

Cerebral Palsy

an information guide for parents

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Cerebral Palsy
An Information Guide for Parents
First edition 1989
Second edition 2000

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ISBN 0958741654

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The valuable assistance provided by the Association for Children with a Disability, particularly Heather Liesis, Anne Maree Newbold, Jenny McAllister and Diane McCarthy, and the Cerebral Palsy Support Network, particularly Victoria Garner, is also acknowledged. Anne Casey also provided advice. The manuscript was prepared by Elizabeth Cassidy and Corinne Shaw, and the booklet designed and illustrated by the Educational Resource Centre. The Waverley Auxiliary provided generous financial support for this publication.

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 abilities.

We have written this book to answer some of your questions. Every child with cerebral palsy is different. In some children the problem may be so slight that he or she is only a little clumsy with certain movements. In other children the problem can be severe.

Because each child is different, the information is presented in a general way. Please discuss your own child's problems 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. 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 problems that you and your family will face over the coming years, help is available.

What is cerebral palsy?

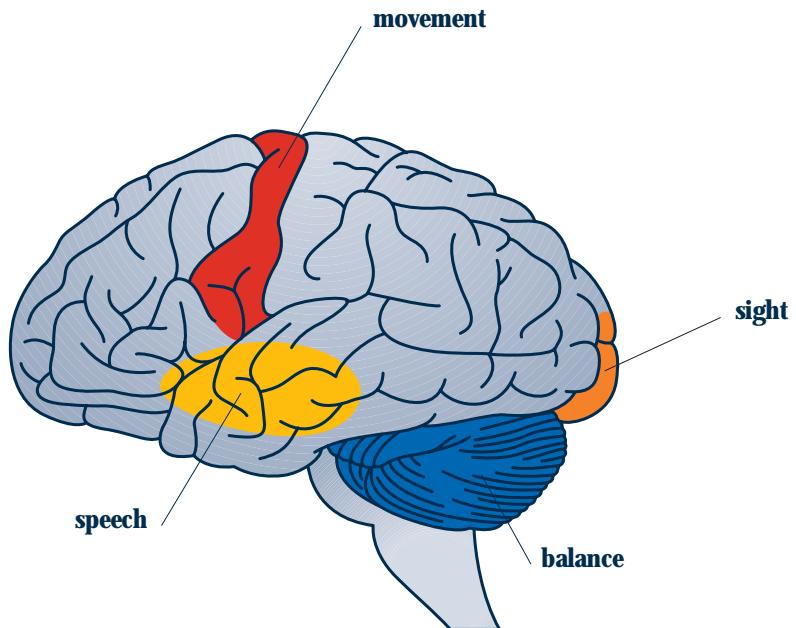
The brain controls all that we do. Different parts of the brain control the movement of every muscle of the body. In cerebral palsy, there is damage to, or lack of development in, one of these areas of the brain.

“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 problem has occurred early in life, to the developing brain.

Children with cerebral palsy can have problems such as weakness, stiffness, awkwardness, slowness, shakiness, and difficulty with balance. These problems can range from mild to severe. In mild cerebral palsy, the child may be slightly clumsy in one arm or leg, and the problem may be barely noticeable. In severe cerebral palsy, the child may have a lot of difficulties in performing everyday tasks and movements.



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 relayed 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.

Athetoid cerebral palsy

Athetoid (or athetosis) is the word used for the uncontrolled movements that occur in this type of cerebral palsy. This 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 involvement with their arm and hand movements.

Quadriplegia – ***both arms and both legs, and the trunk***, are affected (also described as quadripareisis). The muscles of the face, mouth and throat can also be involved.

What are the causes of cerebral palsy?

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

1. If the brain does not grow or form properly.
2. In the early months of pregnancy – for example, if the mother is exposed to certain infections such as Rubella (German Measles), or if there is any abnormality in early brain development.
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 new 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 problems 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.

Problems that lead to permanent neurological deficits up to the age of five to six 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 problem predated the premature delivery or whether the problems 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 the problem and share their concerns with each other and with the people involved in the care of their child.

What other problems may the child have?

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

- 1. Problems with hearing** – all children should be seen by the specialist in hearing (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 problem may be more persistent, and may require the advice of a paediatric neurologist.

- 4. Intellectual or learning disability** – it must be stressed that 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. Perceptual difficulties – problems such as judging the size and shape of objects are termed perceptual difficulties, and may not be apparent until school age.

6. 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.



