



# Life Care Planning for the Child with Cerebral Palsy

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## Abstract

This chapter outlines the purpose and development of a life care plan (LCP) for an individual with cerebral palsy. Potential care needs and their most common treatment options throughout the life span are described. In addition, it explains how the LCP can serve as a guide for families to access community resources and

government benefits. The chapter presents the implementation of an LCP by a nurse case manager working with a child with cerebral palsy.

### Keywords

Cerebral palsy · Life care planning · Case management · Benefits · Community

## Introduction

A life care plan is a dynamic living document outlining the plan of care for an individual's needs throughout his/her life. It is most often developed (sometimes as a result of litigation) for planning for long-term needs of patients with injuries or chronic conditions requiring complex ongoing healthcare interventions and management. The life care plan is considered a flexible document that should be modified with the growth and development of the individual with cerebral palsy (CP).

## Definition of a Life Care Plan

The life care plan is a dynamic document based upon published standards of practice, comprehensive assessment, data analysis, and research, which provides an organized, concise plan for current and future needs with associated costs for individuals who have experienced catastrophic injury or have chronic health care needs. (International Association of Rehabilitation Professionals 2009)

## Purpose of a Life Care Plan

The life care plan that is developed as a result of a lawsuit identifies monies available for future care needs, but it is intended to be used to augment medical insurance and/or community, state or federal benefits, or resources. There are instances when the physician's recommended treatment may not be authorized by the insurance company or payer source. The funds from a special needs trust set aside by family or lawsuit can then be

used to provide out-of-network services and/or additional evaluations, treatment, therapies, and interventions.

Once monies are awarded or designated, it is essential that these dollars are used to meet the specific unique needs of the individual, rather than those of the family. For this reason, these funds will need to be protected in one of several ways:

- A **special needs trust** is created to ensure that the injured party has access to community, state, and federal services which may be limited by existence of financial income or resources. A special needs trust should be prepared by an attorney specially trained to ensure that all benefits are protected. If the individual is a minor or adult who lacks capacity, then a court petition will be required to establish the trust.
- **Blocked account** is a petition filed to allow the court to oversee the disbursement of funds on behalf of a minor or adult with a disability. If the funds are held in a blocked account, they can be reached without a court order and are available to the minor once age 18 is reached.
- **Minor's compromise** is a petition filed with the court to ask the court to approve settlement of a case in which the minor is the plaintiff. The court has supervision over a settlement or compromise and is generally held in Civil Court.
- **Guardianship** or **conservatorship** established by an individual who has been identified to serve as the guardian (for children under age 18) or conservator (for an individual age 18 or older) of the monies and is bonded to ensure protection of the money against abuse.
- **ABLE accounts** are tax-advantaged savings accounts for individuals with disabilities and their families, with a maximum contribution of \$15,000 per year. The ABLE Act limits eligibility to individuals with significant disabilities with an age of onset of disability before turning 26 years of age. If the age criteria are met and the receiving benefits are already under SSI and/or SSDI, the individual is automatically eligible to establish an ABLE account.

A life care plan serves different purposes for families with a child with CP. It can assist in the application for a special needs trust. It can serve as a guide for the family in identifying the types of physicians, frequencies of therapies, services, and equipment that individuals will need at different stages of their lives. It can serve as a guideline for the trustee or administrator in planning for current and future care needs ensuring that resources are available over the life span of the individual. Often the trustee will use the life care plan as the foundation for the rationale of purchasing or going outside of covered services provided by a health plan or to identify appropriate trust expenditures.

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## Goals and Environment

CP is a disorder of movement, muscle tone, or posture; therefore signs and symptoms can vary greatly. (*For detailed “► Classification Terminology in Cerebral Palsy,” see Sect. 1.4 “Pathology and Diagnosis Overview: Diagnosis.”*)

The life care plan can assist the family and healthcare providers as a guide for the care and treatment through the comprehensive array of health services required, spanning all levels or intensity of care and covering all stages of life. It includes recommendations for all functional tasks, such as mobility, gross and fine motor function, communication, etc.

## Healthcare Providers

An interdisciplinary team of healthcare providers is required to meet the physical, emotional, and psychological needs and maximize function while ensuring safety and improving the quality of outcomes of the child or adult with CP. The following providers are part of the core members of the interdisciplinary team and coordinate treatment for the individual with CP on a regular basis:

A **physical medicine and rehabilitation physician/physiatrist** to oversee the treatment plan

by facilitating therapy and medication management and referrals to specialists

A **nurse case manager** to coordinate the implementation and modification of the treatment plan while assisting in navigating the healthcare and school system, attendant and professional services, as well as state and federal programs

An **orthopedic surgeon** to identify musculoskeletal issues and treatment alternatives

A **neurologist** in treating seizure disorders

An **orthotist** for the manufacture or modification of braces or supports

A **psychologist** to work with the child/adult and/or family to provide support and treatment

A **dentist** to provide additional treatment due to oral-motor impairment and medications impacting dental hygiene, which may require sedation or anesthesia in the hospital setting

The following specialists may be needed in the course of the lifetime of an individual with CP, depending on secondary medical problems:

An **urologist** to evaluate and treat underlying pathology for urinary incontinence

A **developmental pediatrician** to identify growth and developmental delays with treatment recommendations using a biopsychosocial perspective

A **neuropsychologist** to assist the individual with CP and the family in determining educational and future life care needs based on neurocognitive issues

A **psychiatrist** to evaluate and prescribe medication designed to treat hyperactivity, anxiety, depression, or issues that impact functional outcomes and independence

A **gastroenterologist** to treat gastrointestinal issues such as reflux and constipation

A **nutritionist/dietician** if oral-motor or cognitive dysfunction impacts nutritional balance

A **sleep specialist** to identify and treat disorders interfering with the sleep cycle

An **ophthalmologist/optometrist** to provide treatment for oculomotor abnormalities and vision impairment

An **otolaryngologist/audiologist** to evaluate for possible hearing impairments and identify appropriate interventions

## Treatment Interventions

Typical growth and development patterns of a child with CP are altered, resulting in deformities of bones, joints, tendons, and muscles. CP-specific growth charts are available through the CDC. Spasticity and/or pain may affect function. At a young age, these issues can be managed with noninvasive treatments, but as the child develops, the deformity may result in impairments or health conditions warranting surgical intervention.

With any treatment intervention, the goal is to optimize function while ensuring safety, fostering self-care, and increasing or maximizing overall quality of life. Many of the interventions may focus on reducing muscle tightness, preventing or treating contractures, reducing pain, and identifying areas that may require assistance for activities of daily living, such as promoting cleanliness and assisting with bathing areas difficult to access (i.e., palms of hands or perineal care).

