Cerebral Palsy

What is cerebral palsy?

Doctors use the term cerebral palsy to refer to any one of a number of neurological disorders that appear in infancy or early childhood and permanently affect body movement and muscle coordination but aren't progressive, in other words, they don't get worse over time. The term cerebral refers to the two halves or hemispheres of the brain, in this case to the motor area of the brain's outer layer (called the cerebral cortex), the part of the brain that directs muscle movement; palsy refers to the loss or impairment of motor function.

Even though cerebral palsy affects muscle movement, it isn't caused by problems in the muscles or nerves. It is caused by abnormalities inside the brain that disrupt the brain's ability to control movement and posture.

In some cases of cerebral palsy, the cerebral motor cortex hasn't developed normally during fetal growth. In others, the damage is a result of injury to the brain either before, during, or after birth. In either case, the damage is not repairable and the disabilities that result are permanent.

Children with cerebral palsy exhibit a wide variety of symptoms, including:

- lack of muscle coordination when performing voluntary movements (ataxia);
- stiff or tight muscles and exaggerated reflexes (spasticity);
- walking with one foot or leg dragging;
- walking on the toes, a crouched gait, or a "scissored" gait;
- variations in muscle tone, either too stiff or too floppy;
- excessive drooling or difficulties swallowing or speaking;
- shaking (tremor) or random involuntary movements; and
- difficulty with precise motions, such as writing or buttoning a shirt.

The symptoms of cerebral palsy differ in type and severity from one person to the next, and may even change in an individual over time. Some people with cerebral palsy also have other medical disorders, including mental retardation, seizures, impaired vision or hearing, and abnormal physical sensations or perceptions.

Cerebral palsy doesn't always cause profound disabilities. While one child with severe cerebral palsy might be unable to walk and need extensive, lifelong care, another with mild cerebral palsy might be only slightly awkward and require no special assistance.

Cerebral palsy isn't a disease. It isn't contagious and it can't be passed from one generation to the next. There is no cure for cerebral palsy, but supportive treatments, medications, and surgery can help many individuals improve their motor skills and ability to communicate with the world.

How many people have this disorder?

The United Cerebral Palsy (UCP) Foundation estimates that nearly 800,000 children and

adults in the United States are living with one or more of the symptoms of cerebral palsy. According to the federal government's Centers for Disease Control and Prevention, each year about 10,000 babies born in the United States will develop cerebral palsy.

Despite advances in preventing and treating certain causes of cerebral palsy, the percentage of babies who develop the condition has remained the same over the past 30 years. Improved care in neonatal intensive-care units has resulted in higher survival rates for very low birthweight babies. Many of these infants will have developmental defects in their nervous systems or suffer brain damage that will cause the characteristic symptoms of cerebral palsy.

What are the early signs?
The early signs of cerebral palsy usually appear before a child reaches 3 years of age. Parents are often the first to suspect that their baby's motor skills aren't developing normally. Infants with cerebral palsy frequently have developmental delay, in which they are slow to reach developmental milestones such as learning to roll over, sit, crawl, smile, or walk. Some infants with cerebral palsy have abnormal muscle tone as infants. Decreased muscle tone (hypotonia) can make them appear relaxed, even floppy. Increased muscle tone (hypertonia) can make them seem stiff or rigid. In some cases, an early period of hypotonia will progress to hypertonia after the first 2 to 3 months of life. Children with cerebral palsy may also have unusual posture or favor one side of the body when they move.

Parents who are concerned about their baby's development for any reason should contact their pediatrician. A doctor can determine the difference between a normal lag in development and a delay that could indicate cerebral palsy.

What causes cerebral palsy?
The majority of children with cerebral palsy are born with it, although it may not be detected until months or years later. This is called congenital cerebral palsy. In the past, if doctors couldn't identify another cause, they attributed most cases of congenital cerebral palsy to problems or complications during labor that caused asphyxia (a lack of oxygen) during birth. However, extensive research by NINDS scientists and others has shown that few babies who experience asphyxia during birth grow up to have cerebral palsy or any other neurological disorder. Birth complications, including asphyxia, are now estimated to account for only 5 to 10 percent of the babies born with congenital cerebral palsy.