7. 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. Regular monitoring or surveillance with hip x-rays is important. A "Hip Surveillance Clinic" takes place in the Orthopaedic Department of the Royal Children's Hospital, to which any child can be referred to have the growth and development of the hip joint checked. Examination of the hips is not enough so all children with cerebral palsy affecting both lower limbs (diplegia, quadriplegia) require one or more x-rays of the hips. Scoliosis (curvature of the spine) is a more unusual problem.

8. 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.

Remember – no one child has all these problems. There are treatments available for them which are discussed in a separate section.

9. Nutritional difficulties – some children with severe cerebral palsy may have difficulties with chewing and coordinating their swallowing, causing prolonged or difficult meal times. This in turn may lead to inadequate food intake. Other children have a tendency to put on weight because of reduced physical activity.

10. Saliva control problems – children often dribble in the early years of life. Dribbling can persist in children with cerebral palsy.

11. Recurrent chest infections – this is a problem in only a very small group of children with cerebral palsy. It is most likely to occur in children who have difficulties with chewing and swallowing. Some of the food and drink may inadvertently pass in to the lungs causing the child to cough and wheeze. These episodes may mimic asthma. If these episodes are severe and persistent the child may develop recurrent attacks of pneumonia. Of course, just like other children, those with cerebral palsy may occasionally develop a chest infection, pneumonia or asthma.

Will my child get better?

“Cerebral palsy” refers to a permanent condition, and the problems 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 can learn to cope with the condition as they grow. 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. 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 muscles more and more, they may become tighter. During growth spurts, the child's bones may grow more quickly than his 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 because they have different treatments.

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 is being “pushed” to achieve a skill, he 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 his 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 some months or even years. Many children with mild and moderate degrees of cerebral palsy do learn to walk.

Will my child learn to talk?

The development of speech involves a number of factors. Children must learn to control the movements around their mouth; they must have progressed in their emotional development; and they have to attain the necessary cognitive (or learning) skills. Some children with cerebral palsy will not have any difficulties in learning to talk; others will need help from a speech pathologist to develop speech or alternative methods of communication.

Will my child be able to look after himself?

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 himself 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. Usually the behaviour is intended to support a function that is impeded by their disability (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 may be able to discuss such behavioural matters and suggest ways to handle the child while new skills are developing.

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 new booklet produced by the Association for Children with a Disability, entitled “Helping You and Your Family – Self-Help Strategies for Parents of Children with a Disability” has useful information about relationships with health professionals.

Will my child have a normal life expectancy?

Most children with cerebral palsy are healthy, and can expect a normal life span. A very 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 a prolonged seizure).

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.





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 10 years. 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 can be considered in three areas:

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

What treatments are available for the movement problem?

Paediatric therapists play a key role in the management of movement problems. Physiotherapy, and sometimes occupational therapy, is essential to provide a program to encourage motor development. Therapy is also necessary to implement the other strategies discussed below.

1. Many children use **orthoses** (sometimes known as braces) for the lower limbs at some stage in their development. They are made of a light-weight material and are individually fitted for each child. In the past metal calipers with leather straps were sometimes used, and may still occasionally be helpful.

2. **Upper limb splints** are sometimes made by an occupational therapist to maintain range of movement, facilitate better grasp and improve overall function of the arm and hand. These splints, usually of plastic material, are individually made for each child. Over recent years, a technique of splinting with dynamic lycra splints has been developed. These splints are often called "second skin".

3. **Plaster casts** are sometimes applied to lower limbs to stretch the calf muscles, and to improve the position of the foot during walking. The casts are changed every one to two weeks, the child walks in the plasters, and generally the plasters remain in use for about six weeks. These plasters are sometimes called "inhibitory casts".

4. **Botulinum toxin A** ("Botox") has recently been introduced as a treatment for tight or spastic muscles. It is most commonly used when tightness in the calf or hamstring muscles is interfering with progress in learning to move. A light anaesthetic is 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 is invasive involving multiple injections; the effects of the drug are not completely predictable and are of short duration; and the toxin is costly.

5. **Oral medications** for spasticity include Diazepam, Dantrolene and Baclofen. These medications are often not effective or may cause too many unwanted effects. Hence they are prescribed relatively infrequently.

