AGES AND STAGES IN LIFE CARE PLANNING

POST-POLIO SYNDROME
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Greetings, and welcome to the belated August issue of the JNLPC. We have an interesting mix of pieces looking at nurse life care planning considerations for cases across the age spectrum. It was an interesting process getting them all together, and kudos is due to your journal committee for chasing down authors and trying to hit deadlines. I hope you won’t have to wonder where the November issue is!

As we approach the end of a second year of uncertainty with COVID ever-present in the background, and still pushing itself to the forefront, I found this poem particularly resonant. Many of us have found our businesses upended. We see the well-meant attempts to look on the bright side and resume normal life be thwarted by a persistent, pernicious, and ever-mutating reality.

Our hopefully anticipated “hot summer” of joyous reunions, meetings, travel, family, and work has turned perforce into yet another summer of Zoom and FaceTime and masks. Even the summer sports scene is disrupted, with the Olympics and Paralympics playing out in empty stadia, football and baseball games postponed or error-prone, college teams not sure of scheduling.

A second set of birthdays has passed without lovely dinners out and family gatherings; the summer theater was gone; more long-term colleagues are calling it quits and retiring.

There are still moments of joy in watching a bumper crop of squirrels and following birdsong. Our woodshed is chockablock full with split maple and ash to warm and perfume our winter. We are finding ways to incorporate such little treats into our lives as we ruefully decide whether or not to upgrade our business attire to sizes to accommodate our personal COVID nineteen (or twenty or more) and avoid the higher-calorie consolations.

Meanwhile, I think it is more important than ever to try to breathe deeply. Our own particular mountains will still be there when we have more energy to climb them.

Warm regards,

Wendie A. Howland
MN, RN-BC, CRRN, CCM, CNLCP, LNCC
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P.S. Nobody got the rebus puzzle right, so no Dr. Fauci bobblehead went out and he’s still face-palming on my window sill. Suggestions?
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.

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- All accepted manuscripts are subject to editing, which may involve only minor changes of grammar, punctuation, paragraphing, etc. However, some editing may involve condensing or restructuring the narrative. Authors will be notified of extensive editing. Authors will approve the final revision for submission. The author, not the Journal, is responsible for the views and conclusions of a published manuscript.
- Submit your article as an email attachment, with document title article_name.doc, e.g., wheelchairs.doc

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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AANLCP JOURNAL OF NURSE LIFE CARE PLANNING

ISSN 1942-4469
Dear Members, Colleagues and Fellow Nurse Life Care Planners,

If there has been one thing we learned over the last year, it’s that no one has all the answers to the plethora of questions that still remain unanswered.

I spent hours wondering how a virtual conference was going to be perceived and if the online experience would enrich and benefit our members and participants. The feedback has been overwhelmingly positive and has exceeded all my expectations. Not only were we able to deepen our knowledge, and widen our horizons, we were able to make meaningful connections and engage in conversations that were of value to us.

The world does not yet have all the answers, but I realized that instead of worrying what might be, working alongside our peers, led to not only a successful event, but created new ways of thinking with a bucket of fresh ideas.

And while the world depends on others to conduct research and answer questions, the ones who trust us with developing their Life Care Plans look upon us for knowledge, guidance and expertise to answer their questions. I wish each and every one of you the ability to focus on the process, to draw from the connections you have made, and to be able to take the first step toward a challenge with less worry – may it be for the development of a complicated Life Care Plan, the start of your own business, or the preparation for an anticipated difficult deposition.

We don’t have to individually produce all the answers. Experts and leaders around the world gain knowledge by collaborating with others, sharing their experiences, conclusions and studies. I’m forever grateful for all of you, who continue to support the association, share their knowledge, provide feedback and are engaged, and who, with much enthusiasm, are providing to each other a pillar for others to lean on, so we can grow in our profession and provide answers for others.

I loved meeting so many of you during our annual conference and look forward to strengthening these new relationships as well as making new connections. Please reach out to me or any of the board members to share your ideas, comments and suggestions, so the Association can continue to provide the education and connections needed to answer questions.

With gratitude,

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

“Interdependent people combine their own effort with the efforts of others to achieve their greatest success.” - Stephen Covey – American Author and Educator
Hello

I wanted to reach out and extend my gratitude for the Journal of Nurse Life Care Planning!