### Common Nonsurgical Interventions

A life care plan may include one or more of the following nonsurgical interventions which are discussed in detail in other chapters:

PT, OT, and speech therapy are often begun as part of an early intervention program and, for the child with CP, are usually part of their treatment throughout childhood. More intensive follow-up physical and/or occupational therapy must be included in life care plan after serial casting, botulinum toxin injections, or surgery.

### Common Orthopedic Surgical Interventions

After nonsurgical treatment interventions have been explored or implemented, surgical intervention may be considered to maintain and/or improve alignment, mobility, and pain relief and maximize gross and fine motor function. The following examples are discussed in detail

throughout the chapters. The life care plan may include:

An **osteotomy** to correct hip dislocation. In the post-op period, bowel and bladder management and wheelchair equipment with elevating footrest will usually be required.

A **spinal fusion** to align and/or stabilize the spine may necessitate home health aides during the recovery period.

**Tendon lengthening/release** may require immobilization for several weeks following the surgery. Adequate support for these care needs is to be included in the life care plan. Splinting and/or bracing may still be indicated post-surgery and/or for long-term maintenance.

**Tendon transfer** may be considered for improved function or hygiene.

**Selective dorsal rhizotomy** for excessive muscle tone or tightness.

## Diagnostics

Periodic **hip x-rays** may be indicated especially if a child is not walking to determine if the hips remain in the sockets. The American Academy of CP and developmental medicine have hip screening guidelines based on the severity of the CP. Yearly **spine x-ray** may be required until growth is completed to determine need for bracing or scoliosis surgery. **EEG (electroencephalography)** may be necessary if the individual with CP has a seizure disorder. **Hearing and vision screening/testing** might be needed throughout an individual's lifetime to adjust the treatment plan. **Urodynamic testing** to assess function of bladder is helpful to determine a treatment plan if symptoms exist. Additional diagnostics such as **magnetic resonance imaging (MRI)/computed tomography (CT), ultrasound, DXA/DEXA, x-ray**, etc. may be indicated with complications.

## Medications

A variety of medications are available to treat the different symptoms and/or disorders for an

individual with CP. Detailed information about each medication regimen and/or condition is available throughout the textbook. Listed below are some of the available treatments included in a life care plan.

### **Medication for Spasticity**

Several different medications are available to treat spasticity, relieve pain, and help achieve greater range of motion. **Baclofen (Lioresal)** can be administered by mouth (tablets) or via a pump into the intrathecal space of the spine, allowing for decreased dosage. The pump requires surgical trial, placement, and regular follow-up visits every 2–6 months with physician for refill and periodic surgical replacement of the battery, device, and/or tubing. Diazepam (Valium), clonazepam, cyclobenzaprine (Flexeril), dantrolene (Dantrium), and tizanidine (Zanaflex) are some alternative antispasticity medications.

### **Antiepileptic Medication**

Seizures may be controlled with medication, ketogenic diet, a device called the vagal nerve stimulator, or epilepsy surgery and are discussed in detail throughout the book. The following listed medications represent some of the available medication treatment options to control seizure activity: carbamazepine (Tegretol), levetiracetam (Keppra), lamotrigine (Lamictal), gabapentin (Neurontin), and phenytoin (Dilantin). A combination of two or sometimes even three antiepileptics may be prescribed. Certain medications require routine or periodic blood level monitoring, and electroencephalogram (EEG) may be recommended for follow-up.

### **Cognitive and Behavioral Medication**

Medications such as Adderall (amphetamine salt combo) and methylphenidate (Ritalin) are commonly prescribed for attention-deficit/hyperactivity disorder (ADHD). Propranolol (Inderal) may be indicated to treat behavioral issues.

### **Medication for Incontinence**

Imipramine (Tofranil) or desmopressin-acetate (DDAVP) nasal spray may be prescribed.

### **Medication for Acid Reflux**

Proton pump inhibitors (PPI) such as omeprazole (Prilosec) or H2 blockers such as ranitidine (Zantac) may be beneficial in treating this condition.

### **Medication for Depression/Anxiety**

Selective serotonin reuptake inhibitors (SSRIs) are some of the commonly prescribed medications.

### **Laboratory**

All medications have potential side effects. It is important to review the indications for periodic laboratory monitoring with the prescribing healthcare provider so that it can be incorporated into the treatment plan. This can include regular blood work and/or urinary tests.

Some of the **antiseizure medications** require regular monitoring of the serum level to determine a therapeutic drug concentration level in the body. If complications arise, such as **pressure wounds, infections, nutritional imbalance**, etc., additional laboratory tests might be required to manage these.

### **Therapy**

Therapies promote, improve, and/or maximize function while reducing pain and alleviating symptoms. This allows the patient to focus on improving abilities and independence at home and school and in the community. Most therapies include evaluation and treatments prescribed at different times over their lifespan. Therapists work collaboratively with physicians, nurses, teachers, parents, caregivers, and other

professionals involved in the care and treatment. Each therapy available is discussed in detail in other chapters throughout this book. Traditional, nontraditional, and mental health therapies may be included in a life care plan.

### Traditional Therapy

**Physical therapy** for gross motor skills and mobility; **occupational therapy** to address activities of daily living and instrumental daily living skills and oral-motor development; **speech and language therapy** to address oral-motor skills and verbal communication and for identification and implementation of alternative communication systems; **sensory integration therapy** for sensory processing; **recreational therapy**; and **relaxation therapy** are some of the therapies available.

### Nontraditional Therapy

The individualized life care plan will include nontraditional therapies such as **music therapy** to improve cognitive function, motor skills, sensory skills, and social skills; **equine therapy**, also known as horse therapy; **pet therapy**; and **aquatic therapy**.

### Mental Health Therapy

Some mental health therapies available are as follows: **play therapy** to help children express and communicate their feelings and develop relationships; **biofeedback** to promote relaxation by learning how to harness the power of the mind to gain control over body functions; **behavioral therapy** to empower the individual and family to control behavioral responses in social situations; and **cognitive behavioral therapy** to provide strategies to alter reactions to difficult situations and emotions.

