CEREBRAL PALSY Information Sheet (1)

(Optional sheet to be included where recipient of PHR has Cerebral Palsy)
The material in this sheet has been adapted from the Therapeutic Guidelines book 'Management Guidelines for People with Developmental and Intellectual Disabilities' and updated from the 2005 version ‚Management Guidelines – Developmental Disability' which can be consulted for more detailed information.

Cerebral palsy is a persistent but not unchanging disorder of movement and posture due to a defect or lesion of the developing brain. It occurs in about two per 1000 live births. It is a lifelong condition.
It can occur as the result of prenatal, perinatal and postnatal factors and it is important to try to establish the cause in each case, although this is not always possible.
Cerebral Palsy can be classified according to:

- the type of motor disorder (spasticity, dyskinesia, ataxia or mixed),
- the distribution of the motor disorder (hemiplegia, diplegia, quadriplegia) and
- the severity of the motor disorder

Major Health Issues	Recommendations - summary
Hearing Assessment	Review every 2-5 years by an audiologist
Vision Assessment	Review every 2-5 years by an optometrist or ophthalmologist
Epilepsy	Awareness of risk of osteoporosis, increased falls and fractures (especially with phenytoin) Monitor medication regularly
Nutrition	Beware of obesity and under-nutrition; involve dietician, speech pathologist
Dental check	Six monthly
Gastro-oesophageal disease	Awareness of high risk and unusual presentations
Genitourinary problems	Awareness that these are common
Constipation	Awareness that this is common
Chronic lung disease	Assess for eating and swallowing difficulties Awareness that recurrent chest problems may be a sign of aspiration Referral to speech pathologist if aspiration suspected
Musculoskeletal effects	Ongoing management by physician and physiotherapist - in childhood, to prevent, contain or treat dynamic tightness and/or contractures - in adulthood, to maintain range of independent mobility and realistic levels of physical exercise, and to reduce fatigue and pain Yearly hip X-rays in children who are not walking independently Management of scoliosis, kyphosis and seating posture
Psychological health	Awareness of risk of psychiatric disorder and psychological impairment Address body image and sexuality issues
Other issues	Saliva control; Communication difficulties; Intellectual disability; Perceptual problems

CEREBRAL PALSY - Additional Information

Management of Child and Adult

An annual review is recommended for people who have cerebral palsy, with special reference to:

Vision - All children and adults require visual **assessment every 2-5 years**. Disorders of vision, particularly strabismus, are common. Visual acuity may be impaired and this can remain undetected.

Hearing - All children and adults need a hearing **assessment every 2-5 years**

Epilepsy - occurs in up to 50% of children and 20% of adults with cerebral palsy. It is most common in those with severe motor problems.

Adults may have been on anti-epileptic medication for many years and are also at increased risk of osteoporosis and therefore, fractures.
Regular review of anti-epileptic medication is important. Estimation of drug levels is only useful for carbamazepine, phenytoin and phenobarbitone. Levels of these drugs should be checked if clinically indicated, eg. uncontrolled seizures, or if there are possible side effects.
Ensuring an adequate intake of calcium and Vitamin D, and educating the person about osteoporosis-prevention may also be required.

Intellectual Disability - Approximately 40-45 % of people with cerebral palsy have levels of functioning in the mildly intellectually disabled range or below. This does not always correlate with the severity of the physical disability.

Perceptual Problems - Perceptual disorders such as motor-planning difficulties, eye-hand coordination and problems of spatial awareness and shape recognition can impact on the person's organisational abilities and living skills. An occupational therapist and psychologist can provide assessment and advice.

Nutritional Problems - particularly obesity and under -nutrition, are common.
Obesity may be due to lack of regular physical activity and poor dietary habits and can cause exacerbation of arthritis and scoliosis and difficulties with independent mobility.
Oropharyngeal incoordination, gastroesophageal disease, dysphagia and poor oral hygiene may contribute to problems with under-nutrition. Education regarding good dietary habits, regular dental visits and the importance of good oral hygiene is essential. It may also be useful to involve a dietician and speech pathologist.

Gastroesophageal Disease - Gastro-oesophageal reflux, oesophagitis and oesophageal bleeding are all common problems in people with severe cerebral palsy. Upper gastro-intestinal tract bleeding is a common cause of hospitalisation, particularly in patients who have a combination of spastic quadriplegia and intellectual disability. Chronic reflux oesophagitis also constitutes a significant cause of aspiration-induced pneumonia.
Oesophagitis may be difficult to diagnose because the patient may not be able to report the symptoms.
Presentation of gastro-oesophageal disease includes: non-specific deterioration in the person's level of functioning; anaemia from subclinical blood loss; vomiting and/or frank upper gastrointestinal haemorrhage; pain and/or irritability; anorexia.
Management may include: Referral to a gastro-enterologist; positioning; anti-reflux medications; anti-reflux surgery (eg Nissen's fundoplication and gastrostomy).

Genitourinary Problems - Urinary incontinence and retention are common problems for both men and women with cerebral palsy. Neurological dysfunction, urinary tract infection, infrequent voiding, inability or difficulty physically accessing the toilet and sensory deficits may all be contributing factors.
Undescended testes is a common but often unrecognised problem that carries an associated cancer risk if not addressed. Screening for other sorts of genital problems, for both men and women, should be in line with general population recommendations.

