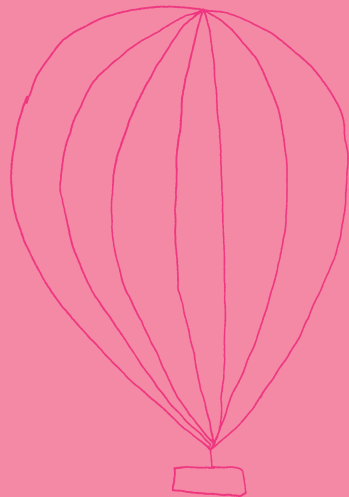




The Royal
Children's
Hospital
Melbourne

Cerebral Palsy

An information guide for
parents and families





Cerebral Palsy

An information guide for parents and families

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About this guide

This book has been written primarily for parents who have a child with cerebral palsy. If your child has recently been diagnosed as having cerebral palsy, you are probably feeling shocked by the news and overwhelmed by the implications of the diagnosis. This is a normal reaction and completely understandable. We know that parents have many questions, concerns and fears in relation to their child's health and development. Remember that you are not alone and that there are many supports for children and their families that will provide assistance and guidance when you need it.

We have written this book to help answer some of your questions. Every child with cerebral palsy is different. In some children the condition may be so slight that he or she is only a little clumsy with certain movements. Other children may have more complex problems.

Because each child is different, the information is presented in a general way, and may or may not be relevant to your child. Please discuss your own child's needs with his or her therapists, social worker, nurse, psychologist or doctor. They may not be able to answer all your questions, but they will honestly try to tell you what they do know, or direct you to someone who may be able to help.

This book will discuss the different types of cerebral palsy, the causes of cerebral palsy, some associated problems, and the range of treatments available. We have provided information about support services and where to turn to for help. We hope to convey the message that no matter how difficult things may seem at present, and despite the many challenges that you and your family may face over the coming years, help and support is available.

What is cerebral palsy?

The brain controls all that we do. Different parts of the brain control the movement of every muscle of the body. In cerebral palsy, there is damage to, or lack of development in, one or more of these areas of the brain.

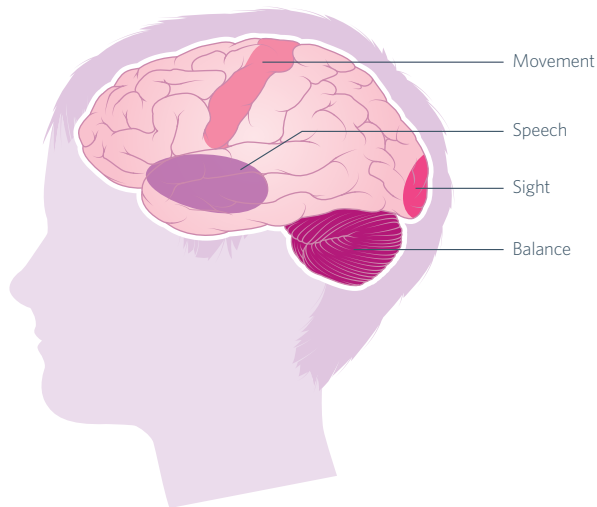
'Cerebral' refers to the brain.

'Palsy' can mean weakness or paralysis or lack of muscle control.

Therefore cerebral palsy is a disorder of muscle control which results from some damage to part of the brain. The term cerebral palsy is used when the injury has occurred early in life, to the developing brain.

Children with cerebral palsy can have problems such as limited mobility, weakness of hands and/or legs, stiffness or floppiness, clumsiness or poor coordination, difficulty starting and controlling movement and reduced smoothness (fluidity) of movements, shakiness and difficulties with balance. These difficulties can range from mild to severe. In mild cerebral palsy, the child may be slightly clumsy in one arm or leg, and the symptoms may be barely noticeable. In severe cerebral palsy, the child may have a lot of difficulties in performing everyday tasks and movements.

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What are the various types of cerebral palsy?

There are several different types of cerebral palsy:

SPASTIC CEREBRAL PALSY

This is the most common type of cerebral palsy. Spasticity means stiffness or tightness of muscles. The muscles are stiff because the messages to the muscles are being sent incorrectly from the damaged parts of the brain.

When people without cerebral palsy perform a movement, groups of muscles contract whilst the opposite groups of muscles relax or shorten in order to perform the movement. In children with spastic cerebral palsy, both groups of muscles may contract together, making the movement difficult.

DYSKINETIC CEREBRAL PALSY

This refers to the type of cerebral palsy with abnormal involuntary movements. It is divided into two types of movement disorders, called dystonia and athetosis.

Dystonia: this is the term used for sustained muscle contractions that frequently cause twisting or repetitive movements, or abnormal postures.

Athetosis: this is the word used for the uncontrolled extra movements that occur particularly in the arms, hands and feet. The lack of control is often most noticeable when the child starts to move—for example, when the child attempts to grasp a toy or a spoon. In addition, children with athetoid cerebral palsy often have very weak muscles or feel floppy when carried.

ATAXIC CEREBRAL PALSY

This is the least common type of cerebral palsy. Ataxic (or ataxia) is the word used for unsteady shaky movements or tremor. Children with ataxia also have problems with balance.

MIXED TYPES

Many children do not have just one type, but a mixture of several of these movement patterns.

Some of these concepts are difficult to understand. Please discuss them further with your therapist or doctor.

Which part of the body is affected?

Again, this varies greatly from one child to another. Certain words are used to describe the parts affected:

Hemiplegia: the leg and arm on *one side* of the body are affected (also described as hemiparesis).



Diplegia: *both legs* are predominantly affected. Children with diplegia usually also have some difficulties with their arm and hand movements.



Quadriplegia: *both arms and both legs, and the trunk*, are affected (also described as quadriplegia). The muscles of the face can also be affected.



Affected area



Less affected area



Unaffected area

How severe is the movement disorder?

The Gross Motor Function Classification System (GMFCS) is a method of describing the range of gross motor function in children with cerebral palsy. The GMFCS describes five 'levels' of motor function, with a particular emphasis on abilities and limitations in the areas of sitting, standing and walking.

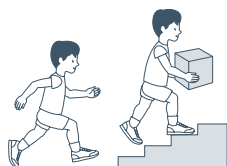
Children with GMFCS levels I and II walk independently, children with GMFCS level III require sticks, elbow crutches or walking frames, and children with GMFCS levels IV and V usually require a wheelchair. You can see a diagram of these different levels on the opposite page.

Using GMFCS levels and a test of gross motor function called the Gross Motor Function Measure (GMFM), it has been possible to draw 'motor growth curves'.

From these curves, we can begin to make a prediction about the pattern of gross motor development of children according to their GMFCS level.

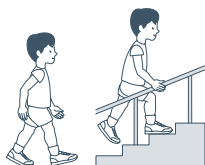
Gross Motor Function Classification System

Extended and revised



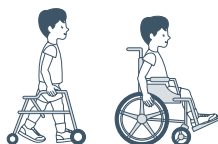
GMFCS Level I

Children walk at home, school, outdoors and in the community. They can climb stairs without the use of a railing. Children perform gross motor skills such as running and jumping, but speed, balance and coordination are limited.



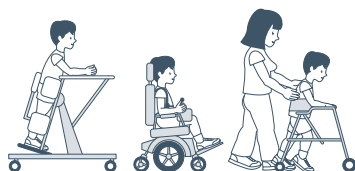
GMFCS Level II

Children walk in most settings and climb stairs holding onto a railing. They may experience difficulty walking long distances and balancing on uneven terrain, inclines, in crowded areas or confined spaces. Children may walk with physical assistance, a handheld mobility device or used wheeled mobility over long distances. Children have only minimal ability to perform gross motor skills such as running and jumping.



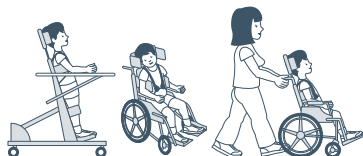
GMFCS Level III

Children walk using a hand-held mobility device in most indoor settings. They may climb stairs holding onto a railing with supervision or assistance. Children use wheeled mobility when traveling long distances and may self-propel for shorter distances.



GMFCS Level IV

Children use methods of mobility that require physical assistance or powered mobility in most settings. They may walk for short distances at home with physical assistance or use powered mobility or a body support walker when positioned. At school, outdoors and in the community children are transported in a manual wheelchair or use powered mobility.



