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Greetings Life Care Planners,

“Children are the future” is a refrain we hear in nearly every walk of life. But pediatrics is, put simply, a challenge. Growing minds and growing bodies create a shifting target that can be difficult to navigate.

We were happy to receive articles covering so much of the pediatric practice, but the subject is in no way covered completely. We are proud of this issue, but expect this subject to come up again.

We hope you find this issue helpful. If you liked it, or have other opinions to express, I will be at our annual conference in Memphis seeking to connect with authors and our audience, in addition to running a panel of my own.

Our next issue subjects will focus on the Business of Life Care Planning and Mental Health. If you are interested in either of these subjects, send an email to Journal@AANLCP.org or come meet me in Memphis.

I’m looking forward to seeing you there!

Stephen Axtell
JNLCP Editor
journal@aanlcp.org
Information for Authors

AANLCP® invites interested nurses and allied professionals to submit article queries or manuscripts that educate and inform the Nurse Life Care Planner about current clinical practice methods, professional development, and the promotion of Nurse Life Care Planning. Submitted material must be original. Manuscripts and queries may be addressed to the Editor. Authors should use the following guidelines for articles to be considered for publication. Please note capitalization of Nurse Life Care Plan, Planning, etc.

Text

- Manuscript length: 1500 – 3000 words
- Use Word® format (.doc, .docx) or Pages (.pages)
- Submit only original manuscript not under consideration by other publications
- Put the title and page number in a header on each page (using the Header feature in Word)
- Place author name, contact information, and article title on a separate title page
- Use APA style (Publication Manual of the American Psychological Assoc. current edition)

Art, Figures, Links

- All photos, figures, and artwork must be in JPG or PDF format (JPG preferred for photos).
- Line art must have a minimum resolution of 1000 dpi, halftone art (photos) a minimum of 300 dpi, and combination art (line/tone) a minimum of 500 dpi.
- Each table, figure, photo, or art must be submitted as a separate file, labeled to match its reference in text, with credits if needed (e.g., Table 1, Common nursing diagnoses in SCI; Figure 3, Time to endpoints by intervention, American Cancer Society, 2019). Graphic elements embedded in a word processing document cannot be used.
- Live links are encouraged. Please include the full URL for each.

Editing and Permissions

- The author must accompany the submission with written release from:
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All manuscripts published become the property of the Journal. Submission indicates that the author accepts these terms. Queries may be addressed to the care of the Editor at: journal@aanlcp.org

Manuscript Review Process

Submitted articles are peer reviewed by Nurse Life Care Planners with diverse backgrounds in life care planning, case management, rehabilitation, and nursing. Acceptance is based on manuscript content, originality, suitability for the intended audience, relevance to Nurse Life Care Planning, and quality of the submitted material. If you would like to review articles for this journal, please contact the Editor.

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Dear Members, Colleagues and Fellow Nurse Life Care Planners,

The new year has begun, and I am so thankful to have been given the opportunity to write another letter. It will be my last one in my role as president of AANLCP. After the departure of the president-elect, the board moved to appoint me to continue in my role to ensure stability and assist our incoming president Misty Coffman during the transition.

And with the change of year, I have been reflecting on the past two years where I had the honor of serving you and our wonderful association. What an exciting journey it has been! To work alongside individuals who volunteered their time, got involved, stepped up when needed, and guided our community and its members with wisdom and kindness has deeply touched me. There were many situations where I have felt challenged, all of them leading to growth within and for our community. They enabled me and the executive board to not only think outside the box, but to realize that some of the challenges led to success and celebrations.

The challenge of navigating our organization through a time where the world seemed to stand still, resulted in virtual conferences where we were able to not only serve our members, but also to stabilize the association’s finances. We now have the means to grow and expand the AANLCP, implementing a strategic plan that will focus on the association’s growth and sustainability.

There is so much to acknowledge – our committees and its chairs and members have worked tirelessly to not only provide our members with their specific services, but to also put in place processes that will guarantee a smooth continuation of each committee while new members are joining.

I am thankful to you all, as without you, willing to undertake time consuming and often challenging roles serving as chairs and committee members, the association cannot exist. I invite all our members to become engaged, explore ways to participate as a volunteer, and whatever challenge occurs, I wish you the courage to continue.

Thank you to all the individuals who have worked behind the scenes as contractors, making sure the day-to-day tasks were taken care of, members were being heard, and emails followed up. Your contributions allow the association to serve its members.

So many individuals have guided me and the executive board with their knowledge and experience, providing a constant source of support, allowing us to implement the functions and services our members rely on. I have made connections and built friendships that will last a lifetime and for that I am grateful.

As I look ahead, I feel confident in the association’s future. The stage is set for an exciting and transformative time, for new opportunities and innovation, for strengthening the existing, and for reaching the sky. As I pass the torch to Misty Coffman, I will continue to serve as the president, until April 2, 2023, and will step into the past president role thereafter. The executive board is preparing for the membership meeting, and I look forward to meeting you all in Memphis in March.

My sincerest thanks to all of you, the association’s executive board, volunteers, and everyone who has served to make a difference. I cherish the memories I made while I had the opportunity to work with all of you! I am deeply grateful to have had the honor to serve as the associations’ president.

With appreciation,

Andrea Nebel, RN, BSN, CNLCP
President, AANLCP | president@aanlcp.org

“Success is not final; Failure is not fatal; It is the courage to continue that counts.”
— Winston S. Churchill
Methodology Memo

By Melinda Pearson, LMSW, CLCP

When Challenged, Are You Prepared to Answer What Your Secondary Resource is Beyond the Core Curriculum?

Imagine that you are testifying when you are challenged on collateral sources. You answer that “based on the core curriculum; you do not provide collateral sources.” You are then asked for a secondary resource. Where would you go from here?

The Life Care Planning Summit is vital as the practice of life care planning grows and develops. Having a centralized authority to help decide on practice creates an authority that can be referred to in times of decision. Standardized approaches must be promoted to foster advancement in the field. Consensus and unity in this diverse field is an evolving process and that is why the Summit takes place every two years. Participation is important for the evolution of this specialty practice because it is important that Best Practices and Consensus and Majority Statements from past summits serve as reinforcement for the work of the life care planner. (Albee, T. RN, Gamez, J.N MA, Johnson, Cloie B. MEd 2017 Life Care Planning Summit Proceedings. Spring 2018 Vol. XVIII No. 1. AANLCP Journal of Nurse Life Care Planning.)

In May of 2017, 102 life care planners from diverse backgrounds and geographic locations attended the tenth planning summit. The summit included submissions by organizations such as International Academy of Life Care Planners (IALCP), American Association of Nurse Life Care Planners (AANLCP), International Commission on Health Care Certification (ICHCC), and Foundation for Life Care Planning Research (FLCPR). The goal of this summit was to further define “associated costs”: how are they derived and what methods are used to determine and utilize collateral sources. A review of past summits was methodically conducted including current consensus and majority statements. A survey was sent out and 187 life care planners from 26 states and a majority reported that they never include collateral sources in the development of a life care plan.

The professional organizations, IALCP, AANLCP, ICHCC, FLCPR, which offer support, certification, education and guidance to life care planners provided updates regarding their organizations and futures. In addition, an ethics workshop was held and they surveyed various credentials for those who prepare life care plans identifying that minimum education and experience requirements, code of conduct, ethics/standards of practice and requirements for continuing education. Panelists were asked various questions regarding how providers charged, and they were asked about collateral sources.

On day 2 participants were methodically assigned to one of four groups that had even distributions in terms of experience, training and knowledge. They rotated through the focus groups and participated in all the discussions. At the end they participants convened in a general session to discuss results and general consensus.


