Syndrome Specific Medical health check guide - Cerebral Palsy (CP)

The NICE guideline [NG62] Cerebral palsy in under 25s: assessment and management (Published date: January 2017) is a useful guide to the key health issues that affect people with cerebral palsy. This is brief summary of the guidance. 50% of people with cerebral palsy have some level of LD with 25% of people with cerebral palsy have severe or multiple and profound LD.

Remember to ask about pain, sleep and distress as part of any clinical consultation with someone with cerebral palsy.

1. Eating, drinking and swallowing difficulties

If difficulties are suspected, you will need to clinically assess the safety of eating and drinking. This should include taking a relevant clinical history, including asking about any previous chest infections and referral to the SALT (speech and language team) for an urgent assessment.

2. Speech, language and communication

Communication difficulties occur in around 1 in 2 people with cerebral palsy with at least 1 in 10 need augmentative and alternative communication (signs, symbols and speech generating devices). Around 1 in 10 cannot use formal methods of augmentative and alternative communication because of cognitive and sensory impairments and communication difficulties. However most parents and familiar paid staff will know how the person can communicate and they can help you directly communicate with a person with cerebral palsy. This is important to allow you and the person with cerebral palsy to develop a relationship and will help when you need to perform a physical examination.

3. Optimising nutritional status

People with cerebral palsy will need their nutritional status assessing regularly by measuring their height and weight. If height and weight cannot be measured consider checking other anthropometric measurements including, knee height, mid-upper arm circumference, waist circumference, head circumference and skinfold thickness measurements.

Check the person is having assessment and support from a dietician if there are concerns and consider enteral tube feeding assessment if oral intake is insufficient.
4. Managing saliva control

Parents and paid staff often report this is a common but important issue. Assess factors that may affect drooling, such as positioning, medication history, reflux and dental issues, before starting drug therapy. To reduce the severity and frequency of drooling in children and young people with cerebral palsy, consider the use of anticholinergic medication such as glycopyrronium bromide (oral or by enteral tube) or transdermal hyoscine hydrobromide.

5. Low bone mineral density

In people with cerebral palsy the following are independent risk factors for low bone mineral density:

- non-ambulant
- vitamin D deficiency
- presence of eating, drinking and swallowing difficulties or concerns about nutritional status
- low weight for age (below the 2nd centile)
- history of low-impact fracture
- use of anticonvulsant medication.

If a child and young person with cerebral palsy has 1 or more risk factors for low bone mineral density assess their dietary intake of calcium and vitamin D. Check serum calcium, phosphate and alkaline phosphatase, serum vitamin D and urinary calcium/creatinine ratio.

Consider a DEXA scan under specialist guidance for children and young people with cerebral palsy who have had a low-impact fracture.

5. Pain, discomfort and distress

Unfortunately pain is common in people with cerebral palsy, especially those with more severe motor impairment, and, together with any carer who is familiar with person, you will need to discuss and address this.

The common condition-specific causes of pain, discomfort and distress in young people with cerebral palsy include:

- musculoskeletal problems (for example, scoliosis, hip subluxation and dislocation)
- increased muscle tone (including dystonia and spasticity)
- muscle fatigue and immobility
- constipation
- vomiting
- gastro-oesophageal reflux disease.
At the same time recognise that usual causes of pain, discomfort and distress that affect young people generally also occur in those with cerebral palsy, and that difficulties with communication and perception may make identifying the cause more challenging. Common types of pain in young people include:

- non-specific back pain
- headache
- non-specific abdominal pain
- dental pain
- dysmenorrhea.

5. Sleep disturbances

Sleep disturbances are common and may be caused by factors such as environment, hunger and thirst. The most common condition-specific causes of sleep disturbances in people with cerebral palsy include:

- sleep-induced breathing disorders, such as obstructive sleep apnoea
- seizures
- pain and discomfort
- need for repositioning because of immobility
- poor sleep hygiene (poor night-time routine and environment)
- night-time interventions, including overnight tube feeding or the use of orthoses
- comorbidities, including adverse effects of medication.

Consider using sleep questionnaires or diaries.
(Global Sleep Assessment Questionnaire GSAQ)

1. Did you have difficulty falling asleep, staying asleep, or did you feel poorly rested in the morning?
2. Did you fall asleep unintentionally or did you have to fight to stay awake during the day?
3. Did sleep difficulties or daytime sleepiness interfere with your daily activities?
4. Did work or other activities prevent you from getting enough sleep?
5. Did you snore loudly?
6. Did you hold your breath, have breathing pauses, or stop breathing in your sleep?
7. Did you have restless or "crawling" feelings in your legs at night that went away if you moved your legs?
8. Did you have repeated rhythmic leg jerks or leg twitches during your sleep?
9. Did you have nightmares, or did you scream, walk, punch, or kick in your sleep?
10. Did the following things disturb you in your sleep: pain, other physical symptoms, worries, medications, or other (specify)?
11. Did you feel sad or anxious?
Management

Try to optimise sleep hygiene and manage treatable causes of sleep disturbances that you have identified. If no treatable cause is found, consider a trial of melatonin to manage sleep disturbances, particularly for problems with falling asleep. Do not offer regular sedative medication to manage primary sleep disorders in children with cerebral palsy without seeking specialist advice. Refer the person to specialist sleep services for multidisciplinary team assessment and management if there are ongoing sleep disturbances.