- Diazepam (“Valium”) is a good medication for spasticity, but may cause sedation. However it is useful following surgery, particularly orthopaedic procedures.
- Dantrolene (“Dantrium”) is generally not helpful, and can rarely cause liver problems. It may also cause drowsiness, dizziness and diarrhoea.
- Baclofen (“Lioresal”) is said to be more useful in spasticity due to spinal lesions than in spasticity due to cerebral lesions. However, there has been increasing interest in trialing it in children with severe spasticity. Side effects are uncommon but may include nausea. It is reported to aggravate seizures though this is a rare problem. There has been recent interest in the use of a pump 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 very small number of children with severe spasticity.

6. **Selective dorsal rhizotomy** is a major operation on the spine occasionally used to reduce spasticity. There is ongoing debate as to whether it has a useful role. Following the procedure a very extensive rehabilitation period is required.

7. **Orthopaedic surgery.** Surgery is mainly undertaken on the lower limb, but occasionally in the upper limb. Some children require surgery for scoliosis. Physiotherapy is an essential part of post-operative management. Gait laboratories 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 often effective for children when the hip problems are detected at an early stage (hence the importance of regular x-rays). Lengthening of the adductor muscles may be all that is required in younger children. However, if the problem progresses, and especially if it is neglected, more extensive surgery to the hip bones is required for a significant number of children. 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 which is frequently painful in later life.
- The knee: Lengthening of the hamstrings can help the knee straighten and so improve the walking pattern. Sometimes transferring a muscle from the front to the back of the knee can also help by reducing stiffness around the knee.
- The ankle and foot: This is the commonest area where orthopaedic surgery is required.

Sometimes children require orthopaedic surgery in several different areas (for example, hip, knee and ankle). Frequently this now 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 between 8 and 12 years old although it can occasionally be helpful for older or younger children. The aims of surgery are to correct 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.

8. Plastic surgery. Tendon transfers and releases can occasionally improve cosmesis 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 epilepsy, and medication is prescribed following a careful diagnosis of the type of epilepsy. Doctors attempt to prescribe medications with the fewest side effects whilst providing good seizure control. The two most commonly used anticonvulsants are:

- Carbamazepine ("Tegretol"). Side effects are unusual but include nausea (in young children this can be manifested as loss of appetite), and skin rash which usually develops shortly after commencing the drug. If the drug is commenced too rapidly initial drowsiness may occur. A controlled release preparation is now available which may be advantageous for those children able to swallow tablets.
- Sodium valproate ("Epilim"). Side effects are unusual, but include nausea, bowel disturbance and hair loss. Liver damage has been reported but is extremely rare.

Several older anticonvulsants are sometimes used because they may suit individual children or lead to better seizure control. These include:

- Phenytoin ("Dilantin"). This drug has a number of unwanted side effects including gum overgrowth, the development of abnormal body hair and occasionally coarsening of facial features. Because the margin between a therapeutic and toxic dose is narrow, signs of overdose – nausea, unsteadiness and drowsiness – do sometimes occur, necessitating regular blood tests.
- Phenobarbitone. This drug can occasionally cause irritability and aggravate constipation.
- Primidone ("Mysoline"). This drug has some of the side effects of phenobarbitone.
- Nitrazepam ("Mogadon"). This drug may cause drowsiness and increased bronchial secretions. It is also used as an hypnotic occasionally in children but more commonly in adults.
- Clonazepam ("Rivotril"). This drug can cause irritability, drowsiness and disruptive behaviour. It can also worsen drooling.
- Clobazam ("Frisium"). This drug is from the same family as clonazepam. Drowsiness or dizziness may occur but is usually mild. This drug is one of the more recent anticonvulsants and is similar to clonazepam and nitrazepam in chemical structure.

There are a number of newer anticonvulsants:

- Vigabatrin (“Sabril”). Side effects may include drowsiness, irritability and agitation. There have been reports that this drug may cause problems with vision.
- Lamotrigine (“Lamictal”). This is the most useful of the new drugs, but is usually used as an “add on” to drugs in the previous groups. It is said to cause an increase in alertness which can be a positive effect. The most worrying unwanted effect is a severe skin rash. If a skin rash develops, the drug should be ceased. It may also cause gastro-intestinal disturbance (for example, nausea or diarrhoea).
- Topiramate (“Topimax”) and gabapentin (“Neurontin”) are more recent drugs. Their place in the management of childhood epilepsy is being evaluated.

2. **Gastro-oesophageal reflux.** Conservative measures, such as ensuring that the infant or child is propped upright after a meal and thickening liquids, may be helpful. Two medications are frequently used, particularly when there is evidence of oesophagitis or gastritis (inflammation of the oesophagus or stomach):

- Cisapride (“Prepulsid”) enhances stomach movements and may accelerate gastric emptying and shorten intestinal transit time. Diarrhoea may occur. Rare cases of cardiac arrhythmias have been reported. Patients experiencing arrhythmias have usually been on multiple medications.