Staying active in your organizations, participating on committees and taking part in the Life Care Planning Summit has a direct impact on how well you do in your practice and on the stand. The answer to the original question about your second source is the 2017 Life Care Planning Summit Proceedings that states the majority of life care planners do not include the collateral sources.
Contributors to this Issue

Melinda Pearson, LMSW, CLCP
Promedica Verity Group

Ms. Pearson has been providing rehabilitation services since 1997, when she earned her Master’s in Social Work. For more than 25 years, she has been providing services for people with traumatic brain injuries under the New York State Department of Health TBI Medicaid Waiver Services. Melinda has been providing life care plans and medical cost projections for Promedica Verity Group since December 2021. She is a licensed Social Worker and she is board certified through the International Commission of Health Care Certification as a Life Care Planner since 2019. She studied Life Care Planning with FIG in North Carolina. In 1992, she earned her bachelor’s in psychology from Loyola Marymount University, Los Angeles. In 1996, she earned her Master of Social Work from Yeshiva University's Wurzweiler School of Social Work in New York City. She is a member of the Association of Nurse Life Care Planners, and National Association of Social Workers.

Nellie Kreimer BSN

Ms. Kreimer holds a bachelor of science degree in nursing (BSN) from New York University School of Nursing. During her 27 years of nursing, Ms. Kreimer has worked in a variety of settings, but her passion for public health, close patient contact, patient advocacy, and holistic approach to patient care have steered her towards the field of visiting nursing. Ms. Kreimer holds two masters degrees, one in Health Law Administration from Bellevue University, and the second in Health Law and Policy from Hofstra School of Law. As a strong patient advocate, Ms. Kreimer intends to collaborate with pertinent stakeholders and to bring about necessary modifications to the current healthcare delivery practices, especially for the disabled and disadvantaged populations. As intermediaries between the healthcare and the legal systems, and the disabled individuals, the nurse life care planners (NLCPs) have the necessary knowledge and skills to advocate for the population that they serve, and facilitate access to quality, evidence-based healthcare, and necessary supportive and assistive devices, treatments and therapies across the life span of the individual.

Edward Kagan, PharmD

Edward Kagan graduated from the Long Island University (LIU) Arnold and Marie Schwartz College of Pharmacy with a doctorate of pharmacy (PharmD) in 2009. Since graduation, Dr. Kagan has worked in a variety of private, independent, and clinical pharmaceutical settings. Currently, Dr. Kagan is enrolled in a Masters in Public Health program. Upon completion, Dr. Kagan intends to apply his extensive pharmaceutical experience to identify and mitigate public health risks pertaining to use, misuse, and abuse of medications. One of Dr. Kagan’s passions includes research into disease pathology and safe and effective use of prescription and non-prescription medications. While in PharmD residency, Dr. Kagan wrote an article in the LIU Journal “Management of Venous Thromboembolism.”
Dawn Cook, RN, CLCP, CNLCP

Dawn Cook is a licensed Registered Nurse who has worked with serious and catastrophic illness and injury with over 40 years of experience in clinical settings and as a life care planner and medical bill reviewer. Dawn holds the certified life care planner (CLCP) and certified nurse life care planner (CNLCP) designations. Dawn has completed over 700 life care reports and 400 past medical bill reports in 34 states and has testified as an expert witness at deposition or trial over 150 times.

Dawn has been a member of the Journal Committee for the Journal of Nurse Life Care Planners since 2015. In 2022, Dawn received the Distinguished Service Award from the American Association of Nurse Life Care Planners for her contributions to the nurse life care planning field.

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is a Pediatric Rehabilitation Medicine Nurse Practitioner with clinical interest in cerebral palsy, spinal cord injury, acquired brain injury, heart failure, transplantation, and neurodevelopmental disabilities. She earned her bachelor’s degree in nursing from Seton Hall University, master of science in nursing from the University of Pennsylvania, and doctor of nursing practice from the University of Pittsburgh.

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Daniel Pollack, MSW, JD is a professor at Yeshiva University’s School of Social Work in New York City. He was also a Commissioner of Game Over: Commission to Protect Youth Athletes, an independent blue-ribbon commission created to examine the institutional responses to sexual grooming and abuse by former USA Gymnastics physician Larry Nassar. Professor Pollack has been retained as an expert witness in numerous child welfare lawsuits across the country. Contact: dpollack@yu.edu.
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Pediatric Pharmacotherapy and Dosing Safety

By: Nellie Kreimer, BSN and Edward Kagan, PharmD

Introduction

Drug therapy is an essential component of nearly all therapeutic, disease-related treatment modalities. Safe and effective drug therapy is premised on health promotion, disease burden reduction, adverse drug events (ADEs) prevention, improvement of functional capacity, and quality of life. Correct medication in appropriate dosage facilitates the attainment of clinical treatment goals, and generally promotes optimal health outcomes in the pediatric and in the adult populations. From simple to complex medications, correct dosing of children’s medications presents unique challenges not only to parents and caretakers, but also to healthcare providers across all healthcare settings. Tailoring medication regimen to adult and pediatric patients alike requires consideration of multiple factors, including but not limited, clinical status, clinical indications, individual patient characteristics, hemodynamics, hepatic and renal functions, and biochemical composition of medications (Sheng-dong Pan et al. 2016). Because the children’s bodily functions are physiologically distinct from those in the adult population, pediatric dosage calculations require implementation of evidence-based methodology. Such dosage-calculating methodology needs to incorporate the weight, the height, and the age of a child in addition to physiological and hemodynamic factors (Enclara, 2020; Cicero, 2020).

Experts in the pediatric emergency medical services (PEMS) contend that there is a marked inconsistency in establishing and adopting standardized weight-based dose calculations across majority of clinical and non-clinical settings, thus subjecting the pediatric patients to an increased risk of receiving wrong dose of medication. By the same token, the error rate in dose calculation increases when the weight is estimated, rather than objectively measured, especially...
in the midst of pediatric resuscitation, seizure and pain management, and in children under 10 years of age (Cicero et al. 2020). As pre-cursors to ADEs, medication errors cause increased morbidity and mortality in the pediatric population which spawns significant monetary, psychosocial, ethical, and moral costs. Based on physiological differences, pediatric patients are at a higher risk for ADEs across multiple healthcare delivery settings, including but not limited to pediatric anesthesiology, emergency departments (ED), Emergency Medical Services (EMS), pediatrician offices, outpatient clinics, and in-patient hospital facilities (Lorinc, et al. 2020). The Society for Pediatric Anesthesia (SPA) through its Wake-Up Safely (WUS) program analyzed 2016-2020 data from 32 institutions, where out of 2,316,635 anesthesia procedures, 2,087 resulted in adverse events. Out of 2,087 ADEs, 276 were medication errors, especially relating to opioids and sedatives/hypnotics, with the majority being a wrong dose calculation (Lorinc et al. 2020). Out of 276 medication errors, 30 happened during preparation of medication, 67 episodes during prescribing, and 179 during administration (Lorinc, et al. 2020).

Basic Tenets of Pediatric Dosing and Relevant Challenges

Regardless of the healthcare delivery setting, pediatric dosing is calculated based on the child’s weight (in kilograms), height, and age, a practice supported by the Emergency Nurses Association, the American Academy of Pediatrics, and the National Association of State EMS Officials. Although the majority of healthcare settings have adopted the pediatric kilogram weight standard. (Sheng-dong et al., 2016) cautions that the “weight based dosing strategy is still challenging due to poor awareness and adherence” by the pediatric healthcare community. Furthermore, weight-based dosing should not be a stand-alone factor in pediatric dose calculation, but should be evaluated within the parameters of clinical hallmarks, the child’s age related and individual fat, muscle, and water composition, renal and hepatic function, and medication properties, such as water or fat solubility (Enclara Pharmacy, 2020; Sheng-dong et al., 2016).