A small number of children have acquired cerebral palsy, which means the disorder begins after birth. In these cases, doctors can often pinpoint a specific reason for the problem, such as brain damage in the first few months or years of life, brain infections such as bacterial meningitis or viral encephalitis, or head injury from a motor vehicle accident, a fall, or child abuse.

What causes the remaining 90 to 95 percent? Research has given us a bigger and more accurate picture of the kinds of events that can happen during early fetal development, or just before, during, or after birth, that cause the particular types of brain damage that will

result in congenital cerebral palsy. There are multiple reasons why cerebral palsy happens – as the result of genetic abnormalities, maternal infections or fevers, or fetal injury, for example. But in all cases the disorder is the result of four types of brain damage that cause its characteristic symptoms:

Damage to the white matter of the brain (periventricular leukomalacia [PVL]). The white matter of the brain is responsible for transmitting signals inside the brain and to the rest of the body. PVL describes a type of damage that looks like tiny holes in the white matter of an infant's brain. These gaps in brain tissue interfere with the normal transmission of signals. There are a number of events that can cause PVL, including maternal or fetal infection. Researchers have also identified a period of selective vulnerability in the developing fetal brain, a period of time between 26 and 34 weeks of gestation, in which periventricular white matter is particularly sensitive to insults and injury.

Abnormal development of the brain (cerebral dysgenesis). Any interruption of the normal process of brain growth during fetal development can cause brain malformations that interfere with the transmission of brain signals. The fetal brain is particularly vulnerable during the first 20 weeks of development. Mutations in the genes that control brain development during this early period can keep the brain from developing normally. Infections, fevers, trauma, or other conditions that cause unhealthy conditions in the womb also put an unborn baby's nervous system at risk.

Bleeding in the brain (intracranial hemorrhage). Intracranial hemorrhage describes bleeding inside the brain caused by blocked or broken blood vessels. A common cause of this kind of damage is fetal stroke. Some babies suffer a stroke while still in the womb because of blood clots in the placenta that block blood flow. Other types of fetal stroke are caused by malformed or weak blood vessels in the brain or by blood-clotting abnormalities. Maternal high blood pressure (hypertension) is a common medical disorder during pregnancy that has been known to cause fetal stroke. Maternal infection, especially pelvic inflammatory disease, has also been shown to increase the risk of fetal stroke.

Brain damage caused by a lack of oxygen in the brain (hypoxic-ischemic encephalopathy or intrapartum asphyxia). Asphyxia, a lack of oxygen in the brain caused by an interruption in breathing or poor oxygen supply, is common in babies due to the stress of labor and delivery. But even though a newborn's blood is equipped to compensate for short-term low levels of oxygen, if the supply of oxygen is cut off or reduced for lengthy periods, an infant can develop a type of brain damage called hypoxic-ischemic encephalopathy, which destroys tissue in the cerebral motor cortex and other areas of the brain. This kind of damage can also be caused by severe maternal low blood pressure, rupture of the uterus, detachment of the placenta, or problems involving the umbilical cord.

What are the risk factors?
Just as there are particular types of brain damage that cause cerebral palsy, there are also

certain medical conditions or events that can happen during pregnancy and delivery that will increase a baby's risk of being born with cerebral palsy. Research scientists have examined thousands of expectant mothers, followed them through childbirth, and monitored their children's early neurological development to establish these risk factors. If a mother or her baby has any of these risk factors, it doesn't mean that cerebral palsy is inevitable, but it does increase the chance for the kinds of brain damage that cause it.

