

Growing up and getting older with cerebral palsy

As children grow and develop into adolescents, adults and later into old age, while the underlying neurological impairment does not change, the various manifestations and implications of having cerebral palsy may do so.

Many health conditions and functional changes occurring with age can – and should – be treated. Most are not inevitable consequences of cerebral palsy.

The healthcare practitioner is central to providing and coordinating health care for adults with cerebral palsy. Offering regular review and monitoring of both function and health status can contribute to people achieving and maintaining optimal health and function over time.

The healthcare practitioner's role includes:

- Managing general and acute health problems.
- Ensuring access to disease prevention (including screening) and health promotion (including healthy diet, weight and exercise programs).
- Ensuring access to medical specialists, allied health professionals and community and disability professionals.
- Contributing to multidisciplinary team aiming to maintain optimal health, independence and function. Rehabilitation medicine professionals are playing an increasing role in this patient group, but often their involvement is short-term.

Taking a proactive approach to care

The role of the healthcare practitioner in monitoring and overseeing issues related to health and function is essential. An annual health assessment allows the healthcare practitioner the time required for this proactive approach to care.

The healthcare practitioner is the **co-conductor of the health and social care professionals** involved in the care of people with cerebral palsy. The other conductor is the person with cerebral palsy. Members of the team may include:

- Family members and friends.
- Disability support practitioners.
- Allied health professionals such as physiotherapists, occupational therapists and speech pathologists.

- Other medical practitioners such as neurologists, orthopaedic surgeons, ophthalmologists, gastroenterologists and rehabilitation specialists.
- Other health professionals such as nurses (practice nurse or continence nurse), dentists and other community health care workers.

Practitioners should encourage adults with cerebral palsy to:

- Have an annual health assessment including weight (consider iron and Vitamin D, B12 and folate levels if nutrition is poor) and review of medications.
- Maintain a regular program of both aerobic and muscle strengthening physical activity to build and maintain cardiovascular fitness, muscle flexibility and strength, and range of movement.
- See a physiotherapist regularly to monitor motor function and for advice on physical exercise and mobility aids.
- Consider options for management of the movement disorder (e.g. spasticity or dystonia) to optimise comfort and function.



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.

- See an occupational therapist regularly for advice on postural support and seating and to optimise upper limb function. People who use a wheelchair need expert attention to their seating and posture control. This is essential for their comfort and upper limb function, and minimises further deterioration in posture and the likelihood of developing pressure injuries. Occupational therapists may also make recommendations about home adaptations and environmental controls.
- Encourage participation in community activities for physical activity, social engagement, social connection and intellectual stimulation.
- Use available home supports and personal care assistance if required.

Assessment

In your assessment consider:

- Those conditions that are common in anyone else of that age and gender.
- Those conditions more likely to occur in people with cerebral palsy.
- Health promotion and disease prevention.

Helpful resources include:

- The RACGP Guidelines for Preventive Activities in General Practice <https://www.racgp.org.au/download/Documents/Guidelines/Redbook9/17048-Red-Book-9th-Edition.pdf>
- Management Guidelines in Developmental Disability <https://tgldcdp.tg.org.au/index>

Health promotion and disease prevention

Health promotion is just as important as for any other patient, including maintenance of:

- Healthy weight;
- Healthy diet; and
- Regular exercise.

Referral to a dietitian and/or physiotherapist may be an important part of addressing these needs.

Immunisation status should be reviewed each year and people with a susceptibility to chest infections benefit from influenza vaccination.¹ Pneumococcal and Covid vaccinations may also be indicated.

Mental health problems are easily overlooked. Psychotic illnesses, mood disorders and anxiety are all more common in people with cerebral palsy. Enquire about sleep problems, lack of appetite and fatigue. Whilst these symptoms can be related to a physical illness, they are also common features of depression.

Cancer screening

Access to any National Cancer Screening Programs for cervical, breast and bowel cancer is the right of every person. People with cerebral palsy may need their healthcare practitioner to educate, remind, advocate and assist with the arrangements for the testing required. For instance, people with cerebral palsy may not receive an invitation for national screening programs. Their routine health needs may not be perceived as a priority.