I entered this world after various nursing roles in the clinical and management settings and have fallen in love – but it has not always been a pretty story. I had a LOT of questions, and it seemed that Google could not comprehend my searches. That initial lack of immediate access to a broad data field can be intimidating for someone new to the field. I needed a resource that specifically pertained not only to the content of my field, but to the business aspect as well.

And lo and behold – I joined the AANLCP and discovered a PRICELESS resource!

Whether it is a pricing question (Spring, 2018), a tech-inquiry (Fall, 2019) or about all the “behind the scenes” aspects of our chosen professions (Spring, 2021), we are blessed to have access to content that is specifically applicable to our vocation. It is a wonderful opportunity for our group to create and sustain elevated expectations, stay current, and gain the gift of experience from those that paved the way for us newbies.

Thanks again and keep it coming!

Sincerely,

Jenn Masse

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Contributors to this Issue

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Andrea K. Goicoechea, MSN, RN, WHNP-BC, PHN
was introduced to nurse life care planning via legal nurse consulting work and the San Diego chapter of AALNC. Her background is in research, public health, and women’s health. Andrea currently works as an independent contractor with Liz Holakiewicz & Associates, and is appreciative of her mentors and the support from AANLCP members.

Shirley Daugherty, RN, CNLCP, MSCC
has worked in long term care as a staff nurse and in management. She began a nurse consulting business (Daugherty & Associates, LLC) in 2004 focusing on long term care consultation. She currently serves as the Secretary on the Certified Nurse Life Care Planner Certification Board. She is currently enrolled in the Family Nurse Practitioner Program (FNP) at Indiana Wesleyan University, with an expected graduation of October 2021. Contact her at shirley@daugherty-legalnurse.com
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Introduction
As technology advances for care of infants and children, tracheostomy (trach) placement is performed earlier in hospitalization. Most children with tracheostomy rely on tracheostomy and related medical technology for long-term survival (Watters, 2017). Historically the primary indication was acute airway obstruction secondary to inflammation, e.g., acute epiglottitis, diphtheria, or croup. Pediatric vaccination programs have successfully decreased these diseases and the need for pediatric tracheostomy in high resource settings (Parrilla et. al, 2007).

Indications
Fixed upper airway obstruction (either congenital or more commonly acquired secondary to prolonged intubation). Examples include subglottic stenosis, bilateral vocal fold paralysis, airway tumors, congenital airway malformations and syndromes. (e.g.: Pierre Robin Sequence, Treacher Collins, Beckwith-Wiedemann) As children grow, so do their airways, with a rapid growth phase up until age 3, followed by a slow growth phase and a second fast growth phase during adolescence (after age 11). (Luscan, R. et. al 2020). Otolaryngology specialists monitor with endoscopic visualization every 3-6 months to ensure that the trach tube size is appropriate. With growth and surgical intervention, many of these children can eventually have their trach tube permanently removed.

Long-term mechanical ventilator support for several clinical indications including:
• severe bronchopulmonary dysplasia (BPD)
• congenital diaphragmatic hernia

Keywords: Tracheostomy, Pediatric, Tracheostomy care, Artificial airway, Sputum

NURSING DIAGNOSES TO CONSIDER
NANDA-I 2021-2023
1. Ineffective airway clearance,
2. Impaired verbal communication
3. Risk for aspiration
4. Risk for infection
5. Impaired breathing pattern

Marsha L. Blount MSN, APRN, CNP • MB Consulting Services LLC
• airway malacia
• neuromuscular disease, central neurologic conditions
• forms of respiratory insufficiency, acute and progressive
• traumatic brain injury
• paralysis
• postinfectious sequelae

Regardless of the primary cause, these children are medically complex with significant morbidity and mortality. (Baker, C., et.al 2018)

Pulmonary toilet/airway clearance: Children with neuromuscular weakness, thoracic insufficiency and/or neurologic compromise can have poor secretion management with pooling of secretions, ineffective swallow, and poor chest wall function resulting in an ineffective cough. Tracheal access allows for more efficient secretion removal, inhaled medication delivery, intrapulmonary percussive ventilation, and cough assist.