Another challenge in pediatric dosing is attributable to insufficient manufacturer instructions (in product packaging and inserts), specifically applicable to the pediatric population, thus leaving dosage calculations to physicians, pharmacists, and other healthcare providers (Enclara Pharmacia, 2020). Likewise, it is difficult to accurately estimate pediatric dosing for off-label medications used in the pediatric population for complex or treatment-resistant conditions. According to an article in the U.S. Pharmacist (2019) and the American Academy of Pediatrics (AAP, 2019), off-label prescribing for the pediatric population is on the rise, especially for antihistamine and antibiotics for treatment of respiratory infections, and antidepressants for ADHD. Whereas some experts voiced concern over using off-label medications for children, others contend that off-label medications are clinically tested and may be beneficial in relieving similar symptoms in diverse diseases (Hoon et al. 2019).

Pediatric obesity causes a dilemma in pediatric dose calculations because obesity impacts drug absorption, metabolism, and elimination (Matson, et al. 2017). According to the Centers for the Disease Control and Prevention (CDC) between 2017-2020, in 14.7 million of children and adolescents between ages of 2-19 years old, the prevalence of obesity was 19.7% (CDC, 2022). Obesity prevalence for 2-5 year age group was 12.7%; 6-11-year-olds 20.7%; and 12-19-year-olds, 22.2%. Obesity is a known factor in high blood pressure, high cholesterol, type 2 diabetes, and joint and respiratory diseases (CDC, 2022). Pediatric obesity is calculated using body mass index, or BMI, by dividing a child’s weight in kilograms by the square of height in meters and comparing the value with children of like age and sex and deriving a percentile value (CDC, 2022). According to CDC and the American Academy of Pediatrics (AAP), children less than 5th percentile are considered underweight; 5th to less than 85th percentile are of normal weight; 85th-95th percentile are overweight; 95th percentile or higher are obese, while 120% of the 95th percentile are severely obese (CDC, 2022; Matson, et al. 2017). Obese children have an increased proportion of body fat and a “larger volume distribution” for fat-soluble drugs, while the water-soluble drug distribution may be either increased or decreased due to increased body mass, blood volume, and decreased total body water concentration (Matson, et al. 2017). Additionally, obese children and adolescents may experience lesser hepatic clearance due to “fatty infiltrates of the liver” (Matson, et al. 2017). Because kidney size increases with increased body weight, the kidneys clear medication by-products faster, which may require increased doses of medications to achieve a desired clinical effect (Matson, et al. 2017).

Considerations in Pharmacotherapy: Differences Between Pediatric and Adult Patients

The pediatric patients’ age ranges from newborn to 18 years of age. Pediatric patients have less mature body organ systems and different fat, water, and muscle body composition than their adult counterparts. As such, drug distribution, metabolism, and the excretion of an identical drug via similar route will differ among the pediatric and the adult population, requiring careful dose adjustment for children (Enclara Pharmacia, 2020; Anesthesia.org). Even within the pediatric age continuum, the neonates, infants, and children have different body composition of fat, water, muscle, and protein and require age-appropriate dose titration. For example, a premature infant’s body composition
is 85% water, while the term infant 75%, while in 6-month-old and older children, it is 60% water (Anesthesia.org). Likewise, in comparing fat composition to total body weight, the preterm neonate has 4%, term infant 14-15%, the 6 months old 25%, while older children 30% (Anesthesia.org). Muscle mass varies between preterm infant, term infant, 6-month-old, and older children at 18%, 30%, 40%, & 50% of total body weight, respectively (Anesthesia.org).

Variable hepatic maturity between newborns, older children and adults impacts the speed of drug metabolism, while renal maturity and glomerular filtration rate (GFR) regulates excretion of drug by-products from the blood. GFR levels are analyzed via a special formula that incorporates age, sex, ethnicity, height, and weight. GFR calculations utilize a different calculation formula for children and adults (Anesthesia.org). Likewise, binding protein composition affects the amount of a drug and its action depending on how much of the drug is bound to proteins and how much is freely floating in the blood (Anesthesia.org).

### Diseases and Pharmacotherapy in Pediatric Population

The disease trajectories and associated sequelae that affect the pediatric population include but may not be limited to cerebral palsy, diabetes, heart conditions, seizures, brain and spinal cord injuries, cancer, depression, phobias, panic attacks, autism spectrum disorder, bipolar disorder, psychosis, attention deficit hyperactivity disorder (ADHD), anxiety, bedwetting, eating disorders, obsessive-compulsive disorder (OCD), post-traumatic stress disorder, and infections (AACAP, 2017). Pharmacological therapy may include but is not limited to anti-depressants, antipsychotics, mood stabilizers, anti-convulsants, anti-anxiety, hypnotics, muscle relaxants, narcotics, anti-diabetics, and others. Calculating pediatric dosages for any of the aforementioned medications requires careful consideration of indications, clinical status, medication uptake, metabolism, and excretion. For example, Baclofen is a non-paralytic, muscle relaxant that is frequently used for treatment of cerebral and spinal spasticity in children and adults with maximum daily dose of 1,000mcg/day.

Whereas calculation of pediatric dose baclofen calls for the implementation of body weight, BMI, body composition, and hemodynamics in consideration of clinical status of the patient as of outmost importance. Mishaal et al. (2020) presented a clinical case study of 2.5 year old boy admitted to the hospital with hemolytic uremic syndrome and acute kidney injury (AKI). He was treated with baclofen 5mg 3 times daily for cerebral spasticity, however; the medication had to be discontinued because the patient experienced a shallow, slow respiratory rate, and bradycardia. Upon discontinuation and IV fluid replacement, the boy completely recovered and was started on a lower daily dose (2.5mg) of baclofen with a gradual increase to 10mg daily (Mishaal, et al.2020). The second case study involved a 9-year-old girl admitted streptococcal toxic shock syndrome and severe AKI (Mishaal et al.2020). After 8 doses of 20 mg over 4 days, she experienced decreased breathing tone with upper airway obstruction, altered level of consciousness, and was not responsive to painful stimuli. Baclofen was discontinued and after 10 hours, LOC, hemodynamics and respirations returned to baseline (Mishaal, et al. 2020) Mishaal (et al.2020) contends that there is “need for reduced initial dose, slow titration, and close monitoring when initiating baclofen treatment in children with AKI.”