### Education

The Individuals with Disabilities Education Act (IDEA) requires public schools to make available to all eligible children with disabilities free and appropriate public education in the least restrictive environment appropriate to their individual

needs. It also requires that the school system develop individualized educational plans (IEP) which delineate needs and services that the school system will provide. It is important that the parents and caregivers are knowledgeable about the IEP process and how to advocate for their child's needs. Their ability to do this may make the difference in obtaining such benefits. Some of the benefits provided by the school district are one-to-one or group therapy services (physical, occupational, speech, vision, and audiology therapy), an assigned aide during the school day, or supervised bus transportation, as well as adaptive physical education (APE). If the student has physical impairments, dyslexia, or cognitive problems, assistive technology can help her function within the classroom. These tools include any type of equipment or device that helps students to compensate for their learning disabilities. Each state is different, and often the school system is the key to accessing a variety of services. Knowledge of potential resources within the state may help the family to maximize the benefits they receive for their child.

After age 22, local state and county programs can provide pre-employment or volunteer transition services or further education through local community colleges and universities.

### School

Some children with CP require special education programs that are offered at local **public schools**, providing an array of options for their special needs. These children are entitled to participate in educational programs from age 3 until they either graduate from high school or receive a certificate of completion through their high school. If the special education program at the public school is unable to meet the individual's needs, the school may be required to place the child in a nonpublic/**private school**. These schools may be responsible for providing necessary accommodations to meet the child's needs.

Schools are also required to provide resources for children with CP who require accommodations, adaptive equipment, modifications, or one-to-one aide for certain or all classes to meet their educational needs. Their education opportunities

should not be impacted by their physical, motor, or communication ability. This is often addressed through an IEP to ensure appropriate education services. Special education services during the school breaks, known as Extended School Year (ESY), may be part of an IEP. These services are individualized to maintain skills and continue progress toward set goals.

### **Educational Advocate**

An educational advocate is a specially trained professional in education and disability law and is responsible to stay current with the regulations that affect a child in an educational setting. An educational advocate represents the best interest of the child and works with the family, caregivers, and the school personnel to assure that the child receives appropriate educational services in the most appropriate educational environment under the provisions of IDEA.

### **Educational Therapist/Tutor**

Educational therapists identify and assess student learning needs, creating and implementing individual educational therapy plans specific to the learning goals for each student. A tutor may focus on specific subjects and review skills that have already been taught in class.

### **Vocational Rehabilitation Program**

This program enables individuals with functional, psychological, and/or developmental impairments to overcome barriers to access education and training for employment in appropriate occupations. Services offered include educational counseling, job training, apprenticeships, and non-paid work experiences after a comprehensive evaluation which determines abilities, skills, and interests.

### **Day Program**

Adult day programs promote community inclusion, life skills training, and continued development of personal competencies. Programs are typically offered 5 days per week, full or part days, and typically operate during normal business hours. Some programs offer additional days or evenings.

## **Assistive Technology**

Due to the neuromuscular disorder associated with CP, individuals may require adaptive equipment and/or assistive devices offering support in completing activities of daily living, enhancing mobility and/or communication, and improving and maintaining functional abilities. The devices help achieve greater independence and self-confidence in all areas of function. They can include low-tech assistive devices and/or high-tech equipment. The following equipment items and/or devices might be considered:

### **Activities of Daily Living Equipment**

Eating, bathing, dressing, grooming, and toileting are all self-care activities which individuals with CP may have difficulty performing independently or with assistance. Equipment such as adaptation for a toilet seat to compensate for the lack of motor control, bath chairs, transfer boards, dressing aids, and installed grab bars are all items enabling participation and/or independence in self-care.

### **Mobility Equipment**

A physical therapist assesses the individual with CP to determine which mobility equipment is most appropriate to achieve the highest level of independence. Walking sticks and canes, crutches, walkers, standers, lifts, wheelchairs, and scooters are different types of mobility aides which can be modified and customized to fit the individual's needs. For some individuals, a chest support walker or reverse walker might be the best option, while for another child, a suspension walker is more appropriate. An installed ceiling lift might be a better option for one family, while a Hoyer transfer lift is suitable for another. Regular reassessment and modifications are needed, and maintenance of the equipment is required.

### **Assistive Technology for Cognition**

Assistive technology for cognition aids such as computers or electrical assistive devices can help with memory, attention, or other cognitive challenges and enables individuals to have greater control over their own lives. Speech and communication devices, as well as memory aids,

are available in many variations and customized to the individual's needs.

### **Orthotic Devices**

The goals of orthotics, such as splints and braces, are to ensure the individual with CP maintains the level of mobility by correcting physical issues that interfere with function. Orthotics might be pre-fabricated or specially manufactured in specific sizes and must be modified and replaced on a regular basis.

### **Nursing/Attendant Care**

Individuals with CP might need others to provide care for them. The situation for each person is unique, and their care needs vary in numbers of hours and frequency, depending on severity and age of the care recipient. An individual might need support/assistance for ADL's (Activities of Daily Living which refers to self-care activities such as bathing, eating, etc.), IADL's (Instrumental Activities of Daily Living which refers to activities letting an individual live independently in a community such as managing money, cleaning the house, etc.), cognition, or supervision. Providers who specialize in different areas are available, and their function and duties are described below:

#### **Care Attendant**

A care attendant is a person with a medical background and/or specific training, aiding with daily tasks and chores. Some of their duties include providing/assisting with a bath, preparing meals, executing a home exercise program such as passive range of motion, accompanying/driving to appointments, and providing a safe environment for the care recipient to thrive in. A care attendant will provide care where the care recipient is located, which may be at home with family, during school, in a day program, during outings, or in a residential facility/skilled nursing facility.

Certain services such as a complex wound care, tube feeding, intravenous therapy, injections, pulmonary treatments, etc. can only be provided by skilled care personnel, such as a registered

nurse (RN), licensed vocational nurse (LVN), or licensed practical nurse (LPN). Nonmedical home care may be considered to provide relief for family and/or caregivers and might allow an individual with CP to continue to live in his/her current home rather than having to move into a care facility.

#### **Respite Care**

In situations where the family members provide most care hours, respite care provides short-term relief for primary caregivers. This can be arranged for an afternoon, several days, weekends, or weeks and on a regular basis. Care can be provided through a care attendant at home, in a healthcare facility, or at an adult day center.

#### **Life Skills Coach**

A life skills coach, also known as a life coach, is a mentor, coach, and teacher, helping individuals to develop skills needed to integrate into the community, pursue opportunities for employment, and improve quality of life. Hours of training differ, depending on the individual's functional and cognitive abilities and the goals set.

#### **Care Facility**

If the option of living at home with family members and/or caregivers is not available for an individual with CP, a residential facility, such as a board and care, assisted living or skilled nursing facility or a group home, may have to be considered. This will often be the scenario later in life, due to parents/family members no longer being able to care for their loved one.

