

INTRODUCTION

Hi and welcome to the Cerebral Palsy Foundation's ParentWise Podcast series. I'm Robyn Cummins.

In this podcast, Melissa Perrett who is the Health Manager of a large disability service, explains the various medical conditions that can be associated with cerebral palsy and some of the strategies that can be used to manage them.

HEALTH CONDITIONS ASSOCIATED WITH CEREBRAL PALSY

Hi, I'm Melissa Perrett.

Today I'll be outlining some of the main health issues associated with cerebral palsy.

There are a few specific health issues that people with cerebral palsy may experience - however it is important to remember that people with cerebral palsy are just as likely as anyone else to experience other 'lifestyle' health conditions such as heart disease, high blood pressure, stroke, diabetes, lung conditions such as emphysema, and cancers.

Lifestyle choices such as good diet, adequate sleep and exercise, drinking alcohol to the recommended standards, and not smoking are all just as important to the person with cerebral palsy as anyone else in the community.

Most medical conditions associated with cerebral palsy are best managed by a multidisciplinary team. Team members include doctors (GPs and specialists), nurses, dentists and allied health professionals such as occupational therapists, physiotherapists, speech pathologists, psychologists, exercise physiologists and conductive educators.

Because cerebral palsy involves damage to the developing brain, one of the most common health conditions associated with it is epilepsy.

Epilepsy is a disruption of the normal electrochemical activity of the brain that results in seizures.

About 70% of people with spastic type of cerebral palsy may have epilepsy, although people with other types of cerebral palsy may also experience epilepsy.

There are many types of epilepsy and diagnosis is made after careful assessment, usually by a neurologist.

There are many different medications used for the various types of seizures. Some of these have significant side effects. Medication dosages may need regular monitoring sometimes with blood tests but epilepsy is usually managed well with medications.

Many people with cerebral palsy also have difficulties with reflux and it can be very difficult to diagnose it in adults and children who are non verbal.

Reflux, also known as Gastro-oesophageal reflux (GOR), occurs when food and fluids from the stomach regurgitate up into the oesophagus and sometime the mouth.

Reflux may cause a heartburn type of pain and inflammation of the oesophagus called oesophagitis.

In rare cases reflux can cause aspiration (or inhaling of food or drink into the lungs), which may lead to chest infections and pneumonia.

GOR can also be confused with asthma as the regurgitated contents of the stomach may cause the person to cough a lot.

Children and adults with GOR may benefit from being reviewed by a gastroenterologist and a respiratory specialist, especially if they are experiencing repeated chest infections.

Some of the strategies used to control GOR include:

- Ensuring the person is seated semi upright or upright after a meal
- Thickening of the meals
- Slowing the rate of feeding – especially if tube fed and
- Making sure the person doesn't eat highly acidic foods.

Someone with GOR may also need to sleep semi upright and consultation with a dietician is essential.

There are many medications available that do various things such as reducing the acidity in the stomach. You will need to get advice from your doctor before trying any medications.

In some cases, and particularly for child, a surgical procedure called a fundoplication may be recommended to manage GOR.

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As cerebral palsy may affect the muscles of the mouth and throat we often see swallowing difficulties and this in turn may lead to a person with cerebral palsy experiencing increased chest infections.

If a person experiences repeated chest infections, a referral to a respiratory specialist is a good idea and referral to, and assessment by, a speech pathologist is helpful.

The speech pathologist can make suggestions about modifying food and fluids, such as using thickener, to make food easier to swallow.

They can also offer suggestions such as safe positions for mealtimes. All this helps to minimise the risk of inhaling food or fluids into the lungs which can cause chest infections and/or pneumonia.

Some people with cerebral palsy have difficulty gaining and maintaining a good weight and others have problems with being overweight.

In both of these situations, advice from a dietitian experienced in working with people with physical disabilities is invaluable.

Dietitians can offer advice about healthy eating, weight loss, weight gain and the best foods to eat to maintain health. They can also advise about the effects of diet on osteoporosis and high cholesterol.

Some people with cerebral palsy have difficulty maintaining their weight due to swallowing problems.

They may need nutritional support with the use of a PEG or gastrostomy tube.

This is where fluid (formula) and medications are given into a tube which is inserted into the stomach.

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Osteoporosis is a very common condition in adults in the general population, but it is especially prevalent in adults who live with cerebral palsy. If left untreated it can result in bone fractures, often without any injury occurring.

There is some evidence that thinning of the bones (osteopenia) can occur even in young children with the more severe forms of cerebral palsy.

It is important to discuss this risk factor with your doctor, as early diagnosis and treatment can prevent problems such as spontaneous fractures from occurring.

Some of the high risk factors are minimal weight bearing, a diet poor in calcium such as dairy, a long history of some epilepsy medications and a vitamin D deficiency caused by minimal exposure to sunlight.