Low birthweight and premature birth. The risk of cerebral palsy is higher among babies who weigh less than 5 ½ pounds at birth or are born less than 37 weeks into pregnancy. The risk increases as birthweight falls or weeks of gestation shorten. Intensive care for premature infants has improved dramatically over the course of the past 30 years. Babies born extremely early are surviving, but with medical problems that can put them at risk for cerebral palsy. Although normal- or heavier-weight babies are at relatively low individual risk for cerebral palsy, term or near-term babies still make up half of the infants born with the condition.

Multiple births. Twins, triplets, and other multiple births -- even those born at term -- are linked to an increased risk of cerebral palsy. The death of a baby's twin or triplet further increases the risk.

Infections during pregnancy. Infectious diseases caused by viruses, such as toxoplasmosis, rubella (German measles), cytomegalovirus, and herpes, can infect the womb and placenta. Researchers currently think that maternal infection leads to elevated levels of immune system cells called cytokines that circulate in the brain and blood of the fetus. Cytokines respond to infection by triggering inflammation. Inflammation may then go on to cause central nervous system damage in an unborn baby. Maternal fever during pregnancy or delivery can also set off this kind of inflammatory response.

Blood type incompatibility. Rh incompatibility is a condition that develops when a mother's Rh blood type (either positive or negative) is different from the blood type of her baby. Because blood cells from the baby and mother mix during pregnancy, if a mother is negative and her baby positive, for example, the mother's system won't tolerate the presence of Rh-positive red blood cells. Her body will begin to make antibodies that will attack and kill her baby's blood cells. Rh incompatibility is routinely tested for and treated in the United States , but conditions in other countries continue to keep blood type incompatibility a risk factor for cerebral palsy.

Exposure to toxic substances. Mothers who have been exposed to toxic substances during pregnancy, such as methyl mercury, are at a heightened risk of having a baby with cerebral palsy.

Mothers with thyroid abnormalities, mental retardation, or seizures. Mothers with any of these conditions are slightly more likely to have a child with cerebral palsy.

There are also medical conditions during labor and delivery, and immediately after delivery, that act as warning signs for an increased risk of cerebral palsy. Knowing these

warning signs helps doctors keep a close eye on children who face a higher risk. However, parents shouldn't become too alarmed if their baby has one or more of these conditions at birth. Most of these children will not develop cerebral palsy. Warning signs include:

Breech presentation. Babies with cerebral palsy are more likely to be in a breech position (feet first) instead of head first at the beginning of labor.

Complicated labor and delivery. A baby who has vascular or respiratory problems during labor and delivery may already have suffered brain damage or abnormalities.

Small for gestational age. Babies born smaller than normal for their gestational age are at risk for cerebral palsy because of factors that kept them from growing naturally in the womb.

Low Apgar score. The Apgar score is a numbered rating that reflects a newborn's condition. To determine an Apgar score, doctors periodically check a baby's heart rate, breathing, muscle tone, reflexes, and skin color during the first minutes after birth. They then assign points; the higher the score, the more normal a baby's condition. A low score at 10-20 minutes after delivery is often considered an important sign of potential problems such as cerebral palsy.

Jaundice. More than 50 percent of newborns develop jaundice after birth when bilirubin, a substance normally found in bile, builds up faster than their livers can break it down and pass it from the body. Severe, untreated jaundice can cause a neurological condition known as kernicterus, which kills brain cells and can cause deafness and cerebral palsy.

Seizures. An infant who has seizures faces a higher risk of being diagnosed later in childhood with cerebral palsy.

Can cerebral palsy be prevented?
Cerebral palsy related to genetic abnormalities is not preventable, but a few of the risk factors for congenital cerebral palsy can be managed or avoided. For example, rubella, or German measles, is preventable if women are vaccinated against the disease before becoming pregnant. Rh incompatibilities can also be managed early in pregnancy. But there are still risk factors that can't be controlled or avoided in spite of medical intervention.