Pediatric vs Adult Airway

Airway differences illustrate why pediatric tracheostomy tubes are not the same as adult tubes. (Figure 1)

• The pediatric airway is smaller and shorter. The cartilage is softer and more compliant compared to adults. Children are more susceptible to obstruction with negative pressure ventilation, especially with preexisting partial airway obstruction. (Singh, A. 2021)

• The head of the child is larger in proportion to the body and the tongue takes up a large portion of the oral cavity. The short neck makes for a difficult initial trach tube placement and can create significant risk with trach tube changes, sterile/clean suction technique, and monitoring of trach tube securement.

• The location of cricoid cartilage varies with age: at C4 vertebral level at the time of birth, and C6 in adults. The child's airway is narrowest at the level of the cricoid cartilage; an adult's is at the level of the vocal cords. (Watters, K. 2017)

• The epiglottis is short, and omega-shaped. The mucous membrane covering the supraglottic and subglottic parts of the airway are lax in infants and are more prone to edema when injured or inflamed.

• Children are primarily nose breathers. Nasal or nasopharyngeal obstruction in the neonate can predispose to life threatening periods of apnea.

Pediatric vs Adult Tracheostomy Tubes

Neonatal/pediatric tracheostomy tubes are manufactured as single lumen to save space, regardless of the brand, without an inner removable lumen, or inner cannula. Medtronic makes the Shiley tracheostomy tube products which are manufactured with a non-DEHP plasticizer. This new material has been incorporated into the soft, transparent flange that allows for enhanced visualization of the underlying skin and stoma site. [www.medtronic.com/covidien/en-us/products/tracheostomy/shiley-neonatal-pediatric-tracheostomy-tubes.html](http://www.medtronic.com/covidien/en-us/products/tracheostomy/shiley-neonatal-pediatric-tracheostomy-tubes.html).


Fenestrated trach tubes are not manufactured for pediatrics due to the small size of the airway.

Tube type, size, and length are typically determined with airway endoscopy. Pediatric trachs can be custom ordered with a range of options based on anatomy:

• swivel vs. fixed connection
• standard shaft length vs. a hyperflex (allows trach to extend or protrude away from the neck in small children with no visible neck space)
• cuff design and position.

Sizes are described using inner diameter and length measured in millimeters. The smallest neonatal/pediatric trachs have an inner diameter of 2.5mm and the largest pediatric trach with an inner diameter of 6.5mm. It is length of the trach tube that determines whether it is a neonatal or a pediatric tube: a neonatal trach, typically used in infants/children weighing less than 5 kg, is shorter in length than a standard pediatric trach.

Cuffed vs. uncuffed Both neonatal and pediatric trachs can be manufactured with and without a cuff. The cuff is adhered around the distal part of the shaft and can expand with placement of water or air. Generally, it is best if pediatric trachs are uncuffed based on small airway size but cuffed trachs can help regulate leak for long term mechanical ventilation. Cuffs can also help protect the airway from copious secretions.

Maintenance: Trach tube cleaning is performed only after the tracheostomy tube has been completely removed/exchanged with a new trach tube. Typically, in the home, used pediatric trach tubes can be cleaned and reused per manufacturer’s instructions up to 5 times. Most hospitals, due to infection control policies, immediately dispose of used trach tubes and avoid cleaning. Routine trach tube change frequency can be based on provider preference or patient-specific occurring as often as every week to once a month. Generally, trach tubes are changed routinely every two weeks.

Care of the Child with a Tracheostomy Tube

Humidification: The upper airway, the nose and mouth, is the natural mechanism of filtration, ciliary clearance, warming, and humidification. Trach placement bypasses this process. A child with a tracheostomy may experience increased cough, dryer and thicker pulmonary secretions, and increase of tube occlusion. Humidification is essential to reduce the risk of mucus plugs, tube occlusion, and further consequences. There are several devices available that can assist in humidification. Most ventilators have built-in humidifiers. Children who are not on mechanical ventilation frequently wear a heat moisture exchanger (HME) on the end of the trach tube as a filter for heat and moisture exchange (thermal humidifying filters, artificial noses, and Thermovent). During exhalation, the filter captures heat and moisture; during inhalation, the heat and moisture return to the lungs. Regular use of HME filter cassettes may help to keep secretions thin and alleviate increased production of mucus and coughing.

A trach collar or mist collar can provide humidification, especially when mucus is thick or blood-tinged or the child will not tolerate an HME, using aerosol tubing attached to a nebulizer bottle and air compressor. Oxygen can also be delivered if needed. Sterile saline drops or saline nebulizer can loosen thick secretions if they are difficult to suction.