GMFCS Level V

Children are transported in a manual wheelchair in all settings. Children are limited in their ability to maintain antigravity head and trunk postures and control leg and arm movements.

What are the causes of cerebral palsy?

Cerebral palsy occurs in about two in every thousand children. There are many different risk factors and some known causes. A problem with the brain can occur:

1. If the brain does not grow or form properly. The result is that children may have brain malformations.
2. In the early months of pregnancy, for example, if the mother is exposed to certain infections such as Rubella (German Measles), or Cytomegalovirus (CMV).
3. During labour or at birth, for example, if the baby does not receive enough oxygen.
4. In the period shortly after birth, for example, when an infant develops a severe infection, such as meningitis, in the first few days or weeks of life.
5. In children having accidents in the early years of life, causing permanent brain injury. These children are also considered to have cerebral palsy.

In some children it is important to note that, despite a careful review and various tests, the cause of cerebral palsy remains unknown. With technologies such as MRI brain scans and sophisticated blood tests, more causes are slowly being identified.

Current research suggests that approximately 75% of all cerebral palsy is caused by complications that occur during pregnancy, 10–15% by difficulties at birth or in the newborn period, and a further 10% by illnesses or accidents in the early weeks, months or years of life.

Conditions that lead to permanent neurological deficits up to the age of about two years (some groups include children up to five years) are included in the cerebral palsy group.

Children particularly at risk for cerebral palsy are those infants who have been born extremely prematurely. It is sometimes difficult to be sure whether the neurological condition pre-dated the premature delivery or whether the complications that occurred due to prematurity are responsible for the child's cerebral palsy.

Almost all families continue to worry about the cause and why it happened. This is understandable and a natural response. Parents often blame themselves for something they may or may not have done during the pregnancy or birth. But usually the event for which the family blame themselves is either not the cause or could not have been prevented. It is helpful if families can discuss and share their concerns and fears with each other and with the people involved in the care of their child.



Commonly asked questions

How is the diagnosis made?

Cerebral palsy is a clinical diagnosis based on the recognition of delays in reaching motor milestones, for example, delays in sitting, standing or walking, and changes in muscle tone and/or reflexes. A brain MRI is recommended if the cause is not apparent. The MRI may provide information about the approximate time at which the brain injury occurred. In about 10% of children with cerebral palsy, the brain MRI is normal. Sometimes further metabolic and genetic tests are undertaken to establish the cause of cerebral palsy.

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What other problems may my child have?

Sometimes, the child may have additional difficulties. These could include:

1. Problems with hearing:

All children should be seen by the hearing specialist (audiologist) to check for hearing difficulties.

2. Problems with eye sight:

Children with cerebral palsy very commonly have squints. They can also have other problems with vision. Most children are checked by the eye specialist (ophthalmologist) at some time during their early years.

3. Epilepsy: Epilepsy may develop in about one in three of all children with cerebral palsy. There are various types of epilepsy. Some children may only have very occasional seizures whereas in others the condition may be more persistent, and may require the advice of a paediatric neurologist.

4. Intellectual or learning disability:

There is a wide range of intellectual ability in children with cerebral palsy. Unfortunately it is often difficult to assess learning ability in the early years of life. Children with severe physical disabilities may have normal intelligence. If there is a delay in learning in the early years of life, the term 'developmental delay' is sometimes used. Developmental delay is a descriptive term used when a young child's development is delayed in one or more areas compared to that of other children.

5. Speech and communication difficulties:

Children may have difficulty in understanding speech (receptive language difficulties) or with oral speech (talking or expressive language difficulties). They may be reliant on an alternate means of communication such as a communication book or an electronic device.

6. Perceptual difficulties: Problems such as judging the size and shape of objects are termed perceptual difficulties, and may not be apparent until school age.

7. Gastro-oesophageal reflux:

Food comes back up the oesophagus (gullet) more commonly in children with cerebral palsy. Symptoms may include vomiting and discomfort during feeds. A complication of gastro-oesophageal reflux is inflammation of the lower oesophagus (called oesophagitis). Children with this problem may be very unsettled or irritable.

8. Orthopaedic problems: As children grow and develop, muscles with spasticity or stiffness may become shortened, causing muscle or joint contractures. This is most likely to occur at the ankle, knee, hip, elbow and wrist.

In addition, children with cerebral palsy are at risk for developing hip subluxation (movement of the head of the thigh bone out of the hip socket) and dislocation. This is most likely to occur in children that are not walking independently (GMFCS levels III, IV and V). Regular monitoring and surveillance with hip X-rays is important. Physical examination of the hips is not enough so all children with cerebral palsy affecting both lower limbs (diplegia, quadriplegia) require regular hip X-rays (particularly children with GMFCS levels III, IV and V). Hip surveillance guidelines have been

developed to provide guidance about when X-rays should be undertaken in individual children. You can find them at www.aacpdm.org/UserFiles/file/consensus-statement-hip-surveillance-australia.pdf

Scoliosis (curvature of the spine) may also occur and is often seen in children with more severe cerebral palsy.

9. Constipation: This is common in children with cerebral palsy. The cause is not always clear. Sometimes it relates to the lack of usual mobility, or it may be related to the difficulty of eating a high fibre diet.

10. Bone disease: some children with cerebral palsy are not able to be as active as children without disabilities and may have some degree of osteoporosis. Fractures can occur with very minor injuries and sometimes during normal activities such as nappy change or putting an arm through a sleeve. Occasionally children need special medication to promote bone mineralisation.

11. Undescended testes: there is a higher frequency of undescended testes in boys with cerebral palsy.

REMEMBER

No one child has all these problems. There are treatments available to help manage them which are discussed in a separate section (see page 15).



Will my child get better?

'Cerebral palsy' refers to a permanent condition, and the symptoms associated with this condition (such as muscle weakness or stiffness, and unwanted movements) remain throughout the lifetime of a person with cerebral palsy. However, children and their families can learn to cope with the condition as the child grows. Treatment often brings about improvement, though not a cure.

Will my child's condition deteriorate?

The answer is 'No'. The damage done to the brain early in life does not worsen, however sometimes it may seem that the child's condition is becoming worse. There are many reasons for this apparent deterioration and some are listed below.

1. As children grow older, more is expected of them. For a child with cerebral palsy, simple tasks such as learning to dress and eat independently may take a longer time and may be achieved later than usual. This delay in their development might make it seem that deterioration is occurring, but this is not the case.
2. As the child grows and uses his or her muscles more and more, they may become tighter. During growth spurts, the child's bones may grow more quickly than their muscles,

which can lead to a tightening of muscles, and a problem such as toe walking may become more apparent. Stiffness in muscles may be due to spasticity, contractures or a mixture of both. It can be difficult to tell the difference but it is important to distinguish between spasticity and shortening as they are treated differently.

3. Any common childhood illness, such as an ear or throat infection, can cause a child's progress to come to a standstill for a while.
4. Emotional stress — when a child feels he or she is being 'pushed' to achieve a skill that they think is difficult for them to do, they may react by becoming stubborn or refusing to cooperate. In a child with cerebral palsy this can certainly be a reason for lack of progress, but it does not mean that their condition has deteriorated.

If your child loses previous skills, discuss this with your therapist and/or doctor.

Will my child learn to walk?

Parents generally want to know the answer to this question shortly after the condition is diagnosed.

Unfortunately, it is often not possible to be sure until after the child has been observed by the paediatrician and therapist for a period of time. Children with mild cerebral palsy (GMFCS levels I and II) learn to walk independently. Children with a moderate degree of cerebral palsy (GMFCS level III) generally walk with sticks or walking frames. Children with more severe motor problems (GMFCS level IV and V) generally require a wheelchair for most activities. Over the age of about two years, the 'motor growth curves' described on page 6, are helpful in determining whether a child is likely to learn to walk independently.

Will my child learn to talk?

There is a wide range of communicative ability among children with cerebral palsy. Some children will not have any difficulties learning to talk. Other children may have difficulties with controlling the movements around their mouth, or delayed development of cognitive (learning) skills; they will need help from a speech pathologist to develop speech or to learn how to use alternative methods of communication.


Will my child be able to look after themselves?

The aim of treatment is to encourage the child to learn to be as independent as possible. Some children who have mild cerebral palsy will have not have any problems in achieving independence. For others, it will be a slow process. In some with severe difficulties, considerable assistance from others will always be needed.