### Implications for NLCPs

As a valuable member of the interdisciplinary professional team, each nurse life care planner (NLCP) is in strategic position to identify and mitigate medication errors before these become embedded in the nurse life care plan (NLCP). Armed with the Standards of Practice (SOP), the NLCP conducts an assessment of the pediatric subject’s physical, clinical, psychosocial factors, cognitive and age-related milestones, including, but not limited to identifying the child’s age, weight, BMI, and other pertinent data. Through nursing diagnosis and outcome identification, the NLCP identifies potential and actual risks related to improper calculation of medication dosages (both suboptimal and excessive) that may cause decompensation in body systems and minimize therapeutic effect in the pediatric subject. The NLCP evaluates prescribed medication regimen for side effects and potential adverse reactions, and presence or absence of drug monitoring protocols by consulting with various resources, including, but not limited to drug manufacturer, on-line information from credible and authoritative sources, the Food and Drug Administration (FDA), and of course the pharmacist. The pharmacist is one of the most valuable
resources accessible to a Nurse Life Care Practitioner to answer most medication related questions. As a matter of fact, collaboration with the treating provider and consultation with the pharmacist regarding pediatric medication regimen will align the NLCP’s actions with the Standard 13: Collaboration in the NLCP Standards of Practice. Through the planning phase, the NLCP incorporates in the nLCP the necessary parameters for safe medication administration, including calibrated dosage cups, syringes, spoons for accurate administration of liquid medications, proper storage of all prescribed medications, evaluations cost of and access/availability to prescribed therapeutics. The NLCP educates the consumer of the nLCP regarding safe use of prescribed medications. Additionally, the NLCP collaborates with pertinent disciplines, including, but not limited to, the family/significant others, and guardians (when appropriate) regarding caregiver availability to administer, and/or monitor safe administration of medications across the pediatric subjects’s life expectancy. The NLCP considers incorporation of case management services for pediatric NLCP subjects where lack of parental involvement is evident, or later in life when the primary caretakers may be unable to perform the task due to aging or death.

Conclusion

Pediatric medication dosing, especially in complex medication regimens and diverse disease trajectories prove challenging to healthcare providers across a majority of healthcare settings. Multiple factors are considered in pediatric dosing, including but not limited to the child’s age, body weight, body surface area, BMI, clinical parameters and indication, hemodynamics, clinical setting, specific types of clinical interventions, and drug properties. Despite consideration of all of the aforementioned factors in pediatric dose calculation, the rate of erroneous dose calculation remains high. Experts in the pediatric field contend that an increased effort should be exerted by all pertinent stakeholders in order to minimize pediatric dosing errors, including standardization of weight measurement parameters into metric, limiting weight estimation, and standardizing weight/age appropriate dosing. Nurse life care planners are in a unique position to mitigate dosing errors for pediatric subjects of nurse life care plan by adhering to the nursing standards of practice, collaborating with physicians and pharmacists, and accessing pertinent information through credible sources.

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Children 2020, 7(11), 242; https://doi.org/10.3390/children7110242


REFERENCES


Cerebral palsy is a term that describes impairments in movement and posture attributed to a non-progressive disturbance in a developing brain (Baxter et al., 2007). Cerebral palsy can also fall under the construct of neurodevelopmental disability. Neurodevelopmental disorders are defined as “chronic disorders that affect central nervous system function during the developmental period in the domains of motor skills, communication, cognition, and/or behavior” (Ismail & Shapiro, 2019). Additional diagnoses that fall under neurodevelopmental disorders include intellectual disability, autism spectrum disorder, epilepsy, learning disabilities, attention deficit/hyperactive disorder, blindness, and deafness (Ismail & Shapiro, 2019).

Children with neurodevelopmental disabilities can present with a variable presentation of functional impairment(s) and associated comorbidities. Cerebral palsy can be classified based on anatomic involvement (hemiplegia, quadriplegia, diplegia, monoplegia), movement (spastic, dystonic, hypotonic, dyskinetic, ataxic), and functional classification (Gross Motor Function Classification System and Manual Ability Classification System) (Vargus-Adams, et al., 2021).

When identifying the care needs of a child with a neurodevelopmental disability, it is essential to understand the child’s symptom complex, medical management, and recommended surveillance to develop an individualized plan of care. This article will explore common co-morbidities associated with neurodevelopmental disabilities and considerations to integrate in the development of a life plan.

Keywords: Neurology, Developmental, Cerebral

NURSING DIAGNOSES TO CONSIDER NANDA-I 2021-2023

1. Domain 1- Health promotion. Class 2. Health management
3. Domain 9-Coping responses. Class 3. neurobehavioral Stress

Complexities of Children with Cerebral Palsy and Neurodevelopmental Disabilities

By Kristin Clarkson DNP, CPNP-AC, CRRN, CNLC
care plan. Co-morbidities explored in this article include intellectual disability, seizures, spasticity and related disorders, oral motor and pulmonary considerations, bowel and bladder dysfunction, musculoskeletal and functional impairments.

Intellectual Disability

Intellectual disability refers to impairments of mental abilities that relate to adaptive functioning with a focus on abilities and skills related to language, reasoning, mathematics, interpersonal communication skills, personal care, vocational responsibilities, and organization (American Psychiatric Association, 2013). To provide a diagnosis of intellectual disability, clinical evaluations and standardized intelligence assessments should be utilized (American Psychiatric Association, 2013). Pediatric neuropsychologists can provide comprehensive testing exploring a child’s strengths and weaknesses, as well as adaptive functioning. Initial neuropsychology screenings should be considered prior to school entry and follow up evaluations dependent on the child’s cognitive function and learning needs. Results from standardized testing and clinical findings guide the neuropsychologist in developing accommodations that can be utilized in multiple environments; as well as developing an Individualized Education Plan or 504 plan in the educational setting.

Seizures

Seizures are a result of abnormal neuronal discharges associated with alteration in behaviors or sensorimotor function (Major & Thiele, 2007). It is estimated that 22% of those with an intellectual disability have a seizure disorder (Robertson et al., 2015). When seizures are suspected, children should be referred to neurology for evaluation, consideration of electroencephalography, and potential neuroimaging. Seizures can be classified based on patterns identified on electroencephalogram (EEG) and semiology (Marks & Eschbach, 2021). Epilepsy is diagnosed after a child has two seizures at least 24 hours apart (Fisher et al., 2014). Treatment selection is based on the type of seizure, An anti-epileptic drug is usually the first line of treatment initiated. If seizures remain refractory to anti-epileptic drugs, other management strategies, such as the ketogenic diet or surgical options, can be explored. Surgical options such as a hemispherectomy, corpus callosotomy, or placement of a vagal nerve stimulator or responsive neurostimulator system can be explored when seizures remain uncontrolled and the child has been therapeutic on two appropriate anti-epileptic drugs (Marks & Eschbach, 2021).

Spasticity & Related Disorders

Children with neurodevelopmental disabilities can exhibit alterations in movement, muscle tone, and posture that can come with both positive and/or negative implications. Common neurologic manifestations include spasticity, dystonia, and dysautonomia. Spasticity is defined as a “motor disorder characterized by a velocity dependent increase in stretch reflexes with exaggerated tendon jerks” (Lance, 1980). Spasticity can affect gait kinematics, seating/positioning, and comfort. Dystonia presents as sustained or intermittent muscle contractions leading to abnormal postures and/or twisting movements (Sanger et al., 2003). Spasticity and dystonia can present together and respond to similar treatment methods. When treating spasticity, the provider and patient/family should discuss goals in treating the spasticity.

Questions a family may want to consider could be: Can we improve comfort? Prevent deformity? Improve ease of care for caregivers?

Spasticity may have positive effects such as utilizing tone to assist in transfers or maintaining head control and eliminating spasticity may not be beneficial in this situation. All children with abnormal tone and posture should receive physical therapy to improve range of motion, decrease contracture development, and focus on gross motor strengthening. If spasticity or movement disorders are generalized, pharmacologic options may be pursued. Common drugs utilized in spasticity management are baclofen, diazepam, tizanidine and dantrolene. Baclofen can also be delivered via a surgically implanted pump, with doses much lower than enteral dosing. Another surgical option that can be explored is a selective dorsal rhizotomy, which involves severing sensory nerve rootlets that contribute to spasticity (Park & Johnston, 2006). If spasticity presents in a focal presentation, consideration can also be given to botulinum toxin injections and alcohol nerve blocks.