### **Professional Services**

#### **Fiduciary/Trustee**

A fiduciary serving in the capacity of a trustee is an individual person, bank, or member of a board who has the control/powers of administration of assets for the benefit of a third party. They have the legal responsibility to carry out the terms of the trust as stated in the trust document, which generally includes managing money that has been set aside in a trust, such as a special needs trust, for the beneficiary. Some of their responsibilities



might include assisting the beneficiary in maintaining eligibility for public benefits programs, bookkeeping and accounting of trust activities, appropriate investment of trust, and tax reporting for the trust. To provide this service, they must inquire into the needs and welfare of the trust beneficiary, work with family members and care team, as well as consider both current and future needs of the beneficiary.

### **Attorney**

A special needs trust attorney can provide advice on public benefits issues and set up the special needs trust. Once funds are deposited into the trust, an attorney can provide guidance on making distributions in order to preserve the beneficiary's public benefits. A special needs trust provides financial support for the individual without jeopardizing government benefits. Leaving money in a special needs trust allows for improved quality of life.

### **Conservatorship/Guardianship**

A guardianship/conservatorship is a legal relationship created when a person or institution is named in a will or assigned by the court to take care of minor children or incompetent adults. A guardianship is for a minor, and the minor remains under court supervision until the child reaches majority at 18. Conservatorship is a legal concept whereby a court appoints a person to manage an incapacitated adult's financial and personal affairs. The conservator's duties include overseeing finances, establishing and monitoring the physical care of the conservatee, and managing living arrangements.

### **Benefits/Resources**

The goal of applying for benefits is to access funds from organizations that serve the needs of the disabled child/adult. Differences within each program will vary from state to state. Social Security and Medi-Cal/Medicaid benefits are funded by the federal government, and the amount allocated for each state will vary.

## **Federal and State Benefit Programs**

### **Social Security Benefits (All States) and Supplemental Security Income (SSI)**

This program pays benefits to disabled children/adults who have limited income and resources. A special needs trust (SNT) is not counted as a resource.

### **Social Security Disability Insurance (SSDI)**

This program pays benefits to individuals who have accumulated a designated number of work credits. The number of work credits you need to qualify for disability benefits depends on your age when you become disabled. Generally, you need 40 credits, 20 of which were earned in the last 10 years ending with the year you become disabled. However, younger workers may qualify with fewer credits. If you are under age 24, you can earn 6 credits for 1.5 years of work, and if you are 24–30 years, you can earn 8–18 credits for 2–4.5 years of work. Individuals who have a medical condition that prevents him/her from working or is expected to prevent him/her from working for at least 12 months is eligible to receive benefits. If a parent is retired, is deceased, or has a disability, a child or an adult may qualify.

### **Medi-Cal (California)/Medicaid (All Other States)**

This program is funded by federal and states taxes and pays for a variety of medical, psychological, and dental services for children/adults with limited income and resources. There are income and resource restrictions, and the applicant must be a resident of the state where the application is filed.

If an individual is eligible for SSI, he/she is automatically eligible for Medi-Cal/Medicaid. Medi-Cal/Medicaid Waiver Institutional Deeming (ID) is a process to obtain full scope unrestricted Medi-Cal without a share of cost for disabled individuals under age 18. Through ID, the individual's family income and resources are not taken into consideration; the individual is assessed on his/her own merit.

## Developmental Disability Services

This program provides services and supports to individuals with developmental disabilities. The following listed programs represent some of the programs available in the United States. These programs are offered beginning from birth and over the life span. Titles of these programs differ in each state:

**California** – Regional Center

**Utah** – The Division of Services for People with Disabilities (DSPD)

**Colorado** – Regional Center Operations (DRCO)/Division for Developmental Disabilities (DDD)

Other programs are offered from birth through age 21, with some examples below:

**California** – California Children Services (CCS)

**Arizona** – The Children’s Rehabilitative Services (CRS)

**Florida** – Children’s Medical Services (CMS)

**New York** – Children with Special Health Care Needs Program (CYSHCN)

**Ohio** – Bureau for Children with Medical Handicaps (BCMh)

**Texas** – Children with Special Health Care Needs (CSHCN)

## Department of Social Services

The program provides in-home support to disabled individuals with limited income and who are Medi-Cal/Medicaid eligible to remain safely in their home. Eligibility varies by state; examples are below.

**California** – In-Home-Support-Services/Home and Community-Based Services (HCBS)

**Utah** – Home and Community-Based Services (HCBS)/the Aging Waiver program

**Arizona** – Arizona Long-Term Care System (ALTCS)

**Georgia** – Community Care Services Program (CCSP)

**New York** – Managed Long-Term Care Program (MLTC)

**Colorado** – Consumer-Directed Attendant Support Services (CDASS)

## Department of Rehabilitation

The Department of Rehabilitation (DOR) is a state-funded program in all states that provides services to individuals with a physical or mental impairment that substantially impedes their ability to secure employment and vocational rehabilitation services. Receiving social security benefits or possessing a valid ticket to work presumes eligibility for DOR services.

## Recreation

### Camps

Summer camps function as a way for individuals of all ages to spend time participating in activities specifically designed for their enjoyment. There are camps available for specific disabilities, benefiting participants with increased independence and self-confidence and providing the opportunity to interact with other children, develop friendships, and build meaningful relationships. The following website offers a list of summer camps designed to accommodate individuals with CP throughout the USA: [www.verypecialcamps.com/summer/cerebral-palsy-camps/](http://www.verypecialcamps.com/summer/cerebral-palsy-camps/).

### Organizations

Living with CP is different for each person affected. Local or online support groups as well as CP organizations can provide information, helpful resources, and support.

Cerebralpalsy.org, Cerebralpalsygroup.com, International CP Society, and MyChild at CerebralPalsy.org are some of the existing organizations. **United Cerebral Palsy** is an organization that educates, advocates, and provides support services to ensure a life without limits for individuals with CP and their families.

## Home Modifications

Home modifications are changes made to the home to provide a barrier-free environment. It is crucial to eliminate barriers and allow accessibility to promote independence, improve the life of the individual with CP, and prevent isolation and lack of participation. Those can be simple changes, such as installed grab bars, lever handles on doors, or more involved projects such as adding a ramp, installing a lift for interior stairs, or modifying a bathroom for accessibility.