- Ranitidine (“Zantac”) reduces gastric acidity.

Very occasionally surgery for reflux is 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 and programs to improve dribbling problems. For children where these strategies are not effective, medication is occasionally used, particularly in children over the age of six years. These medications are as follows:

- Benhexol hydrochloride ("Artane") reduces salivary secretions. Occasionally irritability or even hallucinations may occur. Blurring of vision, constipation and difficulty with urination are also potential side effects.
- Glycopyrrolate ("Robinul") is similar to benhexol hydrochloride but seems to produce fewer side effects. It is not widely available at present in Australia.

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. A separate booklet about this is available.



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 two most commonly used approaches by therapists in Victoria are Neuro-Developmental Therapy and programs based on the principles of Conductive Education.

1. Neuro-Developmental therapy (often abbreviated to "NDT" and also known as Bobath therapy) is a therapeutic approach to the assessment and management of movement dysfunction in children with neurological dysfunction. The ultimate goal of treatment and management is to maximise the child's functional ability. The therapy was first developed by Dr and Mrs Bobath in the 1940s and hence is sometimes known as "Bobath therapy". Following a thorough assessment, the treatment focuses on making desired movements more possible and preventing undesired movements. Family members and other caregivers receive education in NDT principles to maximise quality of movements and implementation of the program at home, preschool, school and in other community environments.

2. Programs based on the principles of Conductive Education. Conductive Education is a Hungarian system for educating children and adults with movement disorders. In 1940, Professor Andras Peto established the approach by recognising that such disorders are learning difficulties to be overcome rather than conditions to be treated. 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 a variety of programs applying principles of Conductive Education in Victoria. The professionals involved in these programs include special education teachers, therapists and Hungarian "conductors".

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 child care.

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 problems. 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 and assistance in gaining access to them.
4. Information and skills to help them assist their child in the best possible way.
5. Having a break. Time off from child care 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. A simple explanation is often all that is required: that your child has difficulty in controlling his muscles, and that his 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 special 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 a disability.

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 further written material is 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. **The 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. **The 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 such as chicken pox. 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. **The paediatrician.** This is the doctor who specialises in children's health and development. Paediatricians can provide advice regarding the special health problems 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. **Nurses** provide assistance in various ways. Maternal and child health nurses monitor children's early development and provide support to parents. School nurses, either in mainstream or special schools, are able to address everyday health issues such as bowel and bladder management. Community nurses, whether in hospitals or community health centres, may provide advice in areas such as epilepsy management and constipation. The Royal District Nursing Service supports families at home following orthopaedic procedures or where other ongoing medical or nursing interventions are required. Nurses may also be helpful in liaising with and obtaining appropriate health care services.

5. **Paediatric therapists** are skilled in working with children with cerebral palsy and provide assessment, advice and/or treatment. 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. However, they 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. 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** gives advice on how to encourage speech and language development. Some children may need to learn an extra or alternative means of communication. This may be in the form of gestures and hand signs, or a communication book that uses words or pictures. Children with cerebral palsy may have problems with eating and drinking because of poor control of the muscles of the mouth and face. They may dribble excessively at times. The speech pathologist can help with these problems.

6. **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.

7. **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.

8. **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.

9. **The orthopaedic surgeon.** Orthopaedic surgery may be helpful for some children (particularly those with spasticity). Very careful assessment is necessary before operations are recommended.

10. **The orthotist** works closely with the physiotherapist to determine appropriate bracing for those children that need it. The orthotist makes the braces for the children and is also involved in the modification of equipment.

11. **The dentist.** Dental care is very important for your child. Regular check ups and help with toothbrushing and preventing dental decay can be sought from either your local family dentist or the School Dental Service through Dental Health Services Victoria; depending on where you live there are experienced dentists who visit local schools. Alternatively, you can ask your paediatrician to refer you to the Dental Department at the Royal Children's Hospital. While the Dental Department may not be able to provide your child with ongoing regular care it will be able to refer you on to the most appropriate place to seek care.

12. **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.

All of these professionals may assist families to develop advocacy skills. However, parents may choose their own advocate 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 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 friend of the family, or a special "advocate" may be used. Sometimes an advocate can be provided by one of the disability support groups. An advocate also helps the family or the person with a disability develop the skills to speak confidently for themselves.