Another phenomenon that can present with spasticity or dystonia is dysautonomia. Dysautonomia can also be referred to as autonomic dysfunction, thalamic storming, or paroxysmal sympathetic hyperactivity. Autonomic dysfunction can be related to “impairments in the central nervous system that regulate sympathetic outflow” and can lead to alterations in heart rate, respiratory patterns, temperature regulation, blood pressure, facial flushing, and diaphoresis (Berg et al., 2021; Hauer, 2013). The etiology of dysautonomia is not always clear and treatment methods are supportive. Pharmacologic management can include the use of clonidine, benzodiazepines, propranolol, and gabapentin.
**Oral Motor and Pulmonary Impairments**

Oral motor difficulties can present with alterations in chewing, swallowing, saliva management, and expressive language difficulties (Vargus-Adams et al., 2021). For the child with neurodevelopmental disability, it is essential to monitor feeding abilities and growth parameters to ensure the child is meeting caloric requirements. Signs of feeding difficulties can include increased feeding times, refusal of oral intake, and recurrent respiratory difficulties. If there is concern for feeding safety, evaluation with a speech language pathologist and/or occupational therapist should be sought. Therapists can provide oral motor exercises or strategies to improve oral mechanics. If the child is unable to demonstrate safe oral consumption and/or meeting adequate growth parameters, alternate means of nutrition (nasogastric tube or gastrostomy placement) should be considered. A modified barium swallow can provide radiographic evidence to assist in identifying dysphagia and aspiration to delineate further management options in feeding. A nutritionist can also provide guidance in meeting caloric requirements, supplementation options, monitoring growth, and enteral nutrition recommendations.

Sialorrhea is difficulty in swallowing and controlling oral secretions, usually due to a lack of oral motor control (Sabado & Owens, 2020). Sialorrhea can lead to perioral dermatitis, aspiration, and altered body image. The family may need to carry a travel bag that includes a portable suction kit if the child cannot maintain adequate secretion management. Pharmacological options such as glycopyrrolate and scopolamine have shown to be effective in managing secretions. If enteral medications are not successful, the use of botulinum toxin to the submandibular and parotid glands can be trialed. Surgical options can also be explored such as duct ligation, gland excisions, or duct relocation (Glader et al., 2016). Oral motor dysfunction, sialorrhea, aspiration, musculoskeletal impairments, and poor nutritional status can all contribute to respiratory difficulties. During times of illness, close supervision should be provided to ensure respiratory stability. If the child has a prolonged illness or a neuromuscular condition that prevents adequate secretion mobilization, considerations such as a percussion vest, cough assist device, and suction machine can be recommended.

**Bowel and Bladder Dysfunction**

Functional impairments and intellectual disability were found to be factors related to both urinary and fecal incontinence in children (Samijn et al., 2017). In children with cerebral palsy, spasticity of the detrusor muscle can lead to small and frequent voids (Murphy et al., 2021).

Lower urinary tract symptoms that can also occur include retention, hesitancy, bladder distention, and urinary tract infections (Hauer, 2013; Murphy et al., 2021). If a child has recurring urinary tract infections or difficulty voiding, urodynamic studies may be utilized to identify an etiology.

Constipation is quite common in children with severe disabilities and can be caused by medication, lack of ambulation, and nutrition (Veugelers et al., 2010). If constipation is not treated, it can lead to further complications such as impaired voiding, megacolon, visceral hyperalgesia, small bowel obstruction, vomiting, or feeding intolerance (Hauer, 2013). Treatment options for constipation can include diet or medication changes, hydration supplementation, laxatives, stool softeners, stimulants, or enemas. Adaptive toileting systems should be prioritized to improve independence in elimination. If a child is unsuccessful in achieving continence, incontinent supplies such as diapers, pads, condom catheters and/or urine collection systems can be used.

**Musculoskeletal Impairments**

Impaired muscle tone and gait kinematics can lead to musculoskeletal impairments. Contractures develop as the muscle tendon complex is shortened due to immobility, spasticity, or disuse. To prevent contracture formation, management can include the use of orthoses, spasticity management, physical therapy, botulinum toxin injections, serial casting, and/or orthopedic surgery. For children with cerebral palsy, hip surveillance is important to identify hips at risk for subluxation which can lead to pain and impaired function (O’Donnell et al., 2017). Recommendations for hip screening are based on a child’s functional status and age until the child reaches skeletal maturity (O’Donnell et al., 2017). Clinicians can also frequently screen the spine as well to evaluate if a spinal deformity is developing. Scoliosis (a curvature greater than ten degrees) can lead to difficulties in positioning, respiratory function, and pain. When a curvature measurement reaches 40-50 degrees, surgical options may be considered to avoid the development of complications associated with scoliosis.

Orthoses are commonly prescribed to improved function, range of motion, gait, and prevent further deformity. In children, orthoses will be molded to the child and replaced according to growth. Upper extremity orthoses are commonly utilized to allow an open hand posture and to prevent contracture formation at the elbow, wrist, and fingers. Lower extremity orthoses can assist in improving gait kinematics and also decrease contracture formation at the knee, ankle, and foot. Thoracic lumbar sacral orthoses may be prescribed for children with scoliosis, although there is a lack of research to support that bracing can decrease the progression of scoliosis. Thoracic lumbar sacral orthoses may be helpful in improving seating balance and posture.
Impaired Function

To improve function, the rehabilitative plan should focus on treatment modalities that increase independence, quality of life, and meet the patient’s and family’s goals. Along with orthoses, identifying adaptive equipment may be necessary to aid in mobility and activities of daily living. Wheelchairs (power and manual), strollers, floor sitters, adaptive car seats, standers, gait trainers, walkers, bathing/toileting systems, enclosure beds, lifts, adaptive seating, and/or augmentative communication devices are commonly identified pieces of equipment that children with neurodevelopmental disabilities may benefit from. An evaluation with a certified assistive technology professional and skilled therapist can explore appropriate equipment options for the child with a neurodevelopmental disability.

Therapy services are also essential to the rehabilitative plan of care. Children should be evaluated for physical therapy, occupational therapy, and speech language pathology services as soon as functional impairments or developmental delays are identified. Pediatric based physical therapy focuses on gross motor skills, endurance, strengthening and developmental skill progression. Occupational therapy can include fine motor engagement, visuospatial/sensory integration, and activities of daily living. Speech language therapy focuses on receptive and expressive language skills, articulation, feeding, and swallowing skills. Therapeutic modalities utilized during therapy sessions are dependent on the child’s needs and clinician resources at hand. Services can be delivered through early intervention services, school, home-based, inpatient, and outpatient settings depending on the child’s age, goals, and clinical need. Additional therapeutic services that may be offered include vision therapy, orientation and mobility, hippotherapy, or aqua based services. Hippotherapy is therapy services engaged with a horse that can focus on proximal control, sensory integration, and even language skills. Recreational activity is paramount for a child of any age and resources should be identified to allow children with disabilities to engage in adapted services. Engaging children in adaptive recreation can promote physical activity, group learning skills, and teamwork.

Life Care Plan Considerations

Pediatric life care plans can be developed for the child’s life span, but an alternate consideration could be to calculate the child’s total needs until the age of 21. Medical surveillance should include ongoing management with multiple subspecialists, including, but not be limited to: a pediatrician, complex care center, pediatric rehabilitation medicine, neurology, orthopedics, pulmonology, urology, ophthalmology and otolaryngology. Therapeutic modalities can include physical therapy, occupational therapy, speech language therapy, vision therapy and nutrition services. Children are likely to receive school based therapy services. The frequency of therapy services identified in the life care plan should integrate all therapy resources available to the child. Diagnostic studies can include radiographs for orthopedic or pulmonary surveillance. Other routine studies can include electroencephalograms if the child has a seizure disorder or polysomnography if the child has obstructive sleep apnea. If surgical interventions are recommended, procedures and associated costs can be included in the life care plan. Equipment recommendations can include orthoses, durable medical equipment, and adaptive rehabilitative equipment with appropriate replacement intervals.