6. Mental health problems

Mental health problems and emotional difficulties can be as important as physical health problems for people with cerebral palsy and are often compounded by communication difficulties.

People with cerebral palsy have an increased prevalence of:

- mental health and psychological problems, including depression, anxiety and conduct disorders
- behaviours that challenge, which may be triggered by pain, discomfort or sleep disturbances
- neurodevelopmental disorders, including autism spectrum disorder (ASD) and attention deficit hyperactivity disorder (ADHD).
- emotional and behavioural difficulties (for example, low self-esteem) which are reported in up to 25% of children and young people with cerebral palsy.

Consider following contributory factors if a change in emotional state occurs:

- pain or discomfort
- frustration associated with communication difficulties
- social factors, such as a change in home circumstances or care provision
- side effects and drug interactions of multiple medicines (polypharmacy).

Management

Refer the person with cerebral palsy for specialist psychological assessment and ongoing management if emotional and behavioural difficulties persist or there are concerns about their mental health.

7. Other comorbidities

Consider the developmental and clinical comorbidities, and recognise that these can have an important impact on wellbeing, function and participation.
Visual impairment

About 50% of people with cerebral palsy will have some form of visual impairment. These could include 1 or more of the following:

- problems with controlling eye movements
- strabismus (squint)
- refractive errors (short or long sighted or distorted image)
- problems of eye function, including retinopathy of prematurity
- impaired cerebral visual information processing (problems with seeing objects caused by damage to the parts of the brain that control vision)
- visual field defects (loss of the part of usual field of vision).

Try to assess people with cerebral palsy for signs of cerebral visual impairment, which can occur in about 20% of young people with cerebral palsy.

Hearing impairment

Hearing impairment occurs in around 10% of people with cerebral palsy with prevalence increases with increasing severity of motor impairment. It is more common in people with dyskinetic or ataxic cerebral palsy than in those with spastic cerebral palsy. Therefore regular ongoing hearing assessment is necessary.

Behavioural difficulties

Emotional and behavioural difficulties can have a significant effect on a young person's function and participation. Consider that difficulties with registering or processing sensory information may present as behavioural difficulties. Refer the person to specialist services if difficulties persist.

Vomiting, regurgitation and reflux

Vomiting, regurgitation and gastro-oesophageal reflux are common in children and young people with cerebral palsy. If there is a marked change in the pattern of vomiting, assess for a clinical cause.

Constipation

About 60% of children and young people with cerebral palsy have chronic constipation so this should be discussed with the person and their parents or carers and you should examine the abdomen carefully for constipation.
**Epilepsy**

Is common in people with cerebral palsy and the prevalence increases with increasing severity of motor impairment. Try to ensure that dyskinetic movements are not misinterpreted as epilepsy in children with cerebral palsy.

**8. Transition to adults' services**

The person with cerebral palsy and their families will need support from a range of health social care organisations to provide:

- social care services
- financial support, welfare rights and voluntary organisations
- support groups (including psychological and emotional support for the child or young person and their parents or carers and siblings)
- respite (either at home or in another setting) and hospice services.

Try to think about the following aspects:

- mobility
- equipment, particularly wheelchairs and hoists
- transport
- toileting and changing facilities.

Help to effective communication and integrated team working between health and social care providers by copying all correspondence to all providers and the person with cerebral palsy. Take into account:

- the role of any social, cultural, spiritual or religious networks that support the child or young person with cerebral palsy and their family
- that English may not be the first language of children and young people with cerebral palsy or their parents or carers. Provide an interpreter if necessary.

Education Health care (EHC) plan is a legal document that describes a child or young person's special educational, health and social care needs. It explains the extra help that will be given to meet those needs and how that help will support the child or young person to achieve what they want to in their life. This should include a transition plan between a named paediatricians and named clinicians in adults' services, both locally and regionally, who have an interest in the management of cerebral palsy. This should specifically cover emergency care plans. It is important there is named worker to facilitate timely and effective transition, and recognise the importance of continuity of care. As the age of annual health checks starts at 14 years the GP will have an active role in transition and can help act as an advocate for the person with cerebral palsy and their family.