Constipation - Children and adults often develop constipation due to insufficient dietary intake of fibre and fluids, a lack of routine physical movement and certain medications.
Regular bowel evacuation may be achieved by educating the individual and carers of the importance of dietary fibre, adequate fluid intake and physical activity. It is helpful to make parents and carers aware of the importance of using routine and post-meal gastrocolic reflex in bowel management. If these strategies are ineffective a bulk laxative, such as psyllium, may be beneficial.
Other types of bowel medications may be required but should be avoided as long term therapy wherever possible.

Chronic Lung Disease - Some individuals with severe cerebral palsy develop chronic lung disease. It appears that this is due to aspiration which may occur quite silently for a period of time. The presence of coughing during meal times may draw attention to the possibility of aspiration. Aspiration may result in chronic lung conditions such as recurrent pneumonia and asthma. Respiratory conditions are the most significant cause of mortality in people with cerebral palsy.
Management: Regular review by the general practitioner or medical specialist is recommended. If there is a suspicion of eating or swallowing problems, a further assessment by a speech pathologist is often helpful. Barium videofluroscopy may be helpful.
In the presence of severe feeding difficulties, alternate feeding regimes such as the use of gastrostomy, should be considered.

Poor Saliva Control - Referral to a speech pathologist is helpful in many aspects of managing poor saliva control. Paediatricians, dentists, ENT specialists and plastic surgeons may also have a role in this problem. The importance of the social implications of drooling should not be underestimated. Odour problems due to stale saliva can be managed by use of deodorising agents.
Anticholinergic medication such as Benzhexol and Benztropine are useful in both children and adults, but care should be taken to monitor for side effects. Glycopyrrolate (Robinul) appears to be a new, useful and effective drug on the horizon.
Surgery may be indicated when conservative approaches have failed. Dental health should be carefully monitored following saliva control surgery as there is a slightly increased risk of dental caries.

Dental Health - Dental visits are recommended **six monthly.** Due to chewing and swallowing difficulties and common dental conditions such as overbite, people with cerebral palsy are particularly susceptible to dental problems.
Malocclusions are prevalent due to abnormal muscle function. Periodontal disease leads to halitosis, dental caries and the early loss of teeth. Effective oral hygiene may be complicated by carers' inability to correctly brush and floss teeth.

Musculoskeletal Effects - Children are at risk of developing contractures which may require orthopaedic intervention. Physiotherapy interventions such as muscle stretches, serial plasters and splints can assist in preventing and delaying the development of contractures. Ongoing physiotherapy for adults may also assist in maintaining physical independence and movement and may reduce muscle fatigue and pain. Abnormal stress and strain placed on joints and limbs often leads to early onset of age-related conditions such as arthritis.
The following problems may occur: hip subluxation and dislocation; flexion contractures at the knee may require hamstring surgery; equinus deformity at the ankle; gait analysis may assist in the planning of orthopaedic surgical procedures; shoulder dislocations and subluxations may occur in adults and require treatment; surgical procedures of the hands include tenotomies, tendon transplants and arthrodeses to improve and maintain function, but careful assessment is required; palmar hygiene problems are common in individuals with hand flexions; scoliosis develops in adolescence, and may lead to increased respiratory problems, decreased mobility and increased joint and muscle pain.

Psychological Health - An individual's psychological health may impact dramatically on the person's social and emotional wellbeing. Psychological impairments in people with cerebral palsy are common and can be easily overlooked or remain untreated.
Depression, frustration, anxiety and anger are common complaints of adults with cerebral palsy. Loss of independence and changes in functional ability and social access may contribute to these feelings. Medication interactions may contribute to behavioural changes/problems. Referral to a psychologist or psychiatrist may be required. Review of current social supports may be of benefit.

Health Issues related to ageing - Adults with cerebral palsy commonly suffer from conditions associated with the normal process of ageing as early as in their twenties and thirties. Conditions such as unexpected fatigue, loss of physical function and independence, and increased frustration occur. It is important to be proactive in encouraging patients to access appropriate community resources, such as leisure activities and home supports, when required.

<u>Referrals</u>- Referral to, and liaison with, specialist medical services, allied health professionals and teachers is important in the care of young people with cerebral palsy. Adults may require referral to allied health professionals on a regular or as required basis.

- **Paediatricians** - have an important role in the ongoing evaluation and management of childhood disability until transition to adulthood.
- **Physiotherapists** - provide advice and training about methods to encourage movement, and information about orthotics, walking aids and special seating.
- **Occupational therapist**s - aid the development of self care and upper limb skills, and provide advice about equipment and home modifications.
- **Speech pathologists** - assist in the development of speech and communication, and provide guidance about feeding difficulties and saliva control problems. They also advise on the use and availability of augmentative communication devices.
- **Psychologists** - provide psychometric testing of children, functional assessment of adults, vocational aptitude testing, skills training and management of challenging behaviours.
- **Community Case Workers/Advocates** - assist in the development and realisation of personal goals.
- **Vocational Support** - offers support and assistance for the adult in a work situation.
- **Other useful referrals** - nurses, dieticians, social workers, orthotists, orthoptists, ophthalmologists and other medical specialists.

Provision of information about facilities such as multipurpose taxi vouchers and child disability allowance, can be a very important aspect of care. Respite care may be available either in-home or in a centre-based facility. Contact the Disability Services in your state for more information.

Page revised June 2005