Suction: Suctioning clears mucus from the tube and is essential for proper breathing. Also, secretions left in the tube could become contaminated and a chest infection could develop. The American Thoracic Society (Consensus Statement 1999) has issued standards of care.

• “Sterile technique” is the use of a sterile catheter and sterile gloves for each suctioning procedure, the typical method of suctioning in the hospital setting.

• “Clean technique” is the use of a clean catheter and nonsterile, disposable gloves or freshly washed, clean hands for the procedure, the usual method for suctioning in the home setting.

Suctioning should be done on the basis of clinical assessment. Children with no evidence of secretions should have minimal suctioning, at morning and bedtime, to check for tube patency.

Communication: The presence of a tracheostomy tube can limit the normal flow of air upward through the vocal cords. Upper airway obstruction further limits this process and creates complete absence of voice. The Passy-Muir valve, a one-way speaking valve, has successfully used to enable patients to vocalize after tracheostomy. There are, however, strict criteria for its use in children.

Determining patency of airway above the tracheostomy is key. This can be determined by a medical professional with use of a pressure gauge designed specifically for use of a one-way speaking valve. Unfortunately, one-way speaking valves provide no type of humidification and can create a more drying environment, producing thicker secretions and potential occlusion. Although there is extensive research to support the use of speaking valves in the adult population, use in infants and pediatric patients is frequently more challenging, and the literature is limited.

Absence of an effective and consistent communication modality has a negative impact on a child’s medical, psychological, and social well-being. (Zabih et al., 2017). Clinicians can introduce sign language and various types of communication boards as devices to assist children and give caregivers the ability to engage. Ensuring ongoing communication is an important aspect of care for children with tracheostomy tubes. Regular follow up with speech and language providers may be indicated.

Stoma care: Mucus and moisture under the trach tube flanges and rubbing of the tube can irritate the skin around the stoma. The skin around the stoma should be cleaned at least twice a day to prevent odor, irritation and infection; if the area is red, tender or smelly, even more frequently. Skin under the trach flanges and ties may even require a barrier
product to prevent skin breakdown and pressure injury. Trach tube ties typically need changing twice daily, and more often if the ties are wet or soiled.

**Trach Safety:** Tracheostomy in the pediatric population can be more technically demanding than in adults because infants and small children have short necks. Occlusion or decannulation requires a complete trach change due to the single lumen. Trach tubes can be dislodged and hidden under the chin or bib/clothing, making identification of decannulation difficult.

Replacing a dislodged or occluded trach can be difficult when trying to access the stoma. Trach tubes can be misplaced into a false track. Children with trach tubes must always have someone directly observing them. Trach care and planned or unplanned trach tube changes require two people. Children should never allow water into a trach, so bathing in a tub must be monitored closely and swimming is prohibited.

It is crucial to understand the difference between pediatric and adult airway anatomy and physiology before accepting responsibility. Occlusion of a pediatric trach tube or decannulation is an emergent situation that must be addressed by a trained caregiver. The most common tracheotomy-related cause of death has been reported to be cannula obstruction, followed by cannula misplacement and accidental decannulation. (Pavone, et al., 2020).

**Conclusion**

According to the Agency for Healthcare Research and Quality, there are over 100,000 tracheostomies performed per year in the United States, with over 4,000 performed on pediatric patients (2017). These surgeries often result in hospital readmissions with definite cost and caregiver burden. It has been estimated that upwards of 11% of children require 4 or more hospitalizations within 6 months after tracheostomy (Graf et al., 2008; Berry et al., 2009) and approximately 56.4% of children experience at least one hospital admission in the 2 years following tracheostomy.

Readmissions affect caregiver burden in part due to increased days missing from programs or school, and to their own time away from work. Much work has been done in the enormous related economic effects, and suggests that an established education program to improve caregiver training with tracheostomy care. Providing earlier, more timely follow-up with health care practitioners upon discharge can significantly diminish the number trach complications and the number of readmissions after discharge from pediatric tracheostomy.

The nurse life care planner must know the multicomplex needs of the child undergoing tracheostomy tube placement to project future health care cost. A plan should include but is not limited to:

- Routine healthcare provider visits (otorhinolaryngology, speech, occupational therapy, and nutrition)
- Routine (every 3-6 month) airway evaluation under anesthesia
- Trach tubes, supplies and, accessories
- Durable medical equipment (suction, ventilator, Ambu)
- Home nursing by a trained licensed nurse
- Individualized education program
- Psychological parent support via individual or group
- Caregiver education and training

**REFERENCES**

Agency for Healthcare Research and Quality.