## Transportation

Transportation provides a lifeline for people with disabilities to access community, medical, and nonmedical appointments, education, employment, etc. The Americans with Disabilities Act (ADA) of 1990 requires accessibility for public transportation. Despite ADA, transportation services are often not accessible to individuals with disabilities as adequate funding may not be provided to implement the policies. Alternative transportation options are available but vary greatly by state and city. The purchase of a modified van equipped with a ramp or lift to accommodate wheelchair-dependent individuals may be considered where public transportation is limited or unavailable.

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## Technique

Although a variety of professionals are qualified to create a life care plan, as nurses and authors of this chapter, the technique for a nurse life care plan will be explained.

The American Association of Nurse Life Care Planners claims that the American Nurses Association (ANA) Scope and Standards of Practice is the defining conceptual base for nurse life care planning. Nurse life care planners use critical thinking skills of the nursing process (Fig. 1) to formulate a plan of care for an individual's lifetime, often involving decades of healthcare and other needs. The nurse life care planner applies the

nursing process and then develops the plan, which includes the resources necessary to meet current and future medical and nonmedical needs and the costs of these resources.

An assessment of the individual is performed, and through appropriate methods, data relevant to the care needs is collected. Accurate and comprehensive nursing diagnoses determine interventions and outcomes and guide planning and implementation of care. Evidence-based nursing diagnoses are provided by the organization NANDA International. The healthcare team members follow the plan of care with the resources available, routinely evaluate and determine if the expected outcomes were achieved, and modify the care plan when necessary. The life care plan fulfills the role of advocating for the individual with CP and educating healthcare professionals to help plan for the future. Essential elements, such as individual and caregiver goals, reasonable expectations, anticipated functional outcomes, and the means to achieve them, are addressed.

Creating the life care plan, collaborating with healthcare providers, using scientific evidence-based guidelines, nursing research, and identifying community resources and healthcare systems are some of the functions of a nurse life care planner. The cost associated with each care need is outlined in the life care plan and obtained from providers, vendors, and other available reliable sources reflecting the value at the time researched. An economist determines the actuarial figures.

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## Case History

The following described journey of X, who was diagnosed with CP at age 2, demonstrates the value and effectiveness of creating a life care plan to outline future care needs, associated cost, and advocacy while functioning as a crucial guide for implementation of care by the family and nurse case manager (Picture 1).

X was born in 2000 and contracted pneumococcal meningitis at 5 months of age. As a result, he was diagnosed with CP and developed a Lennox-Gastaut seizure disorder. As a result,



**Fig. 1** Critical thinking skills of the nursing process



**Picture 2** X at age 7



**Picture 1** X at age 7

there was a lawsuit and a life care plan prepared in 2002 (Figs. 2, 3, 4, 5, 6, 7, and 8) (Picture 2).

Money was awarded for X's current and future care needs, and the family initially served as the guardians of the estate. A fiduciary and attorney were later identified and appointed to oversee the expenditure of the money and to report to the court. The family used the life care plan to identify the services and frequency that X would need. The court and attorney used the life care plan as a guide for the appropriate expenditure of money and served as the basis for identifying and funding

services to meet X's needs. Federal, state, and county resources were identified and applied to augment X's finances and meet his needs.

Nurse case managers were involved in identifying and accessing physicians, therapy, supplies, equipment, and recreation programs and preparing justifications for home modifications and modified vans. The family relied on the presence of the case managers at physician appointments, clinic evaluations, and educational appointments and to assist them in navigating the healthcare system. Educating the family about treatments and helping them to make informed decisions regarding surgery or placement of a vagal nerve stimulator were important aspects of the case manager's role. The family was often uncomfortable asking questions or clarifying treatment options, but as the years passed, X's mother assumed the role as her son's advocate. Due to X's bilateral cortical infarcts making him visually impaired, advocating for his educational needs

CARE NEED	DESCRIPTION/ RATIONALE
<b>NEUROLOGIST</b>	To monitor and treat seizures Now 4-6X/year through age 18, then 2X/year Pediatric follow up visit \$90-\$110 Adult initial evaluation \$305 Adult follow up visit @ \$90-\$110 EEG @ \$305-\$325/time, every 2-3 years until age 18, then every 5-10 years
<b>PHYSIATRIST</b>	To evaluate and make treatment recommendations 4-6X/year until age 18, then 2-4X/year Initial evaluation \$175-\$275 Follow up visit \$75-\$95/time
<b>ORTHOPEDIST</b>	To evaluate and make treatment recommendations 1-2X/year until age 18 Initial evaluation \$187 Follow up visit \$50-\$110
<b>Possible Heel Cord Lengthening</b>	For 1 leg Surgeon and Anesthesia @ \$680-\$1628 Same day surgery or 1-day hospital stay @ \$8277-\$14586 Cast@ \$203.50, 2X
<b>GASTROENTEROLOGIST</b>	To monitor gastrointestinal issues, yearly until age 18 Initial evaluation \$175 Follow up visit \$100-\$120
<b>ENT</b>	To evaluate and make treatment recommendations 2-4X/year now through age 18, then 1-2X/year Pediatric follow up visit \$50-\$150 Adult initial evaluation \$100-\$125 Adult follow up visit \$65-\$150 Audiogram \$164, 1X
<b>AUDIOLOGIST</b>	Every 6 months until age 7-8, then annually Initial evaluation \$150 Follow up visit @ \$120-\$150 Additional testing @\$100-\$300/time, 3-4X over life time
<b>HEARING AIDES</b>	Currently X has bilateral hearing aides with molds @ \$2690, replace every 3 years until he receives his cochlear implant when he will only need 1 hearing aide Molds @ \$50 per hearing aide, 2 needed until cochlear implant, replace 1 or 2 molds every 4 months until age 6, then every 6 months until age 16, thereafter yearly Batteries @ \$3.25/month for 1 hearing aide, \$6.55/month for 2 hearing aides Insurance for loss or damage of hearing aides - 1st year free of charge, thereafter @ \$120/year

**Fig. 2** X's life case plan

through the IEP (Individualized Education Program) was another role that the case managers assumed.

Currently X is 18 years old and living at home, medically stable, participating in activities with family including swimming and community

outings, and attending school. The case manager's service hours have now been decreased, and her function has changed to that of a resource in planning for the next phase of X's life as the family has learned to advocate for X's needs (Pictures 3 and 4).

