

# Medical care of individuals with cerebral palsy

People with cerebral palsy may have a range of health issues related to both the intrinsic musculo-skeletal issues of cerebral palsy, and the impact of the underlying cause on other body systems.

People with cerebral palsy often have associated disorders and comorbidities requiring input from a multi-disciplinary team. The care co-ordinator role has traditionally been undertaken by a healthcare practitioner, or in some countries, by a general practitioner, family physician or paediatrician. However, any member of the multi-disciplinary team can take on this role as long as they have the confidence of the person with cerebral palsy (either a child or an adult) and their family.

## Some of the associated health implications of cerebral palsy include:

- **Musculoskeletal:** Increased effort required for mobility and muscle weakness leads to fatigue or soft tissue damage; spasticity may cause spasm, pain and contractures; the imbalance of muscle groups acting on joints may lead to joint deformity, subluxation or dislocation; scoliosis or kyphoscoliosis. Osteoporosis is common, particularly in people who do not weight bear; nutritional factors and inadequate Vitamin D may also contribute.
- **Neurological:** learning difficulties, intellectual disability, epilepsy, hearing or vision impairment.
- **Gastrointestinal:** chewing and swallowing difficulties, gastro-oesophageal reflux, oesophagitis and constipation. There is an increased incidence of volvulus related to chronic constipation.
- **Nutrition:** poor nutrition, micronutrient deficiencies and failure to thrive. Nasogastric and gastrostomy feeds may be required.
- **Respiratory:** aspiration, thoracic/abdominal muscle weakness, kyphoscoliosis and recurrent chest infections.
- **Genitourinary:** cognitive, motor and sensory issues may contribute to incontinence; undescended testes are more common.
- **Skin:** immobility, dependency, poor circulation, chilblains, skin breakdown and ulceration. Skin breakdown may be related to pressure areas and/or poor peripheral circulation.
- **Sensation:** differences in registration and perception of sensations, including tactile and proprioceptive sensations. Visual perceptual difficulties are also common.
- **Dental/oral health:** oral sensitivity, problems with oral hygiene, difficulty cleaning, orthodontic issues and communication. For some people saliva control is also a problem that has potential social and cosmetic impacts.

- **Mental health:** people with disability are more at risk of mental health disorders due to social, psychological and biological risk factors.

## The healthcare practitioner's role for someone with cerebral palsy focuses on:

- Optimising health and function.
- Enabling optimal independence, participation and contribution.

## The healthcare practitioner's role includes:

- Providing health promotion and prevention services.
- Managing some chronic health conditions.
- Addressing acute healthcare needs as they arise.
- 'Conducting the orchestra' of the healthcare team.

## Proactive care

Taking a proactive approach to care ensures health issues are detected and addressed in a timely fashion. A proactive approach includes:

- Yearly health assessment.
- Ensuring disease prevention and health promotion interventions are including immunisations and cancer screening as indicated.
- Regular review, particularly the choice, efficacy and side effects of medications.
- Surveillance will include:
  - Nutrition assessment including weight and height (estimate iron and Vitamin D, B12 and folate levels if nutrition is poor);
  - Hearing and vision;
  - Epilepsy management plan;
  - Dental care;
  - Respiratory care;
  - Pain management;
  - Hips and other joints to maintain range of movement and prevent dislocations or subluxations;
  - Spine for kyphoscoliosis; and
  - Bowel care.

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.

In order to address the multifaceted issues involved in the care of individuals with cerebral palsy, health systems of most countries have their own well-defined health strategies, for example, in Australia, Medicare is a national healthcare scheme financed by taxation.

## The healthcare team

No one health professional can address the needs of people with complex health issues. Complexity and the multiple systems involved mean that there is a need for a multidisciplinary team.

For children with cerebral palsy, a public healthcare worker, a paediatrician or a primary care doctor is usually involved. An example of primary care doctor is an RBSK doctor in India. An RBSK doctor is part of an Indian program to improve the overall quality of life of children and is organised by the Ministry of Health & Family Welfare (Rashtriya Bal Swasthya Karyakram — RBSK). It is important that a shared care arrangement be established between the healthcare practitioner and the paediatrician to ensure effective flow of information about the child's health issues and care plan. The family, and the child when appropriate, are key members of the healthcare team.