For example, the use of electronic fetal monitoring machines to keep track of an unborn baby's heartbeat during labor, and the use of emergency cesarean section surgery when there are significant signs of fetal distress, haven't lowered the numbers of babies born with cerebral palsy. Interventions to treat other prenatal causes of cerebral palsy, such as therapies to prevent prenatal stroke or antibiotics to cure intrauterine infections, are either difficult to administer or haven't yet been proven to lower the risk of cerebral palsy in vulnerable infants.

Fortunately, acquired cerebral palsy, often due to head injury, is preventable using common safety tactics, such as using car seats for infants and toddlers, and making sure young children wear helmets when they ride bicycles. In addition, common sense measures around the household, such as supervising babies and young children closely when they bathe, can reduce the risk of accidental injury.

Despite the best efforts of parents and physicians, however, children will still be born with cerebral palsy. Since in many cases the cause or causes of cerebral palsy aren't fully known, little can currently be done to prevent it. As investigators learn more about the causes of cerebral palsy through basic and clinical research, doctors and parents will know more about how to prevent this disorder.

What are the different forms?
The specific forms of cerebral palsy are determined by the extent, type, and location of a child's abnormalities. Doctors classify cerebral palsy according to the type of movement disorder involved -- spastic (stiff muscles), athetoid (writhing movements), or ataxic (poor balance and coordination) -- plus any additional symptoms. Doctors will often describe the type of cerebral palsy a child has based on which limbs are affected. The names of the most common forms of cerebral palsy use Latin terms to describe the location or number of affected limbs, combined with the words for weakened (paresis) or paralyzed (plegia). For example, hemiparesis (hemi = half) indicates that only one side of the body is weakened. Quadriplegia (quad = four) means all four limbs are paralyzed.

Spastic hemiplegia/hemiparesis. This type of cerebral palsy typically affects the arm and hand on one side of the body, but it can also include the leg. Children with spastic hemiplegia generally walk later and on tip-toe because of tight heel tendons. The arm and leg of the affected side are frequently shorter and thinner. Some children will develop an abnormal curvature of the spine (scoliosis). Depending on the location of the brain damage, a child with spastic hemiplegia may also have seizures. Speech will be delayed and, at best, may be competent, but intelligence is usually normal.

Spastic diplegia/diparesis. In this type of cerebral palsy, muscle stiffness is predominantly in the legs and less severely affects the arms and face, although the hands may be clumsy. Tendon reflexes are hyperactive. Toes point up. Tightness in certain leg muscles makes the legs move like the arms of a scissor. Children with this kind of cerebral palsy may require a walker or leg braces. Intelligence and language skills are usually normal.

Spastic quadriplegia/quadriparesis. This is the most severe form of cerebral palsy, often associated with moderate-to-severe mental retardation. It is caused by widespread damage to the brain or significant brain malformations. Children will often have severe stiffness in their limbs but a floppy neck. They are rarely able to walk. Speaking and being understood are difficult. Seizures can be frequent and hard to control.

Dyskinetic cerebral palsy (also includes athetoid, choreoathetoid, and dystonic cerebral palsies). This type of cerebral palsy is characterized by slow and uncontrollable

writhing movements of the hands, feet, arms, or legs. In some children, hyperactivity in the muscles of the face and tongue makes them grimace or drool. They find it difficult to sit straight or walk. Children may also have problems coordinating the muscle movements required for speaking. Intelligence is rarely affected in these forms of cerebral palsy.

Ataxic cerebral palsy. This rare type of cerebral palsy affects balance and depth perception. Children will often have poor coordination and walk unsteadily with a wide-based gait, placing their feet unusually far apart. They have difficulty with quick or precise movements, such as writing or buttoning a shirt. They may also have intention tremor, in which a voluntary movement, such as reaching for a book, is accompanied by trembling that gets worse the closer their hand gets to the object.

Mixed types. It is common for children to have symptoms that don't correspond to any single type of cerebral palsy. Their symptoms are a mix of types. For example, a child with mixed cerebral palsy may have some muscles that are too tight and others that are too relaxed, creating a mix of stiffness and floppiness.