REFERENCES


Introduction

The old adage that children are not little adults is no more apt than in traumatic brain injury (TBI). While brain maturation continues throughout adulthood, it is much more transformative going from early childhood into middle childhood and finally into adolescence – cognitively, emotionally, socially, and sexually. The purpose of this article is to raise awareness to the care needs that may arise for children post brain injury, as they struggle to master intra- and interpersonal relationships. This article will focus on Life Care Plan needs for these individuals.

For example, let’s take a look at 13-year-old Steven who has a known history of severe traumatic brain injury at age nine. He presents for a yearly evaluation to his physical medicine and rehabilitation physician (physiatrist). During the year Steven has been medically stable, without any seizure-like activity, hospitalizations, or sleep issues. He has transitioned into middle school with blended class structure with support and extra tutorial services through a local brain injury center. He remains emotionally immature for his age, tends to have friends who are younger, and at times is overly outgoing and friendly with difficulty defining social and personal space boundaries.

During the evaluation, the physiatrist inquired if there are any issues related to boy/girl relationships. Steven giggled than ignored further questions. At this point his case manager mentioned that he had been called to the principal’s office earlier in the year as a female classmate stated that Steven had touched her inappropriately, but the school looked into this and dismissed it. At this point the physiatrist had a long conversation with him, his mother, and the case manager regarding concerns for future sexual risks.

Keywords: Sexual promiscuity, sexual orientation, sexual risks, privacy, brain injury, secondary diagnoses, TBI

NURSING DIAGNOSES TO CONSIDER NANDA-I 2021-2023

1. Impaired social interaction
2. Impaired thought processes
3. Interrupted family processes
4. Sexual dysfunction
5. Risk for injury
6. Ineffective coping
7. Impaired social interaction
8. Risk-prone health behavior

Children with Traumatic Brain Injury & Sexual Risks
Neal Alpiner, MD, FAAP, FAAPMR, CLCP and Kimberly Reen, BSN, BS, RN, CLCP
Questions to consider:

• Did Steven understand the social situation and how it could be misinterpreted?

• Did he intentionally and inappropriately touch the other student because of impulse control issues?

• Did he act aggressively within the situation?

Context

Children with a TBI, especially those injured before 12 years of age, may exhibit social-emotional stagnation and immature behaviors commensurate with their age at injury. This sets up a very tricky scenario when the child continues to mature physically and sexually but has much younger emotional and social skills. This disconnect can lead to very sensitive gender situations.

These behaviors’ neurological origin may not always be easily identified, but certainly consideration should be given to certain medical diagnoses. It is important to evaluate what previous information might be helpful in defining actual present and potential future problems.

The importance of sexual related or perceived sexually related behaviors in children with a TBI should be sought after chart review, historical questioning, and forward presenting conversations with the child, parents, teachers, and paraprofessionals including occupational therapists, physical therapists, speech therapists, psychologists, and treating physicians.

Additional Records or Reports to Review (if available):

• Neuropsychology/psychology/social work reports
• Neuro imaging including MRIs/EEGs/Brain SPECT
• School records
• Brain injury program documents including outings and peer group classes

Possible medical diagnoses:

• Frontal lobe disinhibition syndrome
• Hypothalamic dysregulation with hormonal imbalances
• Temporal lobe seizures
• Hypersexuality disorder

These raise multiple important implications for the life care plan, given the literature review of sexual offenses in the brain injury population. Frequently children with a TBI are not held accountable or taken seriously for these behaviors; little intervention is done to educate and work on social role-playing or identifying the factors that fed into these behaviors. However, once a child turns 18 years old and enters adulthood, very frequently these behaviors are deemed socially inappropriate from a legal standpoint and can lead to devastating legal issues.

Life Care Plan Implications

First and foremost, the life care planner should recognize the existence and identify the symptoms within the history, followed by conversations with the child and treating team regarding those behaviors and how they can lead to long-term problems. Consider the following:

• Medical Providers
  – Physiatry is typically primary in TBI; more frequent evaluations are encouraged during adolescence to identify these issues.
  – Psychiatry to identify sexual behavior diagnoses that may require pharmacologic intervention.
  – Neuropsychology to identify deficient areas.