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 child care centre, and progress on to a local preschool and school. It is important the child receives the extra assistance that may be required.

There has been a trend for specialised services to be available within local communities. Staff may work with children and families at home and later in playgroups, child care 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 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 organisations, Government and non-Government, 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 child care centre or kindergarten. Details of all local agencies are available through the web sites of Early Childhood Intervention Australia Victoria Chapter (www.ecia.-vc.org.au) and the Association for Children with a Disability, which is further detailed below (www.acd.org.au). Many of the same organisations continue to provide assistance to school-age children, although some are restricted to the preschool (early intervention) years. Below is a list of some of the organisations that are helpful.

1. Department of Human Services

Every region has a Specialist Children's Services Department with an Early Childhood Team that provides early intervention services. This team can assist families to find and use other local services. Children aged six years and over who have an intellectual disability in addition to a physical disability are eligible to receive services from Disability Client Services of the Department of Human Services.

Disability Client Services provides access to a range of services for children and their families, including assessment, case management and respite care. Contact the Association for Children with a Disability for information about your local service.

☎ 9500 1232,

☎ freecall (for rural families) 1800 654 013.

2. Hospitals

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. The Royal Children's Hospital conducts information sessions for parents and families at regular intervals.

3. The Yooralla Society of Victoria, The Spastic Society of Victoria and the Villa Maria Society

All provide therapy, educational, respite and recreational programs for children, particularly for those with cerebral palsy and with other physical disabilities. For the Yooralla Society of Victoria, contact Early Intervention or School Aged Services.

☎ 9359 9366.

For Spastic Society of Victoria.

☎ 9537 2611.

For the Villa Maria Society.

☎ 9853 5377.

4. Association for Children with a Disability

The Association for Children with a Disability is the peak Victorian organisation representing children with a disability and their families at all government levels on a broad range of issues including education, early intervention, respite, therapy services, aids and equipment, parent support, post-school transition issues, home and community care, recreation and palliative care. The Association provides support, advocacy and information via a bimonthly newsletter called "Noticeboard"; publications such as "Through the Maze" (which is a guide to benefits and services); "Helping You and Your Family" which outlines self-help strategies for parents of children with a disability; workshops and information forums. There is a website at www.acd.org.au. For more information,

☎ 9500 1232,

☎ freecall (for rural families) 1800 654 013.

5. Cerebral Palsy Support Network

The Cerebral Palsy Support Network aims to empower persons with cerebral palsy and their families, and also raise awareness of the issues that persons with cerebral palsy and their families experience. All persons on the committee are volunteers who either have cerebral palsy or have a family member with cerebral palsy. The Cerebral Palsy Support Network provides disability-specific information in a bimonthly newsletter, telephone information and support, information seminars, links to other members via regional contacts, a web site with links and on line services (cpsn@21century.com.au), support groups in local metropolitan areas, sibling groups, recreational groups and family social activities.

☎ 9348 2677.

6. Noah's Ark Toy Library and Family Resource

Noah's Ark provides early childhood intervention programs, family support, loan of specialist resources including toys and equipment, sibling groups and recreation programs. There are five metropolitan and ten rural sites.

☎ 9529 1466 for further information.

7. Children's Services Resource and Development Officer

Assists children with additional needs to access long day care, occasional care, family day care, before and after school care and school holiday programs. For information about your local service contact your local council or the Association for Children with a Disability,

☎ 9500 1232,

☎ freecall (for rural families) 1800 654 013.

8. Preschool Field Officer

Provides information, support and advice to parents and preschool staff, assistance in developing individual programs and transition to school. Contact your local council or early childhood service.

9. A.D.E.C.

Action on Disability in Ethnic Communities can provide support to families and people with a disability from non-English speaking backgrounds.

☎ 9383 5566.

10. Specific Home Help (in home respite)

Local councils through their specific home help or respite care service can provide family assistance and in home care for a child with cerebral palsy. Local government may also provide limited out of home respite services. Contact your local council.



11. Parent Support

This may be provided by consumer organisations such as:

- Association for Children with a Disability (see description above).
☎ 9500 1232,
☎ freecall (for rural families) 1800 654 013.
- Cerebral Palsy Support Network (see description above).
- Regional Parent Support Programs. Telephone Association for Children with a Disability for further details.
- Local informal support groups.

12. Early Choices

Early Choices programs provide flexible case management, respite and support packages to families who have a child with a severe disability and high support needs. The child must be under school age. The family may be linked with existing services or funding may be used to buy additional respite or support services. Families who have two children with disabilities may also qualify. Contact the Association for Children with a Disability for details of your local program.