It is always important to encourage your child to do as much as possible for him or herself.

Will my child develop behaviour problems?

Over the course of their development, some children with cerebral palsy may develop behaviours that are disruptive, unsociable or difficult to manage. They may also become frustrated due to being unable to move or communicate, for example, a child with little effective speech may resort to screaming in order to initiate interaction with others. These behaviours usually respond to modification, or gradually recede with the emergence of a skill that allows the child greater independence. Psychologists and other members of the team including speech pathologists may be able to assist and suggest ways to support the child while new skills are emerging. Every child has a unique



personality and individual ways must be developed to motivate and encourage the child to feel good about him or herself and to be successful and happy.

Will my child have a normal life expectancy?

Most children with cerebral palsy are healthy, and can expect a normal life span. A small group of children with extremely severe cerebral palsy and associated conditions such as epilepsy may be at risk of reduced life expectancy (for example, they may develop recurrent chest infections or have prolonged seizures).

Will I be told everything that doctors and therapists know about my child?

The answer is 'Yes'. When staff have difficulty answering questions, parents may feel that doctors and therapists are holding back information and not telling all they know. However, this is not the case, and parents are told as much as is known about the child at the time.

A booklet produced by the Association for Children with a Disability, entitled *Helping You and Your Family* has useful information about relationships with health professionals (<http://acd.org.au/wp-content/uploads/2014/07/ACD-resource-Helping-You-and-Your-Family-3rd-edition-2013-PDF-1.2MB.pdf>).

Will my next child have cerebral palsy?

This is extremely unlikely, but you should discuss this with your doctor. Parents should feel free to seek advice from their doctor about genetic counselling and obstetric care of future pregnancies.

Treatment, therapy and early intervention

What treatments are available to help my child?

This brief summary discusses both older and newer interventions. Many new treatments have become available over the past two decades. The management of cerebral palsy requires a team approach with the parents, therapists, doctors, nurses and teachers all contributing to ensure optimal progress is made.

Treatment may be considered in these three areas:

1. Treatment of the movement disorder.
2. Treatment of the associated medical conditions.
3. Provision of therapy and early intervention services.

What treatments are available for the movement disorder?

Paediatric therapists play a key role in the management of movement disorders. Physiotherapy, and sometimes occupational therapy, is essential to provide a program to encourage motor development. Therapy is also necessary to implement the strategies discussed below. Parents should discuss their treatment options with their therapist or doctor. It is important to remember that some treatments may not be suitable for your child.

1. Orthoses (sometimes known as braces) are used for the lower limbs by many children at some stage in their development. These are custom made and individually fitted for each child from a combination of materials including high temperature plastics with velcro closures. Orthoses can be worn inside an ordinary shoe.

SPLINTING

2. Upper limb splints (also called orthoses) are made by occupational therapists to either maintain range of movement or facilitate better grasp. Both purposes aim to improve a child's overall use of their arm and hand. Splints are individually made for each child and depending on their purpose may be fabricated from low temperature plastic, and/or Lycra® or neoprene. A specialist splinting

technique using dynamic Lycra® splints (sometimes called 'Second Skin™') may also assist some children with their upper limb movements.

3. Botulinum toxin A ('Botox') is used as a treatment for tight or spastic muscles, most commonly when tightness in the calf or hamstring muscles is interfering with progress in learning to move, although it is increasingly being used in other parts of the body including the upper limbs. A light anaesthetic or sedation is sometimes required for the injections. There may be some temporary mild pain at the injection site but other side effects are uncommon. Botox can reduce spasticity and provide a period of more normal muscle growth and development, which may be accompanied by progress in the child's movement abilities. Disadvantages include the fact that the administration of Botox involves injections; the effects of the drug are not completely predictable and are of short duration; and the toxin is costly.

MEDICATIONS

4. Oral medications may be effective for spasticity and dystonia.

- **Diazepam** ('Valium') is a good medication for spasticity, but may cause sedation. However it is useful following surgery, particularly orthopaedic procedures.



- **Dantrolene** ('Dantrium') is used infrequently and may cause drowsiness, dizziness and diarrhoea.
- **Baclofen** ('Lioresal') is often used in children with severe spasticity and/or dystonia. Side effects are uncommon but may include nausea. It is reported to aggravate seizures though this is rare.

Very occasionally, a pump is implanted under the skin. The pump is connected to a tube which delivers the drug into the space around the spinal cord. This type of treatment is only suitable for a small number of children with severe spasticity and/or dystonia and is known as **intrathecal baclofen therapy**. A separate booklet is available.

Other drugs used for dystonia include:

- **Benzhexol hydrochloride** ('Artane'). Side effects include irritability and worsening of constipation.
- **L-Dopa** ('Sinemet' 'Madopar'). Side effects include anxiety and tearfulness.
- **Gabapentin** ('Neurontin'). Side effects are very uncommon but agitation is reported on rare occasions.

SURGERY

5. Selective dorsal rhizotomy

is a major operation on the spine occasionally used to reduce spasticity in the lower limbs. It is used mainly in young children with spastic diplegia aged 3–7 years. Following the procedure a very extensive rehabilitation period is required.

6. Orthopaedic surgery: Surgery is mainly undertaken on the lower limb, but occasionally in the upper limb. Some children require surgery for scoliosis, particularly children with more severe motor disorders. Physiotherapy is an essential part of post-operative management. Gait laboratories have several cameras (video and/or infrared) placed around a walkway which are linked to a computer. Using this equipment it is possible for the staff to determine why children with cerebral palsy walk in the way that they do. They are useful in planning the surgical program for children who are able to walk independently or with sticks or walking frames.

- **The hip:** Soft tissue surgery is rarely effective on its own for children with hip problems who are non-ambulant. However, the earlier hip displacement is detected, the more options are available and the better the outcome (hence the importance of regular X-rays). Regular hip surveillance is an essential part of overall hip management so that the right treatment can be offered at the right time. For the majority of children surgery to keep the hips in joint, or to put the hips back in joint, is preferable to leaving the child with a dislocated hip. Recent research shows that more than 90% of hip dislocations are painful and there is no effective treatment for this condition.

- **The knee:** Lengthening of the hamstrings or transferring one of the hamstrings from below the knee to above the knee can dramatically improve straightening of the knee and the overall walking pattern.
- **The ankle and foot:** This is the most common area where orthopaedic surgery is required. However, it is essential that the calf muscle not be overly weakened by too many or too frequent injections of Botulinum toxin nor by early surgical lengthening.

Most children with diplegia require orthopaedic surgery in several different areas (for example, hip, knee, and ankle/foot). Frequently this involves a single hospitalisation and is called 'multilevel surgery'. Multilevel surgery is of most benefit to children who walk independently or with the assistance of crutches. The best age is usually 6–10 years old although it can occasionally be helpful for older or younger children.

The aims of surgery are to decrease deformities and to improve both the appearance and efficiency of walking. Success depends on an accurate assessment of the walking problems, which is done in the gait laboratory.

A carefully planned intensive rehabilitation physiotherapy program, which can last for up to a year, is required to maximise the benefits from this surgery.

7. Plastic surgery: Tendon transfers and releases can occasionally improve appearance or function in the upper limb.

What treatments are available for the associated medical problems?

1. Epilepsy: Our knowledge of epilepsy has increased substantially in the past few years. There are many types of seizures and epilepsy, including in children with cerebral palsy. Some types of epilepsy are a direct consequence of the underlying brain malformation or injury and will persist throughout life. Other types of epilepsy are not directly related to a child's cerebral palsy, and the seizures may be limited to infancy or early childhood. Some seizures and associated EEG (electrical brain wave) disturbances are impair a child's development, but others do not. Specialist neurological input is often necessary to determine the type of epilepsy, its potential impact on a child, the prognosis and the treatment.

Medication is often prescribed following diagnosis of the type of seizures and their cause. Doctors prescribe medications to provide good seizure control with few or no side effects. Medications taken on a daily basis are to prevent seizures or reduce their frequency, duration and severity. Medications are sometimes prescribed to terminate prolonged seizures or manage seizure clusters, for example,

intranasal or buccal midazolam, rectal diazepam, oral clonazepam or clobazam.