What other medical disorders are associated with cerebral palsy?
Many individuals with cerebral palsy have no additional medical disorders. However, because cerebral palsy involves the brain and the brain controls so many of the body's functions, cerebral palsy can also cause seizures, impair intellectual development, and affect vision, hearing, and behavior. Coping with these disabilities may be even more of a challenge than coping with the motor impairments of cerebral palsy.

These additional medical conditions include:
Mental retardation. Two-thirds of individuals with cerebral palsy will be intellectually impaired. Mental impairment is more common among those with spastic quadriplegia than in those with other types of cerebral palsy, and children who have epilepsy and an abnormal electroencephalogram (EEG) or MRI are also more likely to have mental retardation.

Seizure disorder. As many as half of all children with cerebral palsy have seizures. Seizures can take the form of the classic convulsions of tonic-clonic seizures or the less obvious focal (partial) seizures, in which the only symptoms may be muscle twitches or mental confusion.

Delayed growth and development. A syndrome called failure to thrive is common in children with moderate-to-severe cerebral palsy, especially those with spastic quadriparesis. Failure to thrive is a general term doctors use to describe children who lag behind in growth and development. In babies this lag usually takes the form of too little weight gain. In young children it can appear as abnormal shortness, and in teenagers it may appear as a combination of shortness and lack of sexual development.

In addition, the muscles and limbs affected by cerebral palsy tend to be smaller than normal. This is especially noticeable in children with spastic hemiplegia because limbs

on the affected side of the body may not grow as quickly or as long as those on the normal side.

Spinal deformities. Deformities of the spine -- curvature (scoliosis), humpback (kyphosis), and saddle back (lordosis) -- are associated with cerebral palsy. Spinal deformities can make sitting, standing, and walking difficult and cause chronic back pain.

Impaired vision, hearing, or speech. A large number of children with cerebral palsy have strabismus, commonly called "cross eyes," in which the eyes are misaligned because of differences between the left and right eye muscles. In an adult, strabismus causes double vision. In children, the brain adapts to the condition by ignoring signals from one of the misaligned eyes. Untreated, this can lead to poor vision in one eye and can interfere with the ability to judge distance. In some cases, doctors will recommend surgery to realign the muscles.

Children with hemiparesis may have hemianopia, which is defective vision or blindness that blurs the normal field of vision in one eye. In homonymous hemianopia, the impairment affects the same part of the visual field in both eyes.

Impaired hearing is also more frequent among those with cerebral palsy than in the general population. Speech and language disorders, such as difficulty forming words and speaking clearly, are present in more than a third of those with cerebral palsy.

Drooling. Some individuals with cerebral palsy drool because they have poor control of the muscles of the throat, mouth, and tongue. Drooling can cause severe skin irritation. Because it is socially unacceptable, drooling may also isolate children from their peers.

Incontinence. A common complication of cerebral palsy is incontinence, caused by poor control of the muscles that keep the bladder closed. Incontinence can take the form of bed-wetting, uncontrolled urination during physical activities, or slow leaking of urine throughout the day.

Abnormal sensations and perceptions. Some children with cerebral palsy have difficulty feeling simple sensations, such as touch. They may have stereognosia, which makes it difficult to perceive and identify objects using only the sense of touch. A child with stereognosia, for example, would have trouble closing his eyes and sensing the difference between a hard ball or a sponge ball placed in his hand.

How does a doctor diagnose cerebral palsy?
Early signs of cerebral palsy may be present from birth. Most children with cerebral palsy are diagnosed during the first 2 years of life. But if a child's symptoms are mild, it can be difficult for a doctor to make a reliable diagnosis before the age of 4 or 5. Nevertheless, if a doctor suspects cerebral palsy, he or she will most likely schedule an appointment to observe the child and talk to the parents about their child's physical and behavioral development.