<b>CARE NEED</b>	<b>DESCRIPTION/ RATIONALE</b>
<b>- Cochlear Implants</b>	<p>Initial work up                      Comprehensive Audiology evaluation @ \$125, 1X                      Acoustic Reflex @ \$45, 1X                      Typanometry @ \$55, 1X                      Otoacoustic emission @ \$100, 1X                      Brain stem Evoked Response @\$375, 1X                      Cochlear Implant consultation @ \$100, 1X                      Psychological evaluation \$250 (2 hours)                      Test Assistant (under 6 years) @ \$60,                      Otological evaluation @ \$90-\$375, 1X                      CT Scan @ \$675, 1X</p> <p>Surgery - every 10-20/years (first within next 1-3 years)                      Surgeon \$6360                      Facial Nerver Monitoring @ \$600-\$900                      Diagnostic Cochlear Implant Test Battery @ \$100                      Anesthesia fee @ \$1500-\$1600                      Outpatient surgery suite and supplies @ \$6000-\$8000                      Cochlear device @\$18,000</p> <p>Service contract on speech processor (external portion) has 3-year warranty, additional warranty after 3 years @ \$450 every 2 years                      Service contract on head set (coil, microphone, magnet and cables) has 3-year warranty with initial set up, additional warranty after 3 years @ \$195 every 2 years                      Insurance for loss or accidental damage of speech processor @ \$195-year (homeowners should cover theft)</p>
<b>COCHLEAR DEVICE FOLLOW UP AFTER IMPLANTATION</b>	<p>Device set up @ \$125/hour for 35 hours within 1 year, thereafter 3 hours per year                      Cochlear implant speech perception test @\$60, 2-8 hours 2X/year for 2 years, then yearly                      Mapping @ \$125/hour, 2X/year for 2 years, then yearly                      Cochlear Implant Check @ \$60/time, 2X/year for 2 years, then yearly                      Speech/Language Evaluation @ \$360, 2X/year for 2 years, then yearly                      Prosthetic Training \$60 for 30 minutes, 2X/year for 2 years, then yearly                      Test assistant @ \$60, 2X/year for 2 years</p>
<b>ADDITIONAL SUPPLIES FOR COCHLEAR IMPLANT</b>	<p>Additional supplies                      Speech processor @ \$6000, every 5 years                      Padded pouch @\$30, 2 per year                      Lapel clips @ \$12/=5, 2-5 packages per year                      Dry pack @ \$18, yearly                      Magnet @ \$36, 1 per year                      Ear hook @ \$9/#5, 2-5 packages every year                      Signal checker @ \$24, every 3 years                      Lapel microphone @ \$90 - \$104 replace every 1-3 years                      TV Hi-Fi cable @ \$150, replace every 3-5 years, should be available for use within the school district                      Personal Audio cable - for use with computer, etc. @ \$72, every 3 years                      Telecoil @ \$108, every 3 years                      Telephone adapter @ \$50, every 1-3 years                      FM cable for community usage @ \$90, every 3 years                      Rechargeable Batteries @ \$12 for #4, 2 packages every year, charger every year @ \$50/time</p>

**Fig. 3** X's life case plan

CARE NEED	DESCRIPTION/ RATIONALE
<b>OPHTHALMOLOGIST</b>	Annual evaluation Pediatric follow up visit \$75-\$160 Adult initial evaluation \$200 Adult follow up visit \$160/time Glasses @ \$100-\$200/time, yearly
<b>- Vision therapy</b>	2-4X over life time Initial evaluation @ \$79 Vision therapy sessions @ \$75/session, 8-24 sessions with MD follow up in between at no additional charge
<b>PEDIATRICIAN/ INTERNAL MEDICINE</b>	To provide treatment more than the typical child/adult 3-4X/year until age 18, then 2X/year more Pediatrician follow up visit @ \$35/visit Adult internal medicine follow up visit @ \$43/visit Flu @ \$20/year Pneumo vaccine @ \$39, 1X
<b>ADDITIONAL MEDICAL SPECIALISTS</b>	To provide treatment for additional care needs 1-2X/year until age 18, then 2X/year Evaluation @ \$250-\$250/time
<b>DENTIST</b>	To provide treatment more than the typical child/adult 2X/year Exam \$25/time Cleaning \$25-\$50/time Sedation with cleaning at an additional \$150 above cleaning price, 1X/year
<b>PODIATRIST</b>	To deal with foot and nail issues related to disability Now 1X/year until age 18, then 2-4X/year Initial evaluation \$50 Follow up visit \$40 Ingrown nail treatment \$115, 2-3X over life time
<b>MEDICATIONS</b>	Currently on: Phenobarbital 7cc 2X/day Future medications for seizures @ \$120-\$150/month
<b>LAB WORK</b>	2-3X/year CBC @ \$46.41-\$88.20 BMP @ \$102.67-\$144 Seizure medication level @ \$86.50-\$131.04/time
<b>DIAGNOSTIC STUDIES</b>	Spine films 4-5X @ \$215-\$375/time Chest X-ray @ \$150, 3-4X over life time KUB \$187.50, 3-4X over life time Swallowing evaluation @ \$315 and \$75 for MD reading, 1X over life time
<b>EMERGENCY ROOM</b>	1X/year ER \$500-\$1000, MD @ \$150-\$250
<b>HOSPITALIZATION</b>	1 day per year Hospitalization @ \$2375 - \$2988/day MD @ \$75-\$150/day
<b>NUTRITIONIST</b>	To monitor nutritional needs Initially 4-6X/year for 1-2 years, then 2X/year for 2 years Initial evaluation \$80 (1.5 hours) Follow up visit \$40/hour

**Fig. 4** X's life case plan

CARE NEED	DESCRIPTION/ RATIONALE
<b>PHYSICAL THERAPY</b>	Now through age 6, 3X/week Age 7-10, 2X/week Age 10-15, weekly Age 15-21, monthly Initial evaluation \$210-\$216 Follow up visit \$95-\$207
<b>OCCUPATIONAL THERAPY</b>	Now through age 6, 3X/week Age 7-10, 2X/week Age 10-15, weekly Age 15-21, monthly Initial evaluation \$210-\$216 Follow up visit \$90-\$207
<b>SPEECH THERAPY</b>	In addition to services provided by school district Now to age 6, 3-5X/week Age 6-10, 3X/week Age 10-18, 2X/week Initial evaluation \$260-\$320 Follow up visit \$90-\$199.50/session
<b>REHABILITATION RE-EVALUATION</b>	Starting at age 18, evaluation with 2 treatments annually for 5 years, then every 5 years Physical therapy evaluation \$210-\$216 Physical therapy treatment \$95-\$207 /time Occupational therapy evaluation \$210-\$216 Occupational therapy treatment \$90-\$207/time Speech therapy evaluation \$260-\$320 Speech therapy treatment \$90-\$199.50/time
<b>COUNSELING</b>	To assist X and his family with meeting his care needs Weekly for 1 year now and 100 additional sessions over his life time Initial evaluation \$120-\$135 Follow up visit \$120-\$135/session
<b>COMPUTER</b>	Cost of computer @ \$1200-\$2000, now and every 3 years Enlarged screen @ \$1000-\$1399, with purchase of each computer Set up \$150 Initial programs @ \$500 Yearly programs @ \$100-\$300 Training @ \$95/hour, initially 10 hours, thereafter 3 hours per quarter Maintenance @ \$100-\$200/year Internet @ \$21.95/month
<b>AUGMENTATIVE COMMUNICATION</b>	To assist with communication Parakeet 15 @ \$550 cost, 2X Accessories @ \$200-\$300 Maintenance @ \$220/year 9-volt battery every month @ \$2.59 Macaw II - \$2500 cost, 1X Accessories \$200-\$500 Maintenance @ \$220/yr. after first year Training @ \$90-199.50/hour, initially 20-30 hours, then 5-10 hours quarterly for 1 year, then 10 hours every 6 months
<b>EDUCATIONAL ADVOCATE</b>	Now through age 21 Intake or evaluation fee @ \$150-\$500 5-10 hours for observation, attendance at IEP or additional meetings @ \$75-\$110/hour