You should consider having a written epilepsy management plan for your child. The Epilepsy Foundation of Victoria have plans on their website and can also assist with development of individual plans. Visit www.epinet.org.au/

The four most commonly used anticonvulsants which treat epilepsy are:

- **Sodium valproate** ('Epilem', 'Valpro').
Used for various types of focal and generalised seizures, including absences, myoclonic seizures and tonic-clonic seizures. Potential side effects include nausea, abdominal discomfort, weight gain, hair loss and bruising. Liver damage and bleeding problems have been reported but are extremely rare.
- **Carbamazepine** ('Tegretol', 'Teril').
Mainly used for focal seizures. Potential side effects include nausea, loss of appetite, drowsiness and allergic skin rash. If the drug is commenced too rapidly, initial drowsiness may occur then subside. A controlled release tablet preparation is preferable for those children able to swallow tablets.
- **Lamotrigine** ('Lamictal' and other generics).
Used for focal and generalised seizures, often as 'add on' to sodium valproate. It is well tolerated and may cause an increase in alertness. The main unwanted effect is an allergic skin rash which may

occur in up to 5% of children, especially if the drug is introduced too quickly. If a skin rash develops during introduction, the drug should be ceased and your doctor contacted. Sleep disturbance can occur in some children, such that it is often given once a day in the morning.

- **Levetiracetam** ('Keppra' and other generics). Used for focal seizures. Generally well tolerated but can cause irritability, mood disturbance and behavior problems.

There are a number of other anticonvulsants that are used in specific situations or after other drugs have failed. These include:

- **Vigabatrin** ('Sabril'). This drug is used almost exclusively to treat infantile spasms, for which it is very effective. Potential side effects include drowsiness, irritability and agitation. It has potential detrimental effects on peripheral vision and therefore monitoring by an ophthalmologist is necessary.
- **Topiramate** ('Topamax'). This drug is a very effective drug but side effects are not uncommon, including appetite suppression, weight loss, kidney stones and effects on speech, behaviour and temperature regulation.
- **Gabapentin** ('Neurontin'). This drug is used more commonly for pain treatment than for seizure management these days. It needs to be taken three

times a day but is very well tolerated. It can exacerbate some seizures.

- **Oxcarbazepine** ('Trileptal'). This drug has a similar profile to carbamazepine but is often better tolerated.
- **Clonazepam** ('Rivotril', 'Paxam') and Clobazam ('Frisium'). These drugs are often used as add-ons or to manage seizure clusters. They can cause irritability, drowsiness, disruptive behaviour. They can also worsen drooling, especially clonazepam.

For more detailed information on anticonvulsant medication, visit www.rch.org.au/cep/treatments

If anticonvulsant medications are insufficient to control a child's epilepsy, and the seizures are significantly problematic, other treatments might be considered, for example, the ketogenic diet, vagus nerve stimulation or surgery.

2. Gastro-oesophageal reflux (GOR)

is more common in children with cerebral palsy. GOR may result in regurgitation, inflammation of the oesophagus (oesophagitis), difficulty swallowing (dysphagia), and occasionally, aspiration. Conservative measures may help reduce GOR. These include:

- propping the infant or child upright after a meal
- thickening feeds
- slowing the rate of feeding (especially liquid feeds).

If conservative measures fail, medications may be suggested. These include:

- anti-acid medications such as ranitidine, omeprazole and lansoprazole. These will reduce the acidity of the stomach and limit any damage produced by acid reflux. They are unlikely to reduce the amount of reflux.
- prokinetic agents such as domperidone. These are designed to reduce the amount of reflux but are not always effective.

Surgery to prevent reflux is occasionally necessary when medications have failed to control the problem. The surgical procedure is called a fundoplication.

3. Saliva control: The speech pathologist plays a central role and can provide strategies to improve dribbling problems. When these strategies are not effective, medication is occasionally used, particularly in children over the age of 3–4 years. These medications are as follows:

- **Benzhexol hydrochloride** ('Artane') reduces salivary secretions. Occasionally irritability may occur. Blurring of vision, constipation and difficulty with urination are also potential side effects.
- **Glycopyrrolate** ('Robinul') is similar to benzhexol hydrochloride but seems to produce fewer side effects. It is not widely available in Australia.

Botulinum toxin injections into the salivary glands reduce salivary flow, but repeated administration is required as the benefits only persist for 6–12 months.

For older children with persistent dribbling problems, surgical treatment can be offered. The plastic surgeon redirects the submandibular ducts and removes the sublingual glands. This operation usually reduces drooling but does not lead to an unduly dry mouth. It is important that children undergoing this procedure have regular dental follow up as there is an increased risk of dental cavities.

4. Constipation: Children with cerebral palsy often have problems with constipation. A high fibre diet and increased fluid intake can help with this problem. This may not be easily achieved in some children with cerebral palsy. Careful use of laxatives is preferable to severe constipation.

5. Nutrition: A dietitian can provide useful advice about adequate nutrition. Excessive weight gain can be very disadvantageous for children learning to walk. Undernutrition and failure to make adequate weight gains may be related to feeding difficulties. In a small proportion of children, the use of tube feeding can be helpful.


What therapies are available to assist my child?

Therapy is often incorporated in an early intervention program which addresses not only the movement problems but aims to optimise the child's progress in all areas of development. The most commonly

used approaches by therapists in Victoria are listed below.

1. Neuro-developmental therapy (NDT/Bobath) was founded in the 1950s by Dr and Mrs Bobath who developed a holistic and functional approach to the treatment of children with cerebral palsy.





Today, NDT/Bobath-trained therapists work as a team with the child and family, with the focus on identifying the everyday functional areas that a child has difficulty with, analysing why there are difficulties and then planning a variety of intervention strategies to achieve the desired functional outcome. The intervention strategies are individualised for each child and may include active guidance to help learn a new skill as well as how to practice tasks in everyday settings. NDT/Bobath helps parents and carers in practical ways on how to assist their child's daily functioning in the areas of mobility, self-care, play, communication, eating and drinking.

2. Programs based on the principles of conductive education: Conductive education is a system developed in Hungary by Dr Andras Peto for educating children and adults with movement disorders. Peto recognised the importance of meaningful activity and social interaction to stimulate the development of movement and the possible effects of movement challenges on all aspects of a child's development. Conductive education provides an integrated group program where children and their carers/parents learn to develop skills in all areas of life, for example, daily living, physical, social, emotional, cognitive and communication skills. There are some programs that apply the principles of conductive education in Victoria.

3. Modified constraint induced movement therapy, often abbreviated to 'mCIMT' is a therapy for children with hemiplegic cerebral palsy that aims to increase the child's use of their hemiplegic arm and hand. This therapy approach has developed from studies of the effects of constraining the non-affected arm and hand of adults following stroke to 'force' the use of their hemiplegic arm and hand. mCIMT involves constraining a child's unaffected hand and/or arm for a period of time, usually in a modified glove or mitt, while they receive intensive structured training or encouragement to use their affected hand and arm in play activities.

4. Goal-directed training involves the child and/or family identifying specific tasks that the child may need to, want to or have to do at home, school or in their leisure. The approach developed from our understanding of how children learn motor skills. The therapist works with the child and family to identify specific goals or tasks and to assess the child's performance. The therapist may structure aspects of the task or environment to optimise the child's performance. Skills required by the child are identified and developed. Repeated task practice is an important part of the approach and requires the child and family to be active partners in the therapy process.

What do parents need?

The impact on parents of having a child with any sort of difficulty can never be underestimated. Parents may experience emotions such as anger, grief, a sense of disbelief and feelings of isolation. These emotions are often very intense at the time of diagnosis and may recur over time.

Children with severe cerebral palsy may need a lot of assistance with daily living skills such as eating, bathing and dressing, placing enormous stress on the family.

There are a large number of hidden financial costs. These include visits to doctors and other professionals, special equipment, maybe extra nappies and extra childcare.

All parents will have their own individual needs. However, for most parents their needs will include:

1. Having their questions answered:

It is sometimes helpful if parents write down the questions they want answered when they see someone to discuss their child's needs.

2. Support in understanding the nature of their child's condition:

This support will include the opportunity to share the feelings, hopes, and fears they have for their child. Support may be from other family members, friends, parents with similar experiences and professionals.

3. Information about services that can help with the care and wellbeing of the child and parent and assistance in gaining access to them at the time they are needed. Sometimes information can be provided by one of the disability support groups or organisations such as the Cerebral Palsy Support Network (see page 37).

4. Information and skills to help them assist their child in the best possible way.

5. Having a break: Time off from childcare is important for most parents. When the child's daily needs place extra demands on time and energy this is even more important. A break enables families to have a rest and to spend time doing other things.