Doctors diagnose cerebral palsy by evaluating a child's motor skills and taking a careful and thorough look at their medical history. In addition to checking for the most characteristic symptoms -- slow development, abnormal muscle tone, and unusual posture -- a doctor also has to rule out other disorders that could cause similar symptoms. Most important, a doctor has to determine that the child's condition is not getting worse. Although symptoms may change over time, cerebral palsy by definition is not progressive. If a child is continuously losing motor skills, the problem more likely begins elsewhere – such as a genetic or muscle disease, metabolism disorder, or tumors in the nervous system. A comprehensive medical history, special diagnostic tests, and, in some cases, repeated check-ups can help confirm that other disorders are not at fault.

Additional tests are often used to rule out other movement disorders that could cause the same symptoms as cerebral palsy. Neuroimaging techniques that allow doctors to look into the brain (such as an MRI scan) can detect abnormalities that indicate a potentially treatable movement disorder. If it is cerebral palsy, an MRI scan can also show a doctor the location and type of brain damage.

Neuroimaging methods include:
• Cranial ultrasound. This test is used for high-risk premature infants because it is the least intrusive of the imaging techniques, although it is not as successful as the two methods described below at capturing subtle changes in white matter – the type of brain tissue that is damaged in cerebral palsy.
• Computed tomography (CT) scan. This technique creates images that show the structure of the brain and the areas of damage.
• Magnetic resonance imaging (MRI) scan. This test uses a computer, a magnetic field, and radio waves to create an anatomical picture of the brain's tissues and structures. Doctors prefer MRI imaging because it offers finer levels of detail.
On rare occasions, metabolic disorders can masquerade as cerebral palsy and some children will require additional tests to rule them out. Most of the childhood metabolic disorders have characteristic brain abnormalities or malformations that will show up in an MRI.

Other types of disorders can also be mistaken for cerebral palsy. For example, coagulation disorders (which prevent blood from clotting) can cause prenatal or perinatal strokes that damage the brain and cause symptoms characteristic of cerebral palsy. Because stroke is so often the cause of hemiplegic cerebral palsy, a doctor may find it necessary to perform diagnostic testing on children with this kind of cerebral palsy to rule out the presence of a coagulation disorder. If left undiagnosed, coagulation disorders can cause additional strokes and more extensive brain damage.

To confirm a diagnosis of cerebral palsy, a doctor may refer a child to additional doctors with specialized knowledge and training, such as a child neurologist, developmental pediatrician, ophthalmologist (eye doctor), or otologist (ear doctor). Additional observations help a doctor make a more accurate diagnosis and begin to develop a specific plan for treatment.

How is cerebral palsy managed?
Cerebral palsy can't be cured, but treatment will often improve a child's capabilities. Many children go on to enjoy near-normal adult lives if their disabilities are properly managed. In general, the earlier treatment begins, the better chance children have of overcoming developmental disabilities or learning new ways to accomplish the tasks that challenge them.

There is no standard therapy that works for every individual with cerebral palsy. Once the diagnosis is made, and the type of cerebral palsy is determined, a team of health care professionals will work with a child and his or her parents to identify specific impairments and needs, and then develop an appropriate plan to tackle the core disabilities that affect the child's quality of life.

A comprehensive management plan will pull in a combination of health professionals with expertise in the following:
physical therapy to improve walking and gait, stretch spastic muscles, and prevent deformities;
occupational therapy to develop compensating tactics for everyday activities such as dressing, going to school, and participating in day-to-day activities;
speech therapy to address swallowing disorders, speech impediments, and other obstacles to communication;
counseling and behavioral therapy to address emotional and psychological needs and help children cope emotionally with their disabilities;
drugs to control seizures, relax muscle spasms, and alleviate pain;
surgery to correct anatomical abnormalities or release tight muscles;
braces and other orthotic devices to compensate for muscle imbalance, improve posture and walking, and increase independent mobility;
mechanical aids such as wheelchairs and rolling walkers for individuals who are not independently mobile; and
communication aids such as computers, voice synthesizers, or symbol boards to allow severely impaired individuals to communicate with others.