• Diagnostic studies
  – Electroencephalogram (EEG) to look for temporal lobe epilepsy
  – Brain CT to screen for hydrocephalus
  – Laboratory studies: neurohormones (estrogen, free and total testosterone, prolactin) and electrolytes to screen for imbalance

• Therapeutic modalities
  – Behavioral therapy (in and out of school) for role-playing, socialization skills, social boundaries, social space, emotional advancement, and reinforcement of proper behaviors
  – Speech therapy for cognitive remediation and socialization skills
  – Occupational therapy for functional activities related to personal interactive skills.
– Recreational therapy for outings and socialization skills in group and individual settings in more relaxed functional settings.

– Brain injury-specific structured programs to work on coordinated group dynamics.

• **Medications**
  – Medications could include frontal network modulating medications (methylphenidates, amphetamines, or mood stabilizers) and continue into adulthood.

• **Home care**
  – Increase the need for attendant care during adolescence, where many of the situations arise, to remediate and diminish long-term risk for legal issues.

  – One-on-one supervision may be required when an individual starts to exhibit more socially-inappropriate behaviors. This is especially important if the child with TBI has younger siblings.

• **Transportation**
  – Transportation may be needed for those children who require services outside of the home.

**REFERENCES**


In 1953, at the age of eight, I was one of the last polio patients of a large pandemic that continued around the world. Prior to that, I had been a healthy and athletic child.

Polio hits the anterior horn cells of the spinal column, which controls motor but not sensory ability. It can hit one fiber in one muscle, an entire muscle, an entire arm, but often is asymmetric and mixed with a little weakness in many areas, with no particular pattern. The result is flaccid paralysis, not spastic, more like ALS and more like lower motor neuron diseases.

At age eight I went to a summer camp where the well water was probably contaminated. Five to ten days later I developed a sore throat, a little bit of stomach problems with diarrhea, and a high fever. That night I could not stand up on my right leg. By morning, I could not stand. My fever went up to 105º or 106º. I started having headaches and feeling very ill. My pediatrician thought I had either meningitis or paralytic polio. It was a time when polio news was given on radio and television as part of the pollen count and weather report every day, including how many kids were smitten with this infantile paralysis.

When I got to Michael Reese Hospital in Chicago my mother was told that I would get a spinal tap and either end up on the polio ward or end up in a regular hospital ward with meningitis. I ended up on the polio ward. Soon I could not move my arms or my legs, scratch my nose, or close my eyes and was having a hard time breathing. I was put in an iron lung, where I spent many months, then into a rocking bed. The iron lung was a great tool, because instead of being intubated it gave a negative pressure for inspiration, and positive pressure for expiration. It breathed for me for many months until the inflammation started to wane.

I went to a rehab center, Kabat-Kaiser, in Santa Monica. We still used a beach to exercise, ironically called Muscle Beach. We also had an Olympic pool where we spent six to
seven hours a day, five days a week, working on muscles in patterns with resistance using hydrotherapy, hands on physical resistance and stretching work-outs, pulleys, occupational therapy, mat work, and crawling on the beach with sandbags when we could. I was housed with hundreds of kids that had polio, cerebral palsy, muscular dystrophy, multiple sclerosis, and often neck and back injuries causing paraplegia, quadriplegia, or quadriplegias.

I was told I would never walk, but I became a whiz on Canadian crutches. I sometimes used one, but not often. I used a wheelchair for wheelchair athletics, basketball, track, and ping-pong. I learned to deal with learning outside of school, spending my time with my very enriching and supportive family, where I would read several books a day.

I became the first severely handicapped student to be accepted to a Big Ten medical school. I worked my way through school with scholarships because my parents had almost become bankrupt from taking care of me and gave up much of their own careers. My mother, who was a concert pianist, became my scribe and my gofer.

I married several times. I have had four children. I am happily married now to a special person. I became Chief of several programs at UCLA and NIH.

Having said that, my disease is very different than many other people’s polio, let alone post-polio. I had weakness in both arms and legs, but asymmetrically. I lost the use of probably 85% of my abdominal muscles. I had to wear braces. I had a spinal fusion, which happens because there is asymmetric weakness, causing scoliosis before reaching full adult height if not treated.

