management of saliva control, disorders of swallowing and risk of aspiration; communication assessment and advice and support on appropriate communication strategies and aids.
- **Continence nurse:** For assessment and advice on continence and continence aids. Continence nurses can also provide valuable advice on the management of constipation.
- **Dietitian:** For advice on appropriate diet for people who have disorders of chewing and or swallowing and require foods of particular consistency (e.g. thickened fluids) or caloric content (for example concentrated calories for people who are underweight), and reduced calorie diets for people who are gaining weight.
- **Psychologist: Educational psychologists** can provide assessment and detailed information about the child's cognitive functioning and specific learning needs. **Clinical psychologists** can provide counselling support and the development of coping strategies for both children with cerebral palsy and their families. **Family therapy** may be helpful for some families. Psychologists can also play a valuable role in understanding behaviours of concern in people with disability and work with them to develop more adaptive behaviours that better meet their physical, psychological, social and sensory needs. Neuropsychological evaluation identifies the specific strengths and limitations in auditory-linguistic abilities, visual abilities, memory, processing speed, cognitive efficiency, and reasoning, and the factors that enhance or detract from the individual's overall performance, such as attention or motor and sensory abilities.
- **Social worker:** To work with and support individuals and families to link to and participate in their communities, and to access the financial and other supports they require. These may include:
 - **Disability services:** Including early childhood intervention, school age support services, adult services with respect to education, employment, respite, accommodation and behaviour support services.Government-funded support schemes are available in various parts of the world. In Australia, the National Disability Insurance Scheme funds disability related services for people with significant functional impairment.
- In India, the Niramaya Scheme managed by the National Trust provides financial support for expenditure incurred in the care of individuals with cerebral palsy.
- **Carer support services:** These could include Centrelink, local council, parent support groups, counselling services, advocacy and information services such as Carers Australia.

REFERENCES

1. Bourke-Taylor et al., 2010; Bourke-Taylor, Pallant, Law, & Howie, 2012; Gallagher, Phillips, & Carroll, 2010; Gallagher & Hannigan, 2014; Gilson et al., 2018.