

Managing complexity

People with cerebral palsy often have multiple medical and social issues and a systematic approach to managing the complexity inherent in care is helpful to patient and healthcare practitioner alike.

When people present with multiple issues:

- **Access** to healthcare settings needs to be appropriate for people with impairments of mobility, communication, hearing and vision.
- **Prioritisation** enables the most urgent and important issues to be addressed first.
- **Allocation** of further appointment time will enable other issues to be addressed in a timely and systematic fashion.
- **Referral** to the appropriate medical specialists and/or allied health professionals, enables the multidisciplinary team to address the allied health related needs.
- **Ensure** regular dental and oral health needs are being addressed as these can impact on wellbeing, general health, ability to eat, and behaviour.
- **Review** the appropriateness and sustainability of the home environment and the care network around the person.

When people have communication difficulties it may be more difficult to know if:

- Treatment/intervention has been effective.
- The patient has responded as expected.
- Side effects/adverse effects of medication have occurred.

A review appointment, with additional time allowed to monitor the above is a crucial component of care.

2. Proactive healthcare

Proactive care comprises of:

• A comprehensive annual health assessment to enable the time and focus for:

- A comprehensive review of physical, mental and social health;
- Consideration of hearing and vision;
- Disease prevention and health promotion; and
- Ensuring that a multidisciplinary team is in place, the composition of which will depend on the needs of the individual.

Healthcare for people with complex needs falls into two categories:

1. Reactive healthcare

In responding to the presenting health issues, the patient may initiate the appointment or a family member or support worker may do so.

For many people with cerebral palsy it takes longer to take the history and perform an examination. For patients who cannot bear weight, getting out of the chair for an examination is difficult. One examination room could have a ceiling hoist or the practice could have a portable hoist.

Minor illnesses may become more complicated or urgent because of the cerebral palsy. For example, a urinary tract infection may increase urinary frequency resulting in continence issues. A minor chest infection may progress quickly to be a more serious condition. Ordering tests or x-rays may have access difficulties. It may be useful to encourage the person or carers to book a longer appointment whenever possible.

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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.

- **Medication review.** Many people with cerebral palsy are on multiple medications, such as anti-epileptic medications, which can have significant side effects. These require regular monitoring for both efficacy and the detection of adverse effects.
- **Review of seating and posture.** Musculoskeletal changes, including scoliosis, tend to lead to changes in posture and joint position over time requiring regular monitoring to ensure the timely detection of:
 - The need for new or different therapy, aids and equipment. Consider referral to a speech pathologist, occupational therapist or physiotherapist.
 - Changes in function that may be improved with posture support (e.g. communication, self care). Consider referral to an occupational therapist or physiotherapist.
 - Discomfort and pressure points, and referral for wheelchair modification or prescription. Consider referral to an occupational therapist or physiotherapist with expertise in wheelchair prescription for those with complex needs.
 - Increasing scoliosis. Consider referral to a spinal orthopaedic surgeon to discuss the need for intervention.
- **Ensuring implementation of disease prevention interventions.** These include:
 - Immunisation, including annual influenza and pneumococcal vaccination when appropriate, and Covid vaccination
 - Cancer screening: People with disability are at risk of missing out on national screening programs for cervical, breast and bowel cancer screening as well as those indicated for particular patients because of family history or other reasons.
- **Addressing health promotion** strategies including diet, exercise and promoting good mental health.
 - Diet: People with cerebral palsy may be at risk of becoming underweight (chewing or swallowing difficulties) or overweight (lack of physical activity). Achieving and maintaining a healthy weight is an important focus of care to ensure good nutrition and to optimise function and independence.

- Exercise: People who have difficulty walking and/or use a wheelchair for mobility may benefit from the advice of a physiotherapist or exercise physiologist to design an exercise program for them that builds on their physical ability. Exercise programs may include hydrotherapy. Adequate exercise will assist in maintaining an optimal weight and function.
- Sexual health: Contraception, menstrual management, sexual health and menopause issues.
- Fatigue: Many people with cerebral palsy complain of fatigue. Known causes such as anaemia should be excluded.
- Insomnia: This is a common problem and careful consideration should be given to precipitating factors such as pain, bed and type of bedding (an occupational therapist might be helpful) and continence management. See *Module 12* on sleep for more information.
- Mental health: people with cerebral palsy have an increased prevalence of mental health disorders including mood, anxiety and psychotic disorders. These conditions may be more difficult to recognise and treat.

Government support for healthcare of people with cerebral palsy

People with cerebral palsy tend to have chronic and complex health needs. It is acknowledged that this group of patients currently experience health disadvantage and time is required as:

- Consultations take longer – communication, cognitive differences and carer involvement...and paperwork (*irritating but absolutely essential!*).
- There are often multiple people involved – family, support workers, allied health professionals, other doctors.
- There is often a need for carer education with respect to health issues.

Enhanced Primary Care items:

People with cerebral palsy will often have access to health care through government schemes, varying between countries and regions. Country specific information about these schemes will be helpful for healthcare professionals and service users. Some examples of such schemes are as follows:

Australia

- Health Assessments: For people with an intellectual disability – for those with cerebral palsy who also have an intellectual disability. Medicare items 703, 705, 707.
- GP Management Plans & Team Care Arrangements: Medicare items 721, 725.
- Team Care Arrangements: Medicare items 723, 727.
- Case Conferencing: Medicare items 735, 739, 743 (org) and items 747, 750, 758 (part.).

India

- The Rights of Persons with Disabilities Act 2016
- Niramaya Health Insurance Scheme for persons with disabilities



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