I developed arthritis above and below the scoliosis, independent of polio. Spinal fusion was a result of the scoliosis, but the rest of it was related to my own genetics and getting osteoarthritis with bone spurs above and below the fusion. I had several surgeries which straightened or realigned my fingers, a transplant in my left hand, and that was all before the age of 14.

I had pneumonia at least three times by the age of 30 or 35 and was in the hospital and almost had to have a tracheotomy. Since then, I have taken better care of myself, and at the first sign of infection, I treat it with appropriate antibiotics, if that is appropriate. I use inhalers, nebulizer therapy, and work on my breathing. I also strongly believe in vaccines. I am one of the patients who has had breathing problems. Many people who have had polio have not.

In my mid-40s I had less endurance that had nothing to do with fatigue. I have always had restrictive lung disease. So, polio had a dramatic effect on my function. I always used a wheelchair to move quickly. I was able to adapt and become independent and perform all my own activities of daily living. I have used Canadian crutches. I got rid of my braces, got rid of my back brace and scoliosis brace after the fusion. I had many fractures from falling, some of which I think slightly increased my disability, because I never had the time to rehab at all the ways that I should have.

As I hit my 50s, I felt a little more loss of the ability to stand up from a position where I used to be able to push up on my crutches. With age, I have slowly gotten weaker. My restrictive lung disease seems to have gotten worse. I never smoked or drank, and I tried to not do anything that would affect me. I never took pain medication, except when I had my severe
I was expected to die from it before the age of 30. I am now almost 76 years old.

What is post-polio syndrome? I do not know. We have been told by some pseudo-experts that there is a syndrome that as you get older you get weaker, and that the anterior horn cells had produced macro-motor units, meaning there were fewer of the cells to link the brain to muscle fibers. So, as we got older over time, some of those cells died.

Other people do not have that type of severe physical decompensation. Some believe that there is a mild neuroinflammatory basis that occurs again with aging that may cause more degeneration. Nobody has proven that. There are even some who believe that giving intravenous gamma globulin, plasmapheresis, or focused immunotherapy might help, but that is far from being proven.

What specialty should I consult? After the vaccine came the year after I had polio, we went from 40,000 to 50,000 cases with 2 to 10% of those dying or being severely disabled, to two or three years later, dropping down toward 0 in the United States over the next few years. In the last 68 years, we have gotten to a point where it remains in Afghanistan, Pakistan, and equatorial Africa in spots, but not as much.

I have talked to rheumatology and neuromuscular disease experts, but there is no practicing example. There is nobody doing real research on this, except for a rare case. Polio is closely related clinically and pathologically to ALS and there is a great deal of work there. It is related in other ways to muscular dystrophy and lower motor neuron-type diseases.

I have not found anyone who has anything except some hypothetical ideas without clear documentation of metrics of immunity and/or treatments. However, because I have had what I have had, and because I have always been weak, but weaker now in my mid-70s, of course. How does aging affect anybody? We get weaker. Again, without reserve, and having no reserve, losing it at age eight and building it up and overcompensating, we get even weaker proportionally. A great athlete at the age of 50 is unlikely to perform the way he did at age 25, and this is just aging. Could there be approaches like growth hormone, pituitary hypothalamic hormones, androgens, and others that could improve this? Could there be signs of a high inflammatory state? There are no diagnostic tests, other than doing an EMG and a nerve conduction study.

What are the conventional interventions for the so-called PPS that ought to be included in most or all of LCPs? I do not know, because there aren’t any. It is all based on each individual disability; the effect of polio is singular to each person. What we need in polio, ALS, or any of the muscular dystrophy or any type of lower motor neuron disease, is to do stretching and keep range of motion, to do pattern exercises with multiple muscles to get them in movements where they are most functional. This can only be done with hands on resistive therapy. In discussing what physical therapy, ADL, or alteration in mobility aids based on post-polio, it is the same thing that is based on people who have most disabilities, particularly that of weakness and getting older. Everybody is their own experiment and process.

However, we have also been told that as we get older, we should do less exercise, as we can make it degenerate faster. I am not sure that is true. I have had several patients who were told to cut down on exercise and even refrain from swimming, at the age of 70, 80, or even 90. I told them to return for training and hydrotherapy. I got several of them out of a wheelchair and back on their crutches, and back much more ambulatory than before. Clearly, I was not seeking for them to become special Olympic athletes, but I did expect them to become more functional, and that is my goal as well.