If you think your child might be at risk, discuss osteoporosis with your GP. Your child may need to have a bone density scan. Treatment for osteoporosis depends on its severity but may include medications.

Children and adults with cerebral palsy, particularly those who are less mobile, may be at higher risk of developing pressure areas or sores.

These sores are caused by pressure, shearing or friction on the skin.

Sores often develop from being in one position for too long, or can be caused by rubbing of splints against the skin or incorrect clothing. Pressure relieving devices, such as pressure cushions, may also be being used incorrectly.

Skin pressure areas or sores can be prevented by:

- Frequent repositioning and turning
- Keeping skin moisturised and supple, and
- Ensuring any splints or aids, such as wheelchairs or head pointers, are fitted well and reviewed as growth occurs or weight increases or decreases.

An occupational therapist (OT) will be able to guide you in the use of pressure relieving devices like pressure cushions (for example Roho or Jay cushions) on wheelchairs. They will also be able to assist you to choose an appropriately supportive wheelchair.

Some children may need extra support at night in bed and various mattresses are available. Again an OT will be able to help you with this.

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Adults and children with cerebral palsy often have difficulty with constipation.

This is usually due a lack of exercise or lack of adequate amounts of fibre or fluid in the diet (and this may be because of swallowing difficulties).

It can be also caused by lack of ability to 'bear down' when opening bowels, and slow muscles movement (peristalsis) in the bowel.

Changes in diet, exercise, increases in fibre and fluids can all help.

Some people can find that medications are needed to help, some medications may need to be taken daily, others just when needed.

Talk to your GP, or get a referral to a gastroenterologist if the problem is severe.

It's important that medical advice is sought after any changes to regular bowel habits, such as sudden constipation or diarrhoea or if blood is seen in the bowel motion.

Your local continence nurse advisors located at your local hospital or the National Continence Helpline on 1800 33 00 66 are also great sources of advice and information.

Some children and adults with cerebral palsy may experience problems with their continence and may find they occasionally, or even often, have problems with urine leakage or wetness. This can be a very embarrassing problem.

Urinary incontinence can be caused by a variety of issues in someone with cerebral palsy.

It's important to diagnose the cause of incontinence and a referral to a urologist may be necessary. There are also medications available which may be of help.

If it is a new occurrence a thorough medical examination - with a urine sample sent off to pathology - is needed to rule out any infection in the urinary system.

For males, a check of the prostate is also a good idea.

If all of these tests are clear, it may be necessary to talk to your continence nurse advisor or the National Continence Helpline on 1800 33 00 66.

They can advise about what specialised resources are out there to help you, such as incontinence pads, uridomes or catheters and what government funding is available for these resources.

Spinal cord compression is occurring more frequently among people who have cerebral palsy.

It's not a common condition but it can occur at any age and it is thought to be more prevalent in people who have rapid or involuntary head or neck movements.

The onset is often slow and subtle and is often difficult to diagnose.

Some of the signs of spinal cord compression are changes to mobility, an increase in falls or changes to the ability to transfer.

A person's ability to do tasks involving fine motor coordination such as doing up buttons or putting on clothes may also deteriorate.

They may also rarely feel pain, develop ongoing fatigue or experience changes to sensations, such as numbness, pins and needles or tingling.

Additionally, changes to bowel or urinary function may occur.

If any of the above symptoms are noticed, you should visit your GP urgently and request a referral to a neurologist. You should also discuss a specialist referral with your GP to ensure prompt radiological investigation such as a Magnetic Resonance Imaging (or MRI).

Research suggests that screening for symptoms is necessary so that treatment can be started or upgraded before spinal cord injury becomes irreversible.

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About 40% of people with cerebral palsy have some vision problems and some also have hearing difficulties

Prompt referral to an ophthalmologist is recommended and testing of hearing in early childhood is recommended as diagnosis and early therapy can help during the early development of language.

It's estimated that around 80% of adults with cerebral palsy experience some sort of pain.

Pain can be caused by long periods of immobility, contractures, muscle spasm and also a variety of pain causes that anyone can experience.

It's concerning that pain is often under-treated, and it is essential to evaluate the level of pain and type of pain that is being experienced.

This process can be especially difficult in those who are non-verbal. There are various ways pain can be assessed in those people. Please talk to your GP if there are any concerns or issues with pain.

Referral to a pain management clinic may also be required.

Physiotherapy, hydrotherapy and other forms of physical exercise may all help to minimise and manage pain.

If you suspect or know that you or your child is experiencing any of these health problems related to their cerebral palsy, talk to your GP or health team straight away. You can also call the CP Helpline on 1300 30 29 20 for more information and support.

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Thanks for listening. We hope you've found these strategies and ideas useful.

You can download or listen to more episodes in the ParentWise Podcast series at the Cerebral Palsy Foundation's website - www.cpfoundation.com.au