**Fig. 5** X's life case plan



<b>CARE NEED</b>	<b>DESCRIPTION/ RATIONALE</b>
<b>ATTENDANT CARE</b>	Now until age 6 - 10 hours per day Age 6 -21 - 6 hours per day for school days (180 day /year) and 10 hours for non-school days Agency @ \$15.50-\$17.50/hour or Agency Live-in \$140-\$150/day OR Private Placement fee \$150-\$350 (guarantee placement for 90 days) or Placement fee \$480 (guarantee placement for 1 year), 3X Live in private rate @ \$80-\$100/day Age 21- Options 1) Home with live in Agency Live-in \$140-\$150/day OR Private live in @ \$80-\$100/day with placement fee of \$150-\$350 or \$480, 4-5X 2) Residential Casa Colina @ @3900-\$4500/month Learning Services @ \$295/day
<b>RESPITE CARE</b>	To provide the parents and family time away or with additional assistance during vacations with X Monthly respite for 3 days until age 18 - 21 - Agency Live-in \$140 - \$150/day To enable X or participate in family vacation by providing live-in attendant to go with family to provide for his care needs, 1 week per year until age 18-21 Agency Live-in \$140-\$150/day or Private live-in @ \$80-\$100/day
<b>CASE MANAGER</b>	To assist with accessing services and identifying resources Now through age 6, 4 hours per month Ages 7-15, 3 hours per month Ages 15-18, 4 hours per month thereafter 12-24 hours per year Cost @ \$80-\$85/hour
<b>FIDUCIARY</b>	To assist with bookkeeping and reporting to the courts Fiduciary for 5-10 hours per month @ \$75-\$150/hour Attorney cost for court reporting @ \$500-\$1000/year
<b>HANDYMAN</b>	To maintain the safety of the environment Starting at age 18, \$15/hour for 2 hours 4X/year * *needed if X is not residing in a residential placement
<b>HOUSEKEEPING</b>	Starting at age 18, 2X/week for 4-6 hours per time Initial visit @ \$79 for 4 hours, thereafter @ \$64-\$95 for 4-6 hours per time* *needed if X is not residing in a residential placement
<b>QUICKIE PEDIATRIC (MANUAL) WHEELCHAIR</b>	Now and replace every 3-5 years until age 18 Cost of Zippie 2 Wheelchair @ \$1550 Lateral supports @ \$200-\$300 Solid back and seat @ \$500-\$600 Tray table @ \$200, with purchase of each wheelchair Maintenance @ \$150-\$250/year
<b>QUICKIE ADULT (MANUAL) WHEELCHAIR</b>	Starting at age 18, purchase every 5-7 years Cost of Quickie 2 wheelchair @ \$1850, maintenance @ \$150-\$250/year Tray table @ \$200 with purchase of each wheelchair

Fig. 6 X’s life case plan

CARE NEED	DESCRIPTION/ RATIONALE
<b>POWER WHEELCHAIR</b>	Starting at age 8-10, replace every 7-10 years Cost of Quickie @ \$9475, Attendant control @ \$795 Tray table @ \$200 with purchase of each wheelchair Maintenance @ \$500/year Batteries @ \$310/pair, 2 needed yearly
<b>WHEELCHAIR CUSHION</b>	Cushions to prevent skin breakdown or shearing Cost of Roho @ \$399-\$439 or Jay @ \$459.95, replace 1 cushion every 2-3 years, replace cover every year @ \$74.95/each
<b>STANDER/ GRANDSTAND</b>	Cost of stander for child/young adult @ \$1125-\$2500, 2X starting now, with maintenance @ \$250 /year, tray table included Purchase of Grandstand starting at age 18 and 1 additional time over life time, cost @ \$2595, includes tray table, maintenance @ \$250-\$500/year
<b>POWER BED WITH SIDE RAILS</b>	Starting at age 10-13, purchase bed every 10 years Cost of twin power bed @ \$1178-\$1378.95, Maintenance @ \$50/year. Replace mattress every 3 year @ \$169-\$399.99
<b>ANKLE FOOT ORTHOSIS</b>	To assist with foot positioning, transfers and gait Cost of AFO @ \$300-\$700/each, now and every 2-3 years until age 18, then every 3 -5 years Maintenance @ \$25-\$50/year
<b>WALKER</b>	Gait trainer 2X @ \$254-\$275, maintenance @ \$25/year for 5-10 years Rear walker 2X @ \$279-\$319.95, maintenance tips @ \$7.99/pair and wheels @ \$39.95-\$49.95/pair, yearly until age 18-21 Adult wheeled walker with brakes and seat (starting at age 16-18) @ \$445, every 5 years, maintenance @ \$20/year
<b>ADL EQUIPMENT</b>	Hand held shower nozzle @ \$44.95, now and every 2-3 years Long handled sponge @ \$3.95, replace yearly after age 8-10 Folding shower chair with back @ \$71, 2X, tips @ \$15.80, evert other year Cost of additional ADL equipment @ \$300-\$500 now and every 2 years until age 21, then every 3-5 years
<b>ADAPTIVE CLOTHING TUB/SHOWER CHAIR</b>	Cost @ \$100-\$200/yearly To provide for bathing needs Cost of shower/tub bench with back @ \$98.60-\$117. starting at age 5, replace every 3-5 years, every 5 years after age 18 Maintenance @ \$25/year
<b>TOILET SEAT</b>	Adaptive toilet seat @ \$493.95-\$499.95, 2X
<b>WIRELESS MONITOR</b>	Now and every 5-7 years @ \$19.95-\$59.95 Battery (9-volt) @ \$3.00, every 1-2 months
<b>MEDIC ALERT</b>	To identify issues related to X's disability Cost of bracelet/pendant @ \$35. Cost to maintain information in national file @ \$15/year. Replacement of bracelet/pendant @ \$25 every 2-3 year until age 18-21, then every 5 years
<b>THERAPY/PLAY EQUIPMENT</b>	Initial equipment @ \$500-\$900, purchase of additional equipment @ \$100-\$200 every 2-3 years until age 18
<b>ELECTRIC TOOTHBRUSH</b>	Cost of Oral B Kid's Power Brush @ \$29.99, replace every 2 years until age 16 Cost of Oral B Adult Power Brush @ \$49.99 from age 16, replace every 2 years, replacement brushes @ \$19.99 for 3 /pk, every 3 months