Parenting a child with neurodevelopmental disabilities can produce significant emotional and financial stress. Psychological counseling services can be recommended for both parents and children. Children may require counseling services for adjustment or mood disorders that may present with living with a disability. Neuropsychological services should also be included for initial and follow-up evaluations. If vocational training is desired, vocational evaluation and job training services can be presented in the life care plan. Depending on the complexity of the child, case management services may be recommended to assist the family with coordinating medical and therapy appointments, procuring appropriate supervision in the home, and selecting appropriate long-term needs. Skilled care needs can include nursing or home health aide assistance, if required. Respite services should also be considered for parents of children with complex medical requirements. If long-term living arrangements are unclear, costs for care at home and skilled placement can be included in the life care plan. Home costs can explore home modifications and home care staffing. Facility care can range from group home living environments, supported independent living, or long-term care placement.

Developing a life care plan for the child with a neurodevelopmental disability should focus on the child’s specialized needs across the life span. Recommendations should focus on optimizing function and enhancing quality of life. The nurse life care planner should collaborate with the child, family, medical and rehabilitative team members to develop the most comprehensive life care plan.
REFERENCES


Introduction

At times an attorney will require assistance when crafting a surgical letter for a surgeon to indicate what type of future surgery will be necessary for a plaintiff. These recommendations from the surgeon in the letter will then require appropriate cost research for the plaintiff’s geographical location. To be clear, this is not a life care plan, which is an in-depth report for all future care needed. A surgical cost letter will include the surgery and costs for a specific surgery, which includes pre-operative care, day-of-surgery costs, and post-operative care.

This article will cover what needs to be included in the letter or report, foundation, determining the care needed, and how to locate costs for the items. This will all help to ensure that all the reasonable future costs are outlined in the Surgical Letter.

This is Not a Life Care Plan

Again the plaintiff’s attorney does not need a life care plan: a lengthy report that involves a full review of available records, an interview with the injured person, communication with physicians and other providers, or an analysis of the reasonable charges for all the care needed.

The defense attorney does not need any analysis of the plaintiff’s life care plan, medical records and communication with expert physicians and other experts, and then an analysis of the reasonable charges for all the needed care.

Only a short report is needed. Surgeons often create surgical letters, although they may not know the reasonable charges in their community for physician care, facility care and other related needs. So, the attorney may rely upon a life care planner, who is very familiar with methods to determine reasonable charges.

What Needs to Be Included in the Letter or Report?

You have been asked by the plaintiff’s attorney or the defense attorney to calculate the cost of a single surgery. What does this entail?

A surgical letter is a letter of the expected costs for a specific surgery that a surgeon anticipates. The purpose of the letter is to provide a budget for the expected future costs to complete the surgery.
Life care planners have an advantage when determining charges for a procedure. Since the attorney needs to know ALL the costs involved, you will need to provide a comprehensive report.

**Foundation:**
How do you know what the surgeon is proposing? This may come from a medical record, a letter from the surgeon, a Surgical Letter from the surgeon’s office, or deposition transcripts. As well, the attorney may simply request that you find the costs for a surgical procedure that they name. You may also have the opportunity to talk to the surgeon.

**Items to Be Included:**
A complete surgical letter may include the costs for all the following factors:

- **Pre-operative:**
  1. Pre-operative assessment by the surgeon
  2. Pre-operative clearance by the primary care provider or an internist or other specialist
  3. Labs
  4. Radiology or diagnostic imaging
  5. Cardiac and Respiratory assessment
  6. Pre-operative therapy evaluation and home assessment
  7. Durable Medical Equipment and Supplies

- **Day of Surgery:**
  1. The facility
  2. Surgeon and assistant to the surgeon
  3. Hospitalist (if there is a stay involved.)
  4. Anesthesia
  5. Neuromonitoring

- **Post-operative Care:**
  1. Medications
  2. Office visits and radiology
  3. Therapy
  4. Equipment and supplies
  5. Home nursing or therapy

**Details for Determining Type of Care**

**Pre-operative:**
1. Pre-operative assessment by the surgeon, usually a consultation
2. Pre-operative clearance by a primary care provider, other specialist, or a pediatrician in the case of a child. This is usually a consultation, even if the patient usually sees this provider regularly, to accommodate the extended nature of the visit
   - Labs, which could be based on the American Family Physician Association or may include labs for patient-specific conditions. For non-cardiac surgery, this is usually Complete Metabolic Panel (CMP) Complete Blood Count (CBC), possibly a urinalysis if there is an implant anticipated, and perhaps a pregnancy test for those of childbearing age.
   - Radiology or diagnostic imaging for a chest x-ray and possible further assessment of the surgical area, depending on the surgeon’s needs, including MRI or CT of the body-specific location of the proposed surgery.
   - Cardiac and Respiratory assessment, including electrocardiogram (EKG) and possible a stress test for cardiac issues or pulmonary function test for chronic respiratory issues.
3. Therapy evaluation and home assessment may be needed to accommodate other conditions or disabilities, and to prepare the home for post-operative care.
4. Durable medical equipment and supplies such as walkers, canes, shower chairs, handheld showerheads, wheelchairs, elevated toilet seats, ice machines, and continuous movement devices.
5. Labs and testing may need to be done at the facility of the proposed surgery or at a national laboratory or imaging facility to ensure that test results are available on the day of surgery.

**Day of Surgery:**
1. The facility, either in-patient or outpatient facility
2. Surgeon and assistant to the surgeon
3. Implants and equipment applied in the Operating Room
4. Hospitalist for managing other medical conditions if staying overnight at a facility
5. Anesthesia, including general anesthesia, and the additional costs for regional anesthesia, and for co-morbidity care
6. Neuromonitoring for spine or brain surgery, sometimes needed for other surgery
Post-operative Care:
1. Medications for pain, inflammation, or muscle spasms
2. Office visits as follow up with the surgeon and x-rays at the office
3. Physical or Occupational therapy evaluation and number of sessions
4. Possible home nursing and therapy
5. Possible rehab hospital for those with co-morbidities or living alone.
6. Housekeeping and other services

How to Find the Costs for the Surgical Letter
If you are talking with the physician or assisting the attorney before they take the deposition of the surgeon, be sure to mention details needed. For example, do they need inpatient or outpatient surgery, do they need neuromonitoring, how much therapy is needed after surgery, and what medications, equipment, and home supports are needed at home?

If you do not have access to the surgeon, then use the information you do have to determine the usual codes and costs based on your experience as a life care planner.

How to Find the Costs for Pre-operative Care:

Use your usual method of determining reasonable charges for medical care

1. Pre-operative assessment by the surgeon, this is usually CPT code 99244 in a medical office. CPT 99244 - Office consultation for a new or established patient, which requires these 3 key components: A comprehensive history; A comprehensive examination; and Medical decision making of moderate complexity. Counseling and/or coordination of care with other physicians, other qualified health care professionals, or agencies are provided consistent with the nature of the problem(s) and the patient’s and/or family’s needs. Usually, the presenting problem(s) are of moderate to high severity. Typically, 60 minutes are spent face-to-face with the patient and/or family.

2. Pre-operative clearance by a primary care provider or a pediatrician in the case of a child. This is usually a consultation, (CPT 99244) even if the patient usually sees this provider regularly, to accommodate the extended nature of the visit.