☎ 9500 1232,
☎ freecall (for rural families) 1800 654 013.

13. Making a Difference

Making a Difference is a program that provides support for families caring for a child with a disability and with very high support needs. Families may be eligible if they are caring for a child aged between five and seventeen years, with a moderate to severe disability and complex support needs.

There is also a Making a Difference program for those aged 18 years and older. The program can link families to existing services and provide resources for the purchase of additional supports. Contact the Association for Children with a Disability for details of your local program.

☎ 9500 1232,
☎ freecall (for rural families) 1800 654 013.

14. Linkages

Linkages provides assistance and case management to people with a disability (of all ages) and their carers. The family may be linked to existing services, or funding may be provided to assist with individual needs (for example, personal care and respite), and accessing social activities (for example, transport to swimming classes). Contact the Association for Children with a Disability for details of your local program.

☎ 9500 1232,
☎ freecall (for rural families) 1800 654 013.

15. Equipment and Aids

Equipment and aids can sometimes be borrowed from local hospitals. Funding for purchasing equipment is provided through a State Government program called PADP (Program of Aids for Disabled People). There is generally a waiting list for PADP so you need to remember this when applying for equipment and think ahead about future needs.

- Yooralla's Equipment Services has three programs:
 - 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 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).

For further enquires about these programs, contact Yooralla's Equipment Services.

 9362 6111.

- TREC is a business unit of the Spastic Society and provides equipment and services which enhance the quality of life for people with disabilities including a wheelchair service centre and customised seating.
 9532 0611.
- The Equipment Recycling Network sells good second hand equipment for people with disabilities.
 9879 5211.
- TADVIC (Technical Aid to the Disabled) has volunteer members who design, construct or modify equipment for people with disabilities provided no commercially available product or service will meet their needs. There is no charge for the TADVIC service and clients are only asked to reimburse the volunteer for any cost of materials and travelling expenses incurred.
 9853 8655.

16. Disability Information Victoria

The internet site is www.disabilityinfo.org.au and

 1300 650 865.

Disability Information Victoria is a key resource for people with a disability, their families and their carers.

17. Financial Assistance

The Commonwealth Department of Social Security provides a number of allowances and pensions for eligible families and people with a disability. Some of these are:

- Carer Allowance
- Carer Payment
- Disability Support Pension (for people aged 16 years of age and older)
- Mobility Allowance (for people aged 16 years of age and older).

Apply to Centrelink for this. Centrelink has a central number for persons with disabilities and their families. Telephone 132717. The Association for Children with a Disability can also provide further information.

 9500 1232,

 freecall (for rural families) 1800 654 013.



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 provide information and resources about schooling for children with cerebral palsy. There are several publications that may be useful for families. "Going to School – the Move from Preschool to School for Children with Disabilities" is published by the Specialist Children's Services Unit, Victorian Government Department of Human Services and is available through the Association for Children with a Disability. A handbook to assist families of children with disabilities in the school setting is available through regional Department of Education offices and schools.

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. It is important that both parents and professionals keep an open mind about new approaches but also be prepared to critically examine their claims.

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 Royal Children's Hospital has a substantial cerebral palsy research program, spread over several different departments of the Hospital.

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 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.

other publications and websites that may be helpful

- Cerebral Palsy A Practical Guide. Marion Stanton. 1992. Optima.
- Children with Cerebral Palsy – A Parent's Guide. Edited by Elaine Geralis. 1998. Woodbine House.
- Handling the Young Cerebral Palsied Child at Home. Nancy Finnie. 1997. Butterworth-Heinemann.

There are three main websites for information about cerebral palsy.

- The first is the CP Resource Centre at <http://www.twinenterprises.com/bissell/cp.htm>
The CP Resource Centre is designed by Cynthia Bissell and includes Frequently Asked Questions, a series of articles and comprehensive links to other sources of information available on the net.
- The second site is the home page of CP Parents at <http://www.mindspring.com/~paul4/cpparent.htm>
CP Parents is a family-oriented mailing list for the discussion of any aspect of the care of a child with cerebral palsy. Archives of past discussions on CP Parents are available at <http://maelstrom.stjohns.edu/CGI/wa.exe?S1=cpparent>
- The third web site has book reviews, journal articles, articles by parents, and recommended resources on and off the net and is at http://www.comeunity.com/disability/cerebral_palsy/index.html