What shall I tell my friends and relatives?

It is sometimes difficult to know what to tell your relatives and friends. Each family will manage this differently and at varying times. It is your personal choice and you should feel able to do this in your own time when you are ready. A simple explanation is often all that is required: that your child has difficulty in controlling his muscles, and that his or her progress in some areas will be slower.



What about the rest of the family?

Sometimes it may seem impossible to fit all the activities suggested into the daily schedule. Parents may then feel guilty that they have insufficient time to carry out therapy programs with their child. All parents face the same problem and it is important to set aside time with your partner or other children as well. The needs of brothers and sisters must not be overlooked, and it is understandable that sometimes they might feel jealous or left out because of the extra attention given to the child with cerebral palsy. Sibling groups are organised by several organisations where brothers and sisters of children with disabilities, get together to share experience and gain support.

Hurtful comments or teasing can be a problem for both the child with cerebral palsy, for brothers and sisters, and for the rest of the family. 'Spastic' has become an unfortunate term because it can be used in an unpleasant way. However, to doctors and therapists, the word simply means stiffness or tightness of muscles. There are ways of coping with teasing, and books are available about this subject.

Sometimes the difficulties seem overwhelming. Remember that you are not alone and that help and people who understand are always available: other parents, parent support groups, and all the people who work with your child.

Who is available to help my child?

A number of professionals work with children with cerebral palsy and their families. Depending on needs, some children may be seen by all of these people, others only by one or two. Different professionals will be helpful at various stages of the child's development.

Some of the people involved are:

1. Parents: Parents are the most important people of all as they know most about their child. All children need the love and security parents provide. In day to day family life parents will incorporate many of the suggestions made by therapists and teachers into the daily routine.

2. Family doctor/general practitioner:

Children with cerebral palsy have the same health problems as other children of a similar age. They are just as likely to develop coughs and colds and other common childhood illnesses. The family doctor will help with these problems. General practitioners may also know the whole family and be able to provide support and encouragement.

3. Paediatrician: This is the doctor who specialises in children's health and development. Paediatricians can provide advice regarding the special health conditions that occur in children with cerebral palsy, such as epilepsy. The paediatrician works closely with all

the people who are involved in helping children with cerebral palsy and can make referrals to other specialists as necessary.

4. Paediatric rehabilitation specialist

assesses and treats children and young people with limitations in function or disability. The aim of Rehabilitation Medicine is to allow the child or young person to function at the fullest level they are capable of in physical, mental, social, educational and vocational domains. Rehabilitation Medicine specialists may recommend various interventions, including the involvement of allied health professionals. They may prescribe medications, recommend adaptive devices or modifications to the environment of the child or young person. Paediatric rehabilitation specialists are trained in the administration of Botulinum toxin injections for the management of increased muscle tone.

5. Other medical specialists may at times be helpful including paediatric neurologists, gastroenterologists, endocrinologists, respiratory physicians and orthopaedic surgeons.

6. Nurses provide assistance in various ways. Maternal and child health nurses monitor children's early development and provide support to parents. If your infant needs more monitoring than is typical, your maternal and child health nurse may refer you to an enhanced maternal and child health service.



School nurses, who are in some mainstream and special schools, are able to address everyday health issues such as nutrition, immunisations, bowel and bladder management. You may be referred to other specialty nurses, such as continence nurses, stomal nurses, epilepsy nurses or gastrointestinal nurses who have specific expertise in an area.

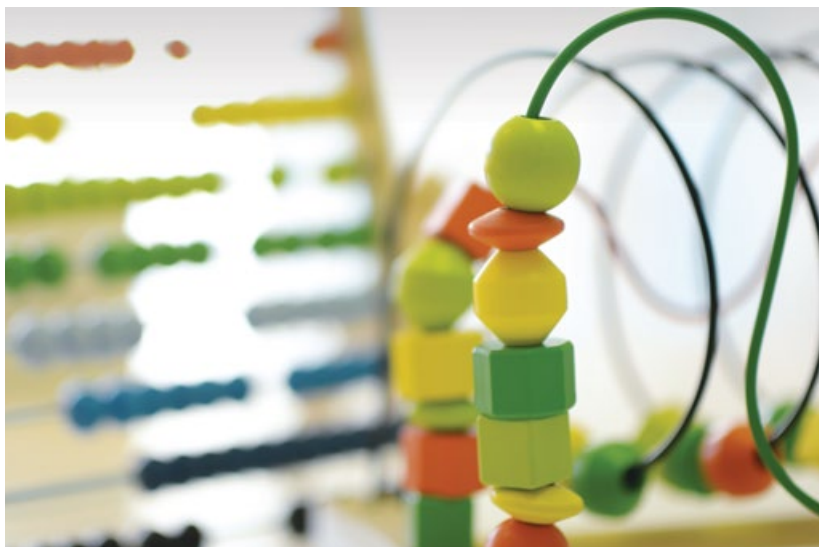
Following any procedures, such as orthopaedic or gastrointestinal surgery where ongoing medical or nursing interventions are required, arrangements can be made for nurses to visit at home to support you. Nurses may also be helpful in liaising with and obtaining appropriate health care services.

7. Paediatric therapists are skilled in working with children with cerebral palsy and provide assessment, advice and/or treatment. Depending on the setting, they may work with children and their parents either individually or in small groups. Those most commonly assisting children with cerebral palsy are physiotherapists, occupational therapists, and speech pathologists. Not every child needs to have assistance from all of these people. For children with complex needs, the therapists often work together in planning or providing treatment.

Therapists aim to teach parents how best to help their children learn to move and acquire all the practical skills needed for living and ensure optimal functioning. All young children learn through play and this principle is used when advising parents about the best way to encourage their child's development.

The special areas in which each therapist works are as follows:

a. The **physiotherapist** advises parents on ways to encourage children to move, and to develop skills such as sitting, crawling and walking. Practical advice on ways to lift and carry children, and on positioning children for play and eating, can also be given. The physiotherapist may also give advice on suitable footwear, splints to improve children's foot posture and gait, and equipment such as supportive chairs and standing and walking frames.



b. The **occupational therapist** specialises in hand skills and activities of daily living, and advises about play and appropriate toys. Occupational therapists also suggest easier ways of bathing, feeding, dressing and toileting. As children become older, occupational therapists help them to become more independent in these self-care tasks. They also assist children to acquire skills needed for kindergarten and school (such as handwriting).

c. The **speech pathologist** sees children with difficulty talking, understanding speech and swallowing difficulties. Advice is given to families on how to encourage speech and language development. Some children

may need to learn an additional or alternative means of communicating, such as using hand signs, a communication book with words or pictures or an electronic communication device. Children with cerebral palsy may have difficulties with eating and drinking due to poor control of the muscles of the mouth, face and throat. They may dribble excessively at times. The speech pathologist can help with these problems.

8. The social worker can provide information about services and entitlements and can help find appropriate early childhood intervention programs, kindergartens and schools. The social worker can also provide

information for parents who wish to meet others with similar experiences. Most importantly, social workers can provide counselling and advocacy support. You can talk to social workers about your child and discuss any problems or worries that you and your family are experiencing.

9. The psychologist is concerned with progress in learning and emotional and social development. The psychologist may be available to help if there is concern about a child's emotional well-being and behaviour or difficulties within the family.

10. Special education teachers work in a variety of settings, including family homes, early intervention programs, preschool settings (kindergarten and child care centres), playgroups and special schools.


Special education teachers provide support to families by:

- helping families understand more about their child's disability and the impact it may have on learning and development
- establishing individual therapy/ education program plans
- supporting the child and staff in the child's participation in local kindergarten and child care programs
- assisting with the child's successful transition to school and post-school options.

11. The orthotist works closely with the physiotherapist and doctors to determine appropriate bracing for those children that need it. The orthotist designs and makes braces and is responsible for all ongoing alterations and adjustments to improve fit and function of the brace as the child grows. The orthotist will provide information on suitable footwear types and may also be involved in the modification of some equipment.

12. Dentist: Dental care is very important for your child. Regular check-ups and help with tooth brushing and preventing dental decay can be sought from either your local family dentist or a public community dental clinic. Alternatively, you can ask your paediatrician to refer you to the department of Dentistry at The Royal Children's Hospital (RCH). Eligibility criteria for acceptance are listed at: www.rch.org.au/dentistry/about_us/Eligibility_criteria The department of Dentistry at the RCH will be able to provide your child with ongoing regular dental care until 18 years of age. Your child will then be transitioned to an adult special needs service for future dental care.