3. Labs and radiology or diagnostic imaging:
   a. For outpatient surgery, it is likely that a national laboratory can do the testing, and you can do your usual cost research for the correct CPT codes.
b. For inpatient surgery, you may need to determine the costs for these tests at the same hospital as the surgery will be at. Use your hospital-based cost research for this.

4. Cardiac and Respiratory assessments are consultations with the respective physician specialists. Use a consultation code. There may be a need for additional testing before clearance is issued, for example pulmonary function tests or cardiac stress tests.

5. Therapy evaluation and home assessment: A physical therapy pre-operative evaluation is CPT code 97162. CPT 97162 - Physical therapy evaluation: moderate complexity, requires these components: - A history of present problem with 1-2 personal factors and/or comorbidities that impact the plan of care; An examination of body systems using standardized tests and measures in addressing a total of 3 or more elements from any of the following: body structures and functions, activity limitations, and/or participation restrictions; An evolving clinical presentation with changing characteristics; and Clinical decision making of moderate complexity using standardized patient assessment instrument and/or measurable assessment of functional outcome. Typically, 30 minutes are spent face-to-face with the patient and/or family.

6. Durable medical equipment and supplies: many of these items can be purchased from department stores and larger pharmacies. Do an online search at Amazon, Wal-Mart, CVS pharmacy, Walgreens, or other well-known providers to determine the cost for each item. If there are unusual items, you may need to call your local medical supplier or do online research. Examples include rentals of ice machines and continuous movement machines.

Day of Surgery:

1. Facility costs for in or outpatient surgery. If this letter is for inpatient surgery, then you need to determine the correct DRG code in order to do cost research. For outpatient surgery, you can do facility research using all the codes that the surgeon will be billing for.

2. Surgeon and assistant surgeon costs. You need to know what codes are used for this particular surgeon, and if an assistant is usually needed. If you are not sure about the need for an assistant to the surgeon, consider looking up each CPT code in “Guidelines for assistants to surgeons, Assistants at Surgery.” American College of Surgeons and other surgical specialty organizations review all procedures listed in the “Surgery” section of the American Medical Association’s Current Procedural Terminology (CPT TM).

3. If the patient is receiving a “pass-through” implant such as a pulse generator, there will be additional charges from the facility for this equipment if at an out-patient facility. This is usually included in the hospital charge for in-patient care.
4. If it is anticipated that there will be any equipment such as a leg brace or a neck brace or any ice pad placed on the patient immediately following surgery, be sure to get the cost for this, as well from the out-patient facility, as this is usually an additional charge.

5. Hospitalists may be needed, if the patient is staying overnight, to manage the other medical conditions they may have.

CPT 99221 - Initial hospital care, per day, for the evaluation and management of a patient, which requires these 3 key components: A detailed or comprehensive history; A detailed or comprehensive examination; and medical decision making that is straightforward or of low complexity. Counseling and/or coordination of care with other physicians, other qualified health care professionals, or agencies are provided consistent with the nature of the problem(s) and the patient's and/or family's needs. Usually, the problem(s) requiring admission are of low severity. Typically, 30 minutes are spent at the bedside and on the patient's hospital floor or unit.

CPT 99231 - Subsequent hospital care, per day, for the evaluation and management of a patient, which requires at least 2 of these 3 key components: a problem focused interval history; A problem focused examination; Medical decision making that is straightforward or of low complexity. Counseling and/or coordination of care with other physicians, other qualified health care professionals, or agencies are provided consistent with the nature of the problem(s) and the patient's and/or family's needs. Usually, the patient is stable, recovering or improving. Typically, 15 minutes are spent at the bedside and on the patient's hospital floor or unit.

CPT 99238 - Hospital discharge day management; 30 minutes or less

6. Anesthesia costs can be estimated based on the CPT codes that the surgeon will be billing for. You can do your usual cost research for this.

7. Neuromonitoring for spine or brain surgery, sometimes needed for other surgery. There is often a group that provides these services at your facility. Give them a call and ask what the charge will be, giving all the CPT codes for surgery and the patient's co-morbidities or ICD-10 codes.

Post-operative Care:

1. Medications for pain, inflammation or muscle spasms prices can be obtained by calling the patient's usual pharmacy or using an on-line service such as www.GoodRx.com

2. Follow up physician office visits are included (no charge) in the global period, 90 days for most surgeries. Determine how often the surgeon will want to see the patient back in the office, and will x-rays be done at the office? Although the office visit in the first 90 days is no charge, the site-specific x-ray will be billed.

3. Physical or Occupational therapy evaluation and number of sessions can usually be determined by the surgeon ahead of time. Sessions are usually one hour.

4. Possible home nursing and therapy. Based on the patient's condition and if they have any support at home, the patient may need additional help in the first two weeks, including having their dressings checked by a nurse at home, and the initial PT evaluation, and therapy done at home. Nursing home-visit costs can be obtained from home health or nursing agencies.

5. Possible rehab hospital for those with co-morbidities or lack of assistance at home. Ask the surgeon about how long the patient should be in rehab, and then, if they will still need help at home.

6. Extra help at home: Depending on the surgery, the patient may not be able to bathe without assistance or do housework or prepare meals for a period of time following their return home. Consider that an agency may need to send a home health aide for personal care. This can be determined by a phone call to a few agencies in your area. For housecleaning and meal preparation, do a google search or ask the patient if they sometimes use a cleaning agency, to get a cost estimate.

There may be additional medical needs that I have not outlined here. Be sure to describe the surgery planned, location and how you got your costs.

Even though this is a short report, you may have to testify to this, so use the same diligence you use for a full life care plan.
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United States Supreme Court Justice Potter Stewart is famous for writing in his concurring opinion in Jacobellis v. Ohio (1964), regarding the definition of pornography: “I have reached the conclusion... that under the First and Fourteenth Amendments, criminal laws in this area are constitutionally limited to hard-core pornography. I shall not today attempt further to define the kinds of material I understand to be embraced within that shorthand description; and perhaps I could never succeed in intelligibly doing so. But I know it when I see it, and the motion picture involved in this case is not that.” (Emphasis added). Within a decade, the Court, in Miller v. California (1973), provided a three-prong test regarding what constituted obscenity. Still, it is difficult to ascertain a “bright line” rule for precisely indicating what actions are considered protected versus unprotected speech/ expression under the First Amendment. Does the same “I know it when I see it” phrase apply to sexual grooming?

In a 2015 American Bar Association article in Child Law Practice, “Understanding Sexual Grooming in Child Abuse Cases,” we wrote:

“In many child sexual abuse cases, the abuse is preceded by sexual grooming. Sexual grooming is a preparatory process in which a perpetrator gradually gains a person’s or organization’s trust with the intent to be sexually abusive. The victim is usually a child, teen, or vulnerable adult. Understanding sexual grooming and common sexual grooming behavior can help professionals prevent sexual abuse before it occurs. Evidence of sexual grooming can be used to convict offenders—in those jurisdictions where sexual grooming is a crime—and substantiate allegations of sexual abuse where a victim’s testimony is unclear or misleading.