Changes in function over time

Alterations in function over time may occur because of:

- **Musculoskeletal changes:** People with cerebral palsy have disorders of movement that put unusual stress on muscles, bones and joints.
 - Over time, this increased physical wear and tear is associated with muscle fatigue, weakness, strains and sprains, joint deterioration and arthritis. Contractures, joint subluxation or dislocation may also be present and worsen with age. Back pain (particularly in those with scoliosis) may be a particular concern.
 - In turn, this often leads to premature decline in physical function that may begin as early as the person's twenties and thirties.
 - The associated pain, fatigue and weakness affect independence, participation, and wellbeing.
 - Osteoporosis is more common in people who do not weight bear and may predispose to pathological fractures.
- **Neurological changes:** People with cerebral palsy who have epilepsy may have changes in their seizure types, patterns and medications over time, which may impact on function and participation.
- **Weight gain or loss:**
 - Significant weight gain may make it more difficult for someone with reduced muscle strength to move around independently. It may also be more difficult for those providing personal support.
 - Significant weight loss may reflect difficulties in chewing and swallowing and may be associated with nutritional deficiencies, which may impact on health and function. Weight loss may also herald serious disease, as in anyone of a similar age and gender. Oesophageal cancer is more common in people with cerebral palsy because of chronic reflux oesophagitis.



As all of us age, we are more likely to develop health issues, and this is no different for people with cerebral palsy. Regular review of cardiovascular, genitourinary, neurological and other systems is required to ensure timely interventions.



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- **Medications:** People with cerebral palsy are often taking a range of medications for musculoskeletal, gastroenterological, neurological and other associated conditions. Some of these may have side-effects that impact on physical and or cognitive function.
- **Changing physical health status:** As all of us age, we are more likely to develop health issues and this is no different for people with cerebral palsy. Regular review of cardiovascular, genitourinary, neurological and other systems is required to ensure timely interventions.
- **Changing mental health status:** People with cerebral palsy may develop disorders of mental health during their lifetime. Refer to *Module 9* on mental health.

Dental and oral health concerns. These can be associated with a range of implications including discomfort, pain, halitosis, tooth loss.



Physical health conditions

Physical health conditions that are more common in people with severe cerebral palsy who are getting older include:

- Musculoskeletal pain related to:
 - Arthritis in joints – particularly of the lower limb, shoulders and spine;
 - Muscle strain, sprain; and
 - Pathological fractures.
- Lower respiratory tract infections (particularly in people with swallowing difficulties and/or aspiration).
- Dermatological issues including skin breakdown in flexures or pressure areas related to position and support in bed or wheelchair, orthotics, other appliances, personal clothing or equipment.
- Reflux oesophagitis and oesophageal bleeding (particularly in people with kyphoscoliosis). This may result in anaemia.
- Constipation causing abdominal pain, nausea and/or incontinence of faeces.
- Conditions associated with poor peripheral circulation such as chilblains or leg ulcers.
- Continence problems: Treatable causes must be energetically addressed (e.g. constipation, urinary tract infection, irritable bladder). Continence problems may also relate to decreasing mobility and increasing difficulty accessing the toilet, or to carer knowledge or expectations.
- Sleep disturbance is common, often with shorter sleep duration and higher risk of sleep-related breathing disorders.
- Changing seizure patterns.
- Dental and oral health concerns associated with a range of implications including discomfort, pain, halitosis or tooth loss.

Review of support needs

People with cerebral palsy may find that their physical ability and function decreases earlier than that of their age peers. Joint and muscle pain may also be a factor. This may lead to reduced ability to engage in social, educational and employment activities.

Active treatment of musculoskeletal issues through analgesia, exercise, physiotherapy, massage, and/or equipment modification should all be considered. Levels of support provided by paid staff should be regularly reviewed. Increased hours should be suggested if lack of support is impacting on the ability of the person to complete activities of daily living and to engage in the social and economic life of the community.

REFERENCES

1. Australian Technical Advisory Group on Immunisation (ATAGI). *The Australian immunisation handbook 10th ed (2017 update)*. Canberra: Australian Government Department of Health, 2017.
2. Therapeutic Guidelines Limited. *Management guidelines: developmental disability*. Version 3. Melbourne; Therapeutic Guidelines Limited; 2012.