13. The audiologist tests children's hearing to make sure they can hear well enough to learn to speak and understand language. Some children with physical disabilities, and very young infants, cannot respond consistently to sound. They sometimes cannot show us how



much they hear. Audiologists have special tests to measure the hearing of such children. If deafness is detected the audiologist works with the ear specialist (otolaryngologist) to improve children's hearing. If that is not possible the audiologist will arrange for hearing aids to be fitted and advise parents in their use.

14. The ophthalmologist assesses vision, manages eye disorders and prescribes glasses and other treatments that may be necessary for children with cerebral palsy.

WORKING WITH EARLY CHILDHOOD INTERVENTION PROFESSIONALS

Early Childhood Intervention (ECI) professionals are qualified in specialist areas such as early special education, health, occupational therapy, physiotherapy, psychology and speech pathology.

ECI professionals work from a child and family-centred approach where an equal partnership is created between parents and ECI professionals to help each family build on its strengths and develop new skills.

In state funded ECIS, as much as possible you will work with one key worker who supports your family, to reduce the need for you to tell your story over and over. Your key worker will assist you to identify which therapies and supports may be helpful to assist your child to learn and develop.


They will communicate your child's needs to other professionals who can provide advice or work directly with your child when necessary.

Your ECI professional will be someone you trust, who is skilled and wants to work with you to learn what works for you and your family. They will help you to think about what they can do and what is possible for you and other family members to do to help your child.

It is important to work with an ECI professional with whom you feel comfortable. Some ECI professionals will assist you with a wide range of activities such as linking into other services, setting goals for your child and family and establishing and refining routines. Home, childcare or kindergarten-based sessions are especially valuable for linking therapy strategies to your child's needs in daily life. It is useful to check whether your therapist or service can offer sessions in different settings.

Sometimes ECI professionals may have experience with particular developmental concerns — it can be worth asking if they have experience with children with similar needs to your own child.

When working with ECI professionals it is good to trust your instincts. If necessary ask a lot of questions. Communicate your needs clearly.



If you haven't experienced the support you'd hoped for and the approach doesn't feel right for your family, you can always change to a different ECI professional, key worker and service.

All of these professionals may assist families to develop advocacy skills. However, parents may choose their own advocate or support person to accompany them to meetings and appointments to provide support.

What is advocacy?

Some families who have a child with cerebral palsy feel they need someone to help them gain access to services or insist on their own or their child's rights. This service is known as advocacy. An advocate works alongside the family, often attending important meetings with them and sometimes speaking on their behalf. People involved in the care of the child, a case manager, a friend of the family, or a special 'advocate' may be used. Sometimes an advocate can be provided by one of the disability support groups or organisations such as the Association for Children with a Disability. An advocate also helps the family or the person with a disability develop the skills to speak confidently for themselves.

Where will my child go to school?

Choosing the most appropriate school can take considerable time and planning when your child has cerebral palsy.

There are several options available. All children are entitled to an education through their local primary school. This entitlement is known as inclusion, where the special resources for the child are made available to the local school. A small number of schools provide more specialised programs for children with special needs. Workers who know your child well, such as your therapists, pre-school teacher or paediatrician, will be able to provide information and support during the process of choosing a school. The final decision should be yours.

Schools may request assessment reports to establish your child's needs and your doctor or therapist can ensure these are performed and made available to you to provide to the school.

Regional offices of the Department of Education and Training provide information and resources about schooling for children with cerebral palsy. There are several publications that may be useful for families including the *Program for Students with Disabilities*, which is available from the Department of Education and Training website www.education.vic.gov.au

What about different approaches to treatment?

Every child is an individual. Just because a particular child is receiving one type of therapy does not mean that another child needs the same therapy.

Therapists and paediatricians keep up-to-date with the latest treatment approaches, and are happy to discuss different approaches with parents.

There are many non-mainstream (or 'alternative') treatments available and parents should always feel free to enquire about them, both from the practitioners of these therapies and from the child's paediatrician and paediatric therapists. Sometimes great claims are made for alternative approaches.

These claims are not always justified. Every parent and professional wants the best outcome for children with cerebral palsy, so families can be reassured that any new treatment that is of value will be assessed and incorporated in to mainstream practice. There is currently no evidence that suggests alternative methods are better than conventional therapies and many of these alternative methods are very expensive. It is important that both parents and professionals keep an open mind about new approaches but also be prepared to critically examine their claims.

What are the current trends in the provision of services?

Children with cerebral palsy benefit from the same activities as other children. Hence a child may attend a local playgroup or childcare centre, and progress on to a local preschool and school. It is important the child receives the extra assistance that may be required.

Specialised services are often available within local communities. Staff may work with children and families at home and later in playgroups, childcare centres and kindergartens.

Some children may benefit from attendance at a specialised program. Specialised programs are provided by a variety of agencies, and may include early childhood intervention programs, preschools and schools. It is important that parents are aware of all available programs.



Which organisations are helpful?

Children with cerebral palsy can use any of the regular early childhood and children's services such as maternal and child health centres, playgroups, child care centres, family day care, kindergartens and schools.

There are also a large number of Government and non-Government organisations that can provide additional help. Early intervention and school services may include special education, therapies, family support, parent

education, parent-to-parent contact, and assistance to the childcare centre or kindergarten. Details of all local agencies are available through the websites of Early Childhood Intervention Australia Victoria Chapter (www.eciavic.org.au) and the Association for Children with a Disability (www.acd.org.au), which are further detailed later in this booklet. Many of the same organisations continue to provide assistance to school-age children, although some are restricted to the preschool (early childhood intervention) years. On the next page is a list of some of the organisations that are helpful. Some do charge a fee so please enquire about this.

EARLY CHILDHOOD INTERVENTION SERVICES

Early Childhood Intervention Services (ECIS) support children with a disability or developmental delay from birth to school entry and their families. ECIS provides special education, therapy, counselling, service planning and coordination, assistance and support to access services such as kindergarten and child care. Services are tailored to meet the individual needs of the child and focused on supporting the child in their natural environments and in their everyday experiences and activities. These services are funded through the Department of Education and Training (DET) and provided by Specialist Children's services teams and Early Childhood Intervention agencies.

The overall aim of these services is to provide parents and families with the knowledge, skills and support to meet the needs of their child and to optimise the child's development and ability to participate in family and community life. All services are provided using a family-centred approach, recognising the importance of working in partnership with the family.

For ECIS central intake:

Telephone: 1300 662 655 metropolitan
1300 662 655 rural

www.education.vic.gov.au/childhood/parents/needs/Pages/ecis.aspx

DEPARTMENT OF HEALTH AND HUMAN SERVICES (DHHS)

Children eligible to receive services from Disability Services, the Department of Health and Human Services have a disability defined as sensory, physical or neurological impairment or acquired brain injury which:

- is permanent or likely to be permanent
- causes substantially reduced capacity in at least one of the areas of self-care, self-management or communication, and
- requires significant ongoing or long-term support.

Case management, respite care and behaviour support may be available.

Disability intake and response service:

Telephone: 1800 783 783

<http://dhhs.vic.gov.au/>

www.dhs.vic.gov.au/home

HOSPITALS

Limited therapy services are provided through some hospitals, particularly The Royal Children's Hospital and the Monash Medical Centre, but also through a number of other metropolitan and rural hospitals. Hospitals may also assist families of children with cerebral palsy through provision of medical and surgical services at various clinics, and through other departments such as social work and psychology. Developmental Medicine at The Royal Children's Hospital provides a range of education and training resources for parents, carers and families which can be viewed from our website.

www.rch.org.au/devmed

YOORALLA

Yooralla provides specialised services for children with disability including cerebral palsy, within their home, community and school from birth through primary and secondary years. This may include therapy, assistance with equipment, home modifications assessments and support with funding applications as well as recreation activities.

Telephone: (03) 9831 5632

www.children@yooralla.com.au



SCOPE

Provides therapy, information, training and education, resources, equipment, respite and recreational programs for children with cerebral palsy.

Telephone: 1300 472 673

www.scopevic.org.au

VILLA MARIA

Villa Maria provides therapy, educational, respite and recreational programs for children with cerebral palsy and with other physical disabilities.