The key elements of sexual grooming may include:
- targeting the victim,
- securing access to and isolating the victim,
- gaining the victim’s trust, and
- controlling and concealing the relationship (citations omitted).“
The federal legal definition of “sexual exploitation of children” can be found at 18 U.S. Code § 2251. It reads, in part: “Any person who employs, uses, persuades, induces, entices, or coerces any minor to engage in, or who has a minor assist any other person to engage in, or who transports any minor in or affecting interstate or foreign commerce, or in any Territory or Possession of the United States, with the intent that such minor engage in, any sexually explicit conduct for the purpose of producing any visual depiction of such conduct or for the purpose of transmitting a live visual depiction of such conduct, shall be punished…”

I was recently doing some yard work. In the process of pruning some bushes, a small thorn became embedded in my thumb. Ouch! I walked over to my neighbors – both parents are nurses. With their three small children looking on, after 15 minutes, they poked and coaxed the splinter out. In gratitude, I slipped the parents a $20 bill. Perhaps they would like to take the kids out for an ice cream sundae? Could an outside observer construe such a gesture as sexual grooming? The answer is ‘perhaps’. That suspicion could be reinforced if there was a pattern of such behaviors, as well as other questionable actions.

I had the opportunity to sit on the “Larry Nassar Commission,” formally called the Game Over Commission to Protect Youth Athletes. In our final report, John-Michael Lander, a former athlete who competed in international springboard and platform diving competitions, writes: “I want to clarify that predators are always lurking in the shadows and constantly evaluating, changing, and adapting their means of grooming. There is no set formula that a predator follows to groom a prey. Each predator’s approach and process are unique and individualized. The predator will pursue who they are attracted to and use their expertise to manipulate the situation and the victim. The one thing that they all have in common is the ability to excuse their actions convincingly (p. 68).”

While on the Commission, I wrote an article, “Children, Sports, and Sexual Groomers: Ten Commandments for Parents to Follow.” Modified, similar commandments apply to the health profession as well:

1. To the extent possible, children should not be left alone with a nurse, physician or other health professional. At least one other responsible person should be present.
2. Health providers should do a thorough background check into every adult who interacts with children. Whether the facility has a worldwide reputation or not, do not assume they are to be trusted with a child.
3. Parents should not give up, and health providers should not attempt to exert, authority over a child.
4. Administrators, and all staff, should be aware of the general culture that a healthcare facility has. Professionalism should reign.
5. If a health care staff member sees physically inappropriate behavior, they should report it immediately to the proper authorities. This might include law enforcement or child protective services. They should not try to smooth things over.
6. A child should never receive texts from a health care professional that do not also go to the child’s parent or guardian.
7. Health care professionals are not a child’s friend. They can be friendly, but they are not friends.
8. Be especially aware of particularly vulnerable children. Groomers have a knack for identifying them.
9. Provide staff with training and information that is designed to help them with skill development in this area. Some resources include:
   • National Sexual Assault Hotline, 1-800-656-4673
   • Many other resources are available at the Child Welfare Information Gateway, https://www.childwelfare.gov/pubs/reslist/tollfree/
10. Unfortunately, sexual grooming is more obvious in hindsight than in real time. And so, the best policy is the ‘roach approach’ – turn on the light!

REFERENCES

Coder’s Specialty Guide for Pain Management Review

By Dawn Cook, RN, CLCP, CNLCP

Keywords: Reference, Review, Pain Management

The Coder’s Specialty Guide for Pain Management from the American Academy of Professional Coders (AAPC) is a comprehensive coding guide for coding pain management medical care which includes code descriptions, tips, CCI edits, ICD-10 information, and much more.

Life Care Planners can benefit from this print or electronic book to assist in accurately determining the correct codes for future medical care related to pain management. I found this book to be comprehensive and complete. In its 527 pages, there is complete directions on finding the information professionals need. Updated coding books are provided for purchase each year. The 2023 issue should be released in early 2023.

Specialty Coders Guide Compared to CPT Guides, Digging Deeper

Life Care Planners can use the definition of a medical CPT (Current Procedural Terminology) code from the American Medical Association (AMA). CPT coding books are published by the American Medical Association (AMA) each year with rules and guidelines for the AMA’s CPT Editorial Panel. If you want to dig a bit deeper to understand the anatomy, injury, treatment and pain management goals, this book will bring you closer to your goal. Compared to a standard CPT coding book, this “Coders’ Specialty Guide” is divided into sections to assist with deeper comprehension of this medical specialty.

CPT Codes:

First, each code, even somewhat related to pain management, are arranged in numerical order. The first section (from pages 5 to 307) includes codes from CPT code 10035 to 99499 that may be related to pain management.

Each code has information to help further understand the code.
1. There is a code definition first.
2. Then “Clinical Responsibility” describes what is actually done.
3. Often there are coding tips such as what code might go with this code, and sometimes, what code is primary and must be included if you use this code. This helps you decide on the actual code and if any add on codes are needed.
4. CCI Alerts (National Correct Coding Initiative) is a long list of codes that are not usually allowed when this code is used.
5. Finally, there is a ICD-10 Cross Ref, so if the ICD is known, it can be checked to see if this is a code that might be used.

Many procedure codes have a diagram of the relevant anatomy and how the test or treatment may be given. This is helpful if you are trying to decide between a few codes.
HCPCS Codes:
The second section is for pain management HCPCS codes, such as temporary codes, medications and others.

The temporary codes have been created by the AMA for new or emerging treatments and usually are a 5-digit numeral, followed by a capital “T.” These have a longer clinical responsibility section, explaining in great detail what is included in these codes. There are also coding tips and CCI Alerts, and ICD-10 CrossRef.

The final section (in the 2022 copy, from pages 367 to 512) has ICD-10 codes in alphabetical and numerical order, with the definition.

Modifiers: Finally, there are ten pages with modifiers that may appear on bills to be added to the CPT code for better clarity.

Terminology: There is a terminology section if some of the medical terms are unfamiliar. (12 pages.)

Code Index: The code index is all of the CPT codes in this book, in numerical order, with the page the information is located upon.

Use for Medical Billing Analyses: Medical Billing Analyses need medical billing code information to accurately interpret past medical bills and compare them to their corresponding medical records for validity. This guide will be very helpful in viewing old bills as well.

Overview:
There is so much information in this specialty coding guide regarding the proper coding for pain management services, including office visits, testing, procedures and medications. This specialty coders book will be a great asset to the life care planner wanting to be more precise in coding for pain management care.

Where to Get this Book:
The AAPC Coders’ Specialty guide for Pain Management includes detailed information about each code that is related to pain management, including physician visits, physician procedures, related labs, and diagnostic imaging. Also included are rules and tips on correct coding and the NCCI (National Correct Coding Initiative) edits or alerts. There is a cross-reference to the related ICD-10 (International Classification of Diseases) codes.

The Coder’s Specialty Guide for Pain Management is available from the American Academy of Professional Coders (AAPC) and can be purchased on their website https://www.aapc.com/ This guidebook is available each year in paper or e-book format or as both the paper and e-book in a bundle. The 2023 issue will be available in January 2023.

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Value of CNLCP® Certification

As healthcare has become more complex, it is increasingly vital to assure the public that healthcare professionals are competent. Individual State Registered Nurse (RN) licensure measures entrance-level competence only; and, in so doing, provides the legal authority for an individual to practice nursing. It is the minimum professional practice standard.

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Similar to consumers knowing to seek out certification status within other professions (e.g., dentists, pharmacists), certification within the field of nurse life care planning has become an important indicator that a certified nurse not only holds state licensure to practice nursing, but is qualified, competent and has met rigorous requirements in the achievement of the CNLCP® credential.

The policies and procedures used by the CNLCP® Certification Board to construct and review items and examination forms for the CNLCP® examination are consistent with guidelines recommended by the American Educational Research Association, the American Psychological Association, and the National Council on Measurement in Education (AERA, APA, NCME; 2014) as well as other industry standards such as: Standards for the Accreditation of Certification Programs (National Commission for Certifying Agencies, 2014) and Conformity assessment — General requirements for bodies operating certification of persons (ISO/IEC 17024).

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