Doctors use tests and evaluation scales to determine a child's level of disability, and then make decisions about the types of treatments and the best timing and strategy for interventions. Early intervention programs typically provide all the required therapies within a single treatment center. Centers also focus on parents' needs, often offering support groups, babysitting services, and respite care.

The members of the treatment team for a child with cerebral palsy will most likely include the following:
A **physician**, such as a pediatrician, pediatric neurologist, or pediatric physiatrist, who is trained to help developmentally disabled children. This doctor, who often acts as the leader of the treatment team, integrates the professional advice of all team members into a comprehensive treatment plan, makes sure the plan is implemented properly, and follows the child's progress over a number of years.
An **orthopedist**, a surgeon who specializes in treating the bones, muscles, tendons, and

other parts of the skeletal system. An orthopedist is often brought in to diagnose and treat muscle problems associated with cerebral palsy.
A **physical therapist**, who designs and puts into practice special exercise programs to improve strength and functional mobility.
An **occupational therapist**, who teaches the skills necessary for day-to-day living, school, and work.
A **speech and language pathologist**, who specializes in diagnosing and treating disabilities relating to difficulties with swallowing and communication.
A **social worker**, who helps individuals and their families locate community assistance and education programs.
A **psychologist**, who helps individuals and their families cope with the special stresses and demands of cerebral palsy. In some cases, psychologists may also oversee therapy to modify unhelpful or destructive behaviors.
An **educator**, who may play an especially important role when mental retardation or learning disabilities present a challenge to education.

Regardless of age or the types of therapy that are used, treatment doesn't end when an individual with cerebral palsy leaves the treatment center. Most of the work is done at home. Members of the treatment team often act as coaches, giving parents and children techniques and strategies to practice at home. Studies have shown that family support and personal determination are two of the most important factors in helping individuals with cerebral palsy reach their long-term goals.

While mastering specific skills is an important focus of treatment on a day-to-day basis, the ultimate goal is to help children grow into adulthood with as much independence as possible.

As a child with cerebral palsy grows older, the need for therapy and the kinds of therapies required, as well as support services, will likely change. Counseling for emotional and psychological challenges may be needed at any age, but is often most critical during adolescence. Depending on their physical and intellectual abilities, adults may need help finding attendants to care for them, a place to live, a job, and a way to get to their place of employment.

Addressing the needs of parents and caregivers is also an important component of the treatment plan. The well-being of an individual with cerebral palsy depends upon the strength and well-being of his or her family. For parents to accept a child's disabilities and come to grips with the extent of their caregiving responsibilities will take time and support from health care professionals. Family-centered programs in hospitals and clinics and community-based organizations usually work together with families to help them make well-informed decisions about the services they need. They also coordinate services to get the most out of treatment.

A good program will encourage the open exchange of information, offer respectful and supportive care, encourage partnerships between parents and the health care professionals

they work with, and acknowledge that although medical specialists may be the experts, it's parents who know their children best.

Do adults with cerebral palsy face special health challenges?
Before the mid-twentieth century, few children with cerebral palsy survived to adulthood. Now, because of improvements in medical care, rehabilitation, and assistive technologies, 65 to 90 percent of children with cerebral palsy live into their adult years. This increase in life expectancy is often accompanied by a rise in medical and functional problems – some of them beginning at a relatively early age – including the following:

Premature aging. The majority of individuals with cerebral palsy will experience some form of premature aging by the time they reach their 40s because of the extra stress and strain the disease puts upon their bodies. The developmental delays that often accompany cerebral palsy keep some organ systems from developing to their full capacity and level of performance. As a consequence, organ systems such as the cardiovascular system (the heart, veins, and arteries) and pulmonary system (lungs) have to work harder and they age prematurely.

Functional issues at work. The day-to-day challenges of the workplace are likely to increase as an employed individual with cerebral palsy reaches middle age. Some individuals will be able to continue working with accommodations such as an adjusted work schedule, assistive equipment, or frequent rest periods. Early retirement may be necessary for others.