Telephone: (03) 9854 5111
or 1800 036 377

CEREBRAL PALSY EDUCATION CENTRE

This Centre provides specialised early childhood intervention services to families who have a child with cerebral palsy or similar motor disability. The services are provided by physiotherapists, occupational therapists and speech pathologists. The services include family support, educational group programs, advice on equipment, individual therapy, and training and support into home, early childhood settings and local schools. Education and training opportunities for professionals, parents and the community are listed on the website. The Centre is located in Glen Waverley.

Telephone: (03) 9560 0700

www.cpec.org.au



KIDS PLUS FOUNDATION

This organisation is situated in Geelong and serves the Barwon region. The purpose of Kids Plus is to deliver specialist multidisciplinary therapy programs for babies, children and young people with neurodevelopmental disabilities, including cerebral palsy with a focus on supporting children and their families maximise their participation and engagement in daily life.

Telephone: (03) 5223 1475

www.kidsplus.org.au

ASSOCIATION FOR CHILDREN WITH A DISABILITY (ACD)

ACD is a not-for-profit organisation that provides free information, support and advocacy to families who have a child with any type of disability or developmental delay in Victoria. Services include free telephone support about any disability related issue, including aids and equipment, education, respite, and recreation. Our ACD support team are parents of children with a disability and so they understand issues from a family perspective. Information resources available to families include the booklets *Helping You and Your Family, Through the Maze, Growing Together, Positive Education Planning, Transition to Secondary School* and *Learning to Lead*. Online copies are available through the website www.acd.org.au

ACD also advocates for improvements to government policies and works to increase community awareness about the needs of families of children with a disability, including the need for more appropriate toilet facilities for children and adults who require hoists and larger change tables (see www.changingplaces.org.au). Members receive the quarterly *Notice Board* magazine which includes family stories and updates on services, supports and policy.

Membership cost:

\$16.50 for families or \$55 for organisations and professionals.

Telephone: (03) 9818 2000
or 1800 654 013 (rural)

Email: mail@acd.org.au

www.acd.org.au

CEREBRAL PALSY SUPPORT NETWORK

The Cerebral Palsy Support Network (CPSN) is a not-for-profit organisation providing information and support services to people living with cerebral palsy and their families. It helps empower individuals to lead more independent lives and provides support in a variety of ways to both individuals and families. The CPSN provides a wide range of supports including social, health and recreational programs, fitness programs, camps, website resources, information library, information seminars and workshops, carer

support groups innovative choices respite service and a care centre. The care centre includes services such as advocacy, case coordination, intake, access and referral services, telephone support and information and face to face consultation. Membership is free for individuals with cerebral palsy, as well as their families.

Telephone: (03) 9478 1001

Email: cpsn@cpsn.org.au

www.cpsn.org.au

NOAH'S ARK TOY LIBRARY AND FAMILY RESOURCE

Noah's Ark is one service that provides Early Childhood Intervention Services (ECIS) to families of children from birth to school age with a developmental delay or disability. They can also loan specialist equipment and toys.

Telephone: (03) 8823 8600

SUPPORT AGENCIES

Support agencies help support childcare, family day care and out of school hours care services that may require extra support to include children with additional needs. Supports must be requested by the children's service staff.

www.dss.gov.au/our-responsibilities/families-and-children/programmes-services/early-childhood-child-care/inclusion-and-professional-support-program

PRESCHOOL FIELD OFFICERS

Preschool field officers support teachers to assist children in kindergarten and provide advice to families immediately prior to and during the kindergarten year/s.

www.education.vic.gov.au/childhood/parents

ACTION ON DISABILITY WITHIN ETHNIC COMMUNITIES INC. (ADEC)

ADEC is a state-wide organisation that strives to empower people with a disability from non-English speaking backgrounds, their carers, and families to fully participate as members of the Victorian community.

Telephone: (03) 9480 1666

Toll free number: 1800 626 078

www.adec.org.au

FREE KINDER ASSOCIATION MULTICULTURAL RESOURCE

Provides support to early childhood services for children from culturally and linguistically diverse backgrounds attending children's services.

Telephone: (03) 9428 4471

www.fka.com.au

CARERS VICTORIA

There are times when you may just need a break. The services which enable this break are broadly referred to as 'respite' and can include in-home help provided by a support worker,

recreation-based activities (like camps and excursions) and assistance with special equipment. The services may also include 'residential respite' where the person you care for has a short-term stay at a facility which offers an intimate home-like setting with tailored activities. Every care situation is different. What works for one family may not work for another. Respite can provide a much needed break from the caring routine — time to get other things done, to have fun with the family, or simply to relax and recharge your batteries.

Telephone: 1800 242 636

BETTER START

Better Start is an Australian Government initiative funded by the Department of Social Services (DSS) that supports eligible children and their families by giving them access to early intervention funding and services delivered by registered service providers.

Children who are eligible for the program can access funding of up to \$12,000 (to a maximum of \$6,000 per financial year) for a range of early intervention services, including:

- speech therapy
- occupational therapy
- psychology
- audiology
- physiotherapy
- orthotics
- equipment that is essential to the child's therapy when ordered by an approved provider (up to 35%).

Therapists must be chosen from the Government approved authorised provider panel.

Children must be under six years old to be registered, and families will have until the child's seventh birthday to use the early intervention funding.

Carers Victoria supports the registration and information services for families wanting to access the Better Start program.

Telephone: 1800 242 636

www.betterstart.net.au

PARENT SUPPORT

This may be provided by consumer organisations such as:

- Association for Children with a Disability (see page 37).

Telephone: (03) 9818 2000

1800 654 013 (rural)

www.acd.org.au

- Cerebral Palsy Support Network (see page 37)
- Regional parent support programs.

Telephone Association for Children with a Disability for further details.

Telephone: (03) 9818 2000

or 1800 654 013 (rural)

FLEXIBLE SUPPORT PACKAGES

Flexible support packages provide early preventative supports for people with a disability and their families.

Flexible support packages include the provision of information, planning and low-level, short-term disability supports as well as assistance to access community and mainstream supports.

Telephone: 1800 783 783

Equipment and aids

THE STATE-WIDE EQUIPMENT PROGRAM

The State-wide Equipment Program (SWEP) provides people who have a permanent or long-term disability with subsidised aids, equipment, oxygen, continence and vehicle and home modifications. SWEP aims to enhance the independence and safety of people with a disability in their own home and or facilitate their participation in the community and support families and carers. SWEP is funded by the Department of Human Services.



SWEP incorporates the following programs: Aids and Equipment Program (A&EP), Supported Accommodation Equipment Assistance Scheme (SAEAS), Domiciliary Oxygen Program (DOP), Continence Aids (CA), Vehicle Modification Scheme (VMSS) and Top-Up Fund for Children (TFC).

To be eligible, young people need to have a long-term disability. Clients must be permanent Victorian residents or holder of a Permanent Protection Visa or an asylum seeker. Assessment and prescription is required by a SWEP registered Allied Health Professional or Respiratory Physician. Certification of disability is confirmed by the appropriately qualified medical practitioner.

<http://swep.bhs.org.au>

YOORALLA'S EQUIPMENT SERVICES

Yooralla's Equipment Services have three programs for children, people with disabilities and people who want to maintain independence as they live longer:

- The Independent Living Centre provides advice, assessment and information on daily living aids and equipment.
- The Equipment Library houses assorted equipment and aids, and complements the Independent Living Centre with a short-term loan service.

- ComTEC provides resources and advice in the use of specialised technology by people with disabilities. ComTEC therapists provide individualised assessment of needs. ComTEC also has an enquiry service; an outreach service and an electronic equipment library (hire fees apply).

The Electronic Communication Devices Scheme is co-located with these services at the Brooklyn site. The Electronic Communications Devices Scheme is funded by the Department of Human Services, to provide funding for the purchase of communication devices, voice output software and apps, mounting systems and specialised switches to people of all ages with complex communication needs. Devices, repairs, training and follow up are provided to residents of Victoria with a permanent disability resulting in a severe communication impairment. The ECD program is a subsidy scheme which has ceiling limits for equipment purchases, however many of the requests do fall under these limits.

Telephone: (03) 9362 6111
(03) 9314 9001
1300 885 886

Email: ilc@yooralla.com.au

www.ilcaustralia.org.au

SCOPE GO KIDS

Scope Go Kids is a specialised mobility assessment and intervention service. Scope Community and Inclusion Resource Center provides non-electronic communication aids for children, telephone advice for parents, teachers and other in augmentative and alternative communication, disability education for schools, services and organisations, and workshops and courses in a range of disability-related topics.