In adolescence, discussions about transition from paediatric to adult services will occur.

The care team in adulthood will need to be established in close consultation with the paediatric team and with the adolescent and family. In adulthood the healthcare practitioner is usually the 'conductor of the orchestra' of medical and allied health professionals involved in addressing the complex needs of adults with cerebral palsy.

Which health professionals comprise the team will depend on the particular health issues for each particular patient:

- **Mobility:** physiotherapist, orthotist, rehabilitation physician, orthopaedic surgeon, exercise physiologist, personal trainer.
- **Swallowing and nutrition:** speech pathologist, dietitian.
- **Communication:** speech pathologist.
- **Personal care and independence:** occupational therapist.
- **Gastrointestinal issues including reflux and constipation:** gastroenterologist.
- **Continence:** continence nurse, gastroenterologist.
- **Vision and hearing:** ophthalmologist, audiologist, ENT surgeon.
- **Aetiology:** If the underlying cause of the cerebral palsy has not been established then consider review by a geneticist every five years. Knowing the cause of the disability will provide an explanation, information about future genetic risk, and may inform medical care.

For many of these issues, a multi-disciplinary approach works best, particularly in cases of complex disability.

## Treatment of the movement disorders

Many people with cerebral palsy have spasticity and/or dystonia.

### Spasticity may be treated:

- With oral medication; muscle relaxants such as baclofen or benzodiazepines.
- With injectable agents for specific muscle groups; Botulinum toxin.
- Phenolisation of particular nerves supplying a muscle group, e.g. obturator nerve/hip adductors.
- Intrathecal baclofen.
- Surgical procedures; lengthening of tendons, e.g. Achilles, hamstrings.

### Dystonia may be treated:

- With oral medication; baclofen first line, then trihexyphenidyl and clonidine.
- Intrathecal baclofen.
- Deep brain stimulation (rare).

Please refer to the American Academy of Cerebral Palsy and Developmental Medicine Care Pathway <https://www.aacpdm.org/publications/care-pathways/dystonia>

## Epilepsy

Epilepsy is very common in people with cerebral palsy.

**Epilepsy is more likely to occur** in people with cerebral palsy, and indeed those with other developmental disabilities. It is also more likely that the epilepsy involves more than one seizure type and may be more difficult to treat than that experienced by people in the general population.

### Types of seizures

Epilepsy may be focal or generalised in onset, and may have motor or non-motor manifestations.

Awareness may be unaffected or impaired in focal seizures. Generalised seizures always involve impaired consciousness.

For the current classification of seizure types see [www.epilepsy.com/article/2016/12/2017-revised-classification-seizures](http://www.epilepsy.com/article/2016/12/2017-revised-classification-seizures)

**The treatment of epilepsy** in people with cerebral palsy is designed to decrease the frequency, length and severity of seizures in order to increase quality of life. Good seizure control may also reduce the chance of premature death when seizures are potentially life threatening. It is increasingly recognised that for many people with cerebral palsy and epilepsy, seizures may resolve with time.

**The choice of anti-epileptic medication** depends on a number of factors including the seizure type and other health issues. Trials of medications are often required in order to find the one that best treats the seizures and causes least side effects. Some people require multiple anti-epileptic medications and in some cases it is not possible to prevent all seizures. Regular review of anti-epileptic medication is very important.

### Triggers

People with epilepsy and those who support them in their healthcare need to understand their pattern of seizures and identify triggers. For some, sleep deprivation, strobe lighting, excitement, infection and other factors can be identified as triggers for seizures. For most people, regular routines with adequate sleep help to minimise seizures.

Seizure frequency, severity and type can change over the lifespan.

### Death and epilepsy

Epilepsy is a serious condition that must be optimally managed in order to minimise the impact on the quality and length of life. People who have prolonged generalised motor seizures can become hypoxic and this can lead to brain injury or even death.

There is a condition referred to as Sudden Unexpected Death in Epilepsy (SUDEP). This generally occurs in people with severe and complex seizures and in those whose epilepsy is not well controlled. It is therefore important to review the frequency and pattern of seizures regularly. Shared care with a neurologist is helpful in people with cerebral palsy who have epilepsy.