**Fig. 7** X's life case plan

CARE NEED	DESCRIPTION/ RATIONALE
<b>BOWEL AND BLADDER MANAGEMENT</b>	To provide for bowel and bladder management needs Cost of small diapers @ \$64.25 for #104, 5-6 per day Cost of medium diapers @ \$64.25 for #88, 3-4 per day Cost of large diapers @ \$64.25 for #72, 3-4 per day Hygiene wipes @ \$5.79 for # 46 Chux @ \$39.95 for #90 Gloves @ \$9.99 for #100 Skin shield spray @ \$5.99/bottle K-Y Jelly @ \$1.99 4oz/tube Magic Bullet @ \$19.95/#12
<b>EQUINE THERAPY</b>	To assist X with his balance and coordination Cost of weekly session @ \$100/month until age 8-10
<b>AQUATICS AND FITNESS PROGRAM</b>	YMCA-Child enrollment @ \$75/year Adult (age 18 and up) enrollment @ \$75/year with monthly fees @ \$39 Trainer @ \$35/hour, starting at age 18-21, monthly Private swimming lessons @ \$120 for 8 - 30 min sessions, 5 series per year through age 6 Group swimming lessons @ \$42 for 12 - 30 min sessions, 3 series per year until age 18 24 Hour Fitness- Enrollment @ \$107 1X Monthly fees @ \$19 Trainer @ \$50/hour
<b>SUMMER CAMP</b>	2 weeks per year Camp Harmon @ \$726-\$847, 6-7-day camp, ages 8-40 Camp Eagle Lake @ \$736-\$920, 8-10-day camp, ages 10-25 Happy Adventure Day Camp @ Santa Barbara @ \$90/week, 3-week session, ages 5-18
<b>VAN</b>	To assist X with transportation in the community now, and every 10 years or 60,000 miles Van @ \$20,000,-\$30,000 Conversion @ \$14,000-\$17,000 EZ Lock @ \$1295 Maintenance @ \$1000/year AAA @ \$64 first year, then \$44/year thereafter Cell phone @ \$100-\$200, every 3-5 years Cellular phone service @ \$19.99/month
<b>HOME MODIFICATIONS</b>	To assist with care needs, entrance and exit into home, 1-2X over life time Cost of ramps @ \$5,000-\$10,000 Cost of wheelchair accessible bathroom @ \$20,000-\$30,000
<b>ORGANIZATIONS</b>	To provide resources for the family and care givers regarding disabilities. Epilepsy Foundation, Betty Clooney Foundation and Brain Injury Association of America @ \$100-\$200/year
<b>EDUCATION FOR PARENTS</b>	Abilities Expocon-entrance fee @ \$5/per person, \$50/person for room and board 3 people/year Additional conferences @ \$500-\$1000/year

Fig. 8 X's life case plan



**Picture 3** X at age 14



**Picture 4** X at age 18

## Cross-References

- ▶ Complimentary Therapy Approaches
- ▶ Epilepsy in the Child with Cerebral Palsy
- ▶ Epilepsy Surgery for the Child with Cerebral Palsy
- ▶ General Medical: Complementary Medical Treatments
- ▶ General Medical: Gastrointestinal – Gastroesophageal Reflux in the Child with Cerebral Palsy
- ▶ General Medical: Neuromotor Function – Medical Management of Spasticity in Children with Cerebral Palsy – Intrathecal Baclofen Therapy, Assessment and Medical Management – Intrathecal Medication Administration in Cerebral Palsy – Dorsal Rhizotomy for Spasticity Management in Cerebral Palsy
- ▶ General Medical: Psychologic and Psychiatric Problems – Psychiatric Disorders in Children with Cerebral Palsy
- ▶ Orthopedic: Ankle, Foot, and Toes – Atlas of Foot and Ankle Procedures in Cerebral Palsy
- ▶ Orthopedic: Hip – Hip Reconstruction in Children with Cerebral Palsy – Surgical Atlas of Cerebral Palsy Hip Procedures
- ▶ Orthopedic: Spine: Surgical Treatment of Scoliosis Due to Cerebral Palsy: Spinal Procedure Atlas for Cerebral Palsy Deformities
- ▶ Orthopedic: Upper Extremity – Upper Extremity Operative Procedures in Cerebral Palsy
- ▶ Pathology and Diagnosis Overview: Diagnosis – Classification Terminology in Cerebral Palsy: General Medical: Central Neurologic Problems
- ▶ Therapy Management in Cerebral Palsy: Activity and Participation
- ▶ Therapy Management in Cerebral Palsy: Body Structure Function
- ▶ Therapy Management in Cerebral Palsy: Lifespan Approaches and Environmental Setting

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## Resources

The Internet offers an incredible amount of information. The following websites might be helpful for further information and/or assistance in accessing benefits and services

- <https://archrespice.org/respitemlocator>
- <http://www.askearn.org/>
- <https://www.benefits.gov/>
- <http://www.cdss.ca.gov/>
- <https://www.cerebralpalsy.org/>
- <https://cerebralpalsygroup.com/>
- <https://www.coveredca.com/>
- <https://www.dds.ca.gov/Rates/ReimbRates.cfm>
- <http://dor.ca.gov/>
- <http://www.cdss.ca.gov/In-home-supportive-services>
- <https://www.inhomecare.com/>
- <https://www.mybenefitscalwin.org/>
- <https://nasdds.org/>
- <https://www.ssa.gov/>
- <https://www.thearc.org/>
- <http://ucp.org/>
- <http://www.ucpmobile.org/ucp-programs/adult-services/adult-day-program/>