EQUIPMENT RECYCLING NETWORK INC

Equipment Recycling Network Inc runs a website where clients can place an advertisement for their 'Disability Aids' that they no longer require, including wheelchairs, bedding, chairs and scooters. Desktop PCs are also supplied for people with a disability. For children, a support letter from their paediatrician is required, stating that the child in question has a disability and would benefit from owning their own PC. The cost is \$30 for a PC with Windows 7 and Office 2010.

www.erni.asn.au

www.erni.asn.au/sale-of-computers-for-people-with-disabilities.htm

SOLVE DISABILITY SOLUTIONS

Solve Disability Solutions (formerly TADVIC) custom makes and modifies equipment for people with disabilities when there is no commercially available product or service that will meet their needs. Health professional project coordinators work with volunteers who have a range of technical abilities to assist the client to solve equipment related issues. The service is funded by the state government and charges apply for reimbursement of volunteer expenses incurred. Charges for service costs for NDIA participants (see below) are also included in their quotations.

Telephone: (03) 9853 8655
or 1300 663 243

Email: info@solve.org.au

www.solve.org.au

Continance services/support

CONTINENCE AIDS PAYMENTS SCHEME

Continance Aids Payments Scheme (CAPS) is an Australian Government Scheme that provides payment to assist eligible people who have permanent and severe incontinence to meet some of the cost of their continence products.

Free Help Line: 1800 330 066

www.continence.org.au/pages/national-continance-helpline.html



CONTINENCE SUPPORT SERVICE FOR CHILDREN WITH A DISABILITY (CSS)

Advice for toilet training strategies and products from local continence nurse and provision of disposable product.

Victorian Continence Resource Centre

Telephone: (03) 9816 8266

STATEWIDE EQUIPMENT PROGRAM (SWEP)

For provision of catheters other drainage systems reusable products, that is, bed protection, chair protectors and underwear.

Telephone: 1300 747 937

Financial assistance

The Commonwealth Department of Health and Human services provide payments and services to help families and people who have a disability.

- Carer Payment and Carer Allowance can provide financial assistance if you provide care every day to someone with a disability
- Carer Supplement is an annual lump sum payment to help you with the costs of caring for a person with a disability.
- Child Disability Assistance Payment is an annual payment that helps you with the costs of caring for a child with a disability.
- Mobility Allowance helps you to participate in approved activities when you have a disability, illness or injury.

The allowance helps with transport costs if you cannot use public transport without substantial assistance, either permanently or for an extended period.

- Assistance for Isolated Children Scheme can help parents and carers of school aged students who cannot go to state school on a daily basis because they have a disability or have special health needs.
- Special Disability Trust helps immediate family members of people with severe disabilities make a private financial provision for their future care and accommodation needs.

Centrelink telephone: 13 27 17

For more information:

www.humanservices.gov.au/customer/subjects/payments-for-people-living-with-illness-or-disability
www.humanservices.gov.au/customer/subjects/caring-for-someone-with-an-illness-or-disability

THE COMPANION CARD

This is for people with a lifelong disability who require a companion to enable them to access activities and venues. The cardholder's companion may be admitted to public venues at no cost.

Telephone: 1800 650 611

THE NATIONAL DISABILITY INSURANCE SCHEME

The National Disability Insurance Scheme (NDIS) is a new way for people with a disability and their families to gain support to link into community services. The NDIS will ensure that people with disability are given every opportunity to make their own decisions and exercise choice and control. It is recognised that the role of families and carers is often essential in supporting people with disability to realise these goals and will include them in discussions about supports. The NDIS will provide information, referral and linkage to ensure families and carers are able to access supports in the community to assist them in their role. Where a permanent and significant disability exists, NDIS will fund supports to achieve individual goals. In Victoria, the Barwon region is used as the trial site for the NDIS. Most disability-specific, government-funded programs are transitioning to the NDIS. Roll-out of the full scheme in Victoria, will commence progressively from July 2016.

www.ndis.gov.au

To find out more and to see if you are able to access assistance:

www.ndis.gov.au/my-access-checker

Looking after yourself and your family

COUNSELLING

All families are different and will have competing demands, for example, the number of children in their family and possible financial impacts on family living. This could mean that at different times in their lives parents and carers may need or seek the assistance of others either informally with family, friends or support group members or more formal methods such as counselling.

Assistance for counselling is available through:

ACD

www.acd.org.au

CPSN

www.cpsn.org.au

Regional Parent Support Coordinator

can be located on your Regional Quick Guide: www.acd.org.au/regional-quick-guide

Other support and counselling options are listed on page 22 of ACD's publication *Through the Maze* <http://acd.org.au/through-the-maze> or call ACD for a copy (free for families).

NATIONAL CARER COUNSELLING PROGRAM

Provides free short-term counselling for parents and carers. Your GP or case manager can make a referral or you can contact the service yourself.

Telephone: 1800 242 636

www.carersvictoria.org.au

MENTAL HEALTH CARE PLAN

Anyone who has a mental health condition that lasts longer than six months and needs the care of several providers may benefit from a Mental Health Care Plan. The plan explains the support given by each provider and is done in consultation with your doctor. Medicare will cover some or all of the cost of care planning by a doctor and may rebate some of the costs of specialists or other health professionals. Ask your doctor or mental health professional for more information.

www.betterhealth.vic.gov.au

Is any research being carried out?

In Australia and many other parts of the world there is research into the causes of cerebral palsy. Research is also being carried out to help find the best methods of management and treatment. The Murdoch Childrens Research Institute, with its partners, The Royal Children's Hospital and

The University of Melbourne, has a substantial cerebral palsy research program, spread over the campus.

The Victorian Cerebral Palsy Register, managed by researchers from the Developmental Disability and Rehabilitation research group at Murdoch Childrens Research Institute, collects basic information about people with cerebral palsy born or living in Victoria since 1970. The Register is extremely important in enabling us to determine how the incidence of cerebral palsy has been changing over time in Victoria. It also allows us to better understand any trends in the type and severity of the movement disorder in cerebral palsy, and to advance our knowledge of the multitude of factors that appear to increase the risk of cerebral palsy.

Telephone: (03) 9345 4808

Email: vic.cpregister@rch.org.au

www.mcric.edu.au/research/projects/victorian-cerebral-palsy-register

In March 2006, *Solve! At the RCH* was launched, an initiative of Developmental Medicine. The aim of *Solve! At the RCH* is to research the causes and improve the outcomes for children with disabilities.

www.rch.org.au/devmed

In conclusion

- Focus on what your child can do and how his or her capabilities can be developed to their maximum.
- Your child needs the same love, care and acceptance as all children. However severe the cerebral palsy, your child is more like other children than unlike them and obtains the same enjoyment from play and pleasurable activity.
- Be optimistic about your child's progress, yet be realistic when the problems are severe (this is, of course, often a difficult balance to achieve).
- Good cooperation and communication between parents and professionals will help the child achieve independence. The greatest achievement, however, is the development of the child into a mature person able to adjust to life.
- Take care of yourself. Continue with activities you enjoy, talk to someone who understands what you are going through (join a parent support group), make time for regular exercise, have healthy, regular meals, get enough rest and sleep. Look after your back if you need to lift or transfer the person you are caring for, make sure that you have regular and frequent breaks and make time for yourself each day for relaxation.

Helpful resources

PUBLICATIONS

Finnie's *Handling the Young Child with Cerebral Palsy at Home*.

Edited by Eva Bower, 4th Edition. 2008. Butterworth-Heinemann.

WEBSITES

Cerebral Palsy Support Network (CPSN)

The CPSN website provides a range of resources including an information library and useful links. The site covers an extensive range of topics including CP, education, advocacy services, equipment, financial assistance, mobility, respite and much more.

www.cpsn.org.au

Cerebral Palsy Australia

www.cpaustralia.com.au

Ability Centre

www.abilitycentre.com.au

Cerebral Palsy Alliance

www.cerebralpalsy.org.au

Hemi-Kids

Information for children with hemiplegia

www.hemikids.org



Developmental Medicine

The Royal Children's Hospital Melbourne
50 Flemington Road Parkville
Victoria 3052 Australia
www.rch.org.au/devmed

Melbourne Children's

A world leader
in child and
adolescent
health



The Royal
Children's
Hospital
Melbourne



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