Depression. Mental health issues can also be of concern as someone with cerebral palsy grows older. The rate of depression is three to four times higher in people with disabilities such as cerebral palsy. It appears to be related not so much to the severity of their disabilities, but to how well they cope with them. The amount of emotional support someone has, how successful they are at coping with disappointment and stress, and whether or not they have an optimistic outlook about the future all have a significant impact on mental health.

Post-impairment syndrome. Most adults with cerebral palsy experience what is called post-impairment syndrome, a combination of pain, fatigue, and weakness due to muscle abnormalities, bone deformities, overuse syndromes (sometimes also called repetitive motion injuries), and arthritis. Fatigue is often a challenge, since individuals with cerebral palsy use three to five times the amount of energy that able-bodied people use when they walk and move about.

Osteoarthritis and degenerative arthritis. Musculoskeletal abnormalities that may not produce discomfort during childhood can cause pain in adulthood. For example, the abnormal relationships between joint surfaces and excessive joint compression can lead to the early development of painful osteoarthritis and degenerative arthritis. Individuals with cerebral palsy also have limited strength and restricted patterns of movement, which puts them at risk for overuse syndromes and nerve entrapments.

Pain. Issues related to pain often go unrecognized by health care providers since individuals with cerebral palsy may not be able to describe the extent or location of their pain. Pain can be acute or chronic, and is experienced most commonly in the hips, knees, ankles, and the upper and lower back. Individuals with spastic cerebral palsy have an increased number of painful sites and worse pain than those with other types of cerebral palsy. The best treatment for pain due to musculoskeletal abnormalities is preventive – correcting skeletal and muscle abnormalities early in life to avoid the progressive accumulation of stress and strain that causes pain. Dislocated hips, which are particularly likely to cause pain, can be surgically repaired. If it is managed properly, pain does not have to become a chronic condition.

Other medical conditions. Adults have higher than normal rates of other medical conditions secondary to their cerebral palsy, such as hypertension, incontinence, bladder dysfunction, and swallowing difficulties. Curvature of the spine (scoliosis) is likely to progress after puberty, when bones have matured into their final shape and size. People with cerebral palsy also have a higher incidence of bone fractures, occurring most frequently during physical therapy sessions. A combination of mouth breathing, poor hygiene, and abnormalities in tooth enamel increase the risk of cavities and periodontal disease. Twenty-five percent to 39 percent of adults with cerebral palsy have vision problems; eight to 18 percent have hearing problems.

Because of their unique medical situations, adults with cerebral palsy benefit from regular visits to their doctor and ongoing evaluation of their physical status. It is important to evaluate physical complaints to make sure they are not the result of underlying conditions. For example, adults with cerebral palsy are likely to experience fatigue, but fatigue can also be due to undiagnosed medical problems that could be treated and reversed.

Because many individuals with cerebral palsy outlive their primary caregiver, the issue of long-term care and support should be taken into account and planned for.

Information resources

BRAIN
P.O. Box 5801
Bethesda, MD 20824
(800) 352-9424
http://www.ninds.nih.gov

March of Dimes Birth Defects Foundation
1275 Mamaroneck Avenue
White Plains, NY 10605
askus@marchofdimes.com
http://www.marchofdimes.com
Tel: 914-428-7100 888-MODIMES (663-4637)
Fax: 914-428-8203

Easter Seals
230 West Monroe Street, Suite 1800
Chicago, IL 60606-4802
info@easterseals.com
http://www.easterseals.com
Tel: 312-726-6200 800-221-6827
Fax: 312-726-1494

United Cerebral Palsy (UCP) Research & Education Foundation
1600 L Street, NW, Suite 700
Washington, DC 20036
national@ucp.org
http://www.ucp.org
Tel: 202-973-7140 800-USA-5UCP (872-5827)
Fax: 202-776-0414

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