I currently live in a beautiful house along the coast. It is a multilevel house looking out at the ocean and it has a professional elevator for me to wheel in and out. I can even get a gurney in and out. It goes up and down four different floors, including the garage. I have driven most of my life with hand controls, very fast cars, and have a ball doing it. I raised four kids and am happily married, with many grandchildren and many kids between us. I am still actively working eight to ten hours at least four days a week and seeing patients, really researching two or three of the weekend days that I have left, and I am deeply involved in applied clinical research.

As human beings, we have a remarkable ability to adapt and be flexible. If we have been given a reasonable brain, we can figure out a way to make it into something that becomes the very support that can give us a very happy, loving, healthy, and exciting adventure in life. Sometimes, you need a great sense of humor, so that you look at this not as a disease and a curse, but as an opportunity and something you are in a game to win.
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**Transportation and Aging**

1) Clinician’s Guide to Assessing and Counseling Older Drivers  

2) Elder Care Locator  
[www.eldercare.gov](http://www.eldercare.gov)  
Assists with finding available transportation

3) Fitness-to-Drive Screening Measure  
[http://fitnessodrive.phhp.ufl.edu](http://fitnessodrive.phhp.ufl.edu)  
This research based tool classifies you (or your loved one) as an at-risk, routine, or accomplished driver and offers recommendations

4) How to Help an Older Driver, A Guide for Planning Safe Transportation  

5) Roadwise Rx  
Roadwise Rx is a tool designed to help learn more about your medications and how they may affect driving.

6) Senior Driving  
[www.seniordriving.aaa.com](http://www.seniordriving.aaa.com)  
Skills assessment driving course and resource

7) Tips Keeping Older Drivers Safe  
[https://www.aota.org/~/media/Corporate/Files/AboutOT/consumers/Adults/Older-Driver.pdf](https://www.aota.org/~/media/Corporate/Files/AboutOT/consumers/Adults/Older-Driver.pdf)

8) Older Drivers’ Perceptions of Driving Cessation  
[https://www.aota.org/AboutAOTA/Membership/Tools/Periodicals/Older-Drivers-Perceptions-Driving-Cessation.aspx](https://www.aota.org/AboutAOTA/Membership/Tools/Periodicals/Older-Drivers-Perceptions-Driving-Cessation.aspx)

**Aging in Place**

The ability to live in your own home safely and independently as you get older.

1) AARP  
[https://www.aarp.org/](https://www.aarp.org/)

2) American Occupational Therapy Association  
[https://www.aarp.org/](https://www.aarp.org/)

3) Elder Care  
[https://eldercare.acl.gov/Public/Index.aspx](https://eldercare.acl.gov/Public/Index.aspx)

4) National Aging in Place Council  
[www.ageinplace.org](http://www.ageinplace.org)

5) Medical alert devices.  
[www.lifealert.com](http://www.lifealert.com) or [www.lifeline.philips.com](http://www.lifeline.philips.com)

6) National Association of Home Builders  
[www.nahb.org](http://www.nahb.org)
Aging in Place Continued

7) Pill reminders
https://www.epill.com/epillstation.html
http://www.medelert.net/
www.medminder.com

8) Wellness independent living system. Sensors.
www.alarm.com

9) Whole-home monitoring
www.nest.com
www.honeyco.com

Pain in Elders

http://www.painmed.org/library/clinical-guidelines/

2) Association Between Psychological Interventions and Chronic Pain Outcomes in Older Adults A Systematic Review and Meta-analysis
https://jamanetwork.com/journals/jamainternalmedicine/article-abstract/2680318

Abstract: “Chronic noncancer pain (hereafter referred to as chronic pain) is common among older adults and managed frequently with pharmacotherapies that produce suboptimal outcomes. Psychological treatments are recommended, but little information is available regarding their efficacy in older adults.”

3) Interventional Spine and Pain Procedures in Patients on Antiplatelet and Anticoagulant Medications (Second Edition): Guidelines From the American Society of Regional Anesthesia and Pain Medicine, the European Society of Regional Anaesthesia and Pain Therapy, the American Academy of Pain Medicine, the International Neuromodulation Society, the North American Neuromodulation Society, and the World Institute of Pain. Chronic and Interventional Pain: Special Article

Abstract: “The American Society of Regional Anesthesia and Pain Medicine (ASRA) 2012 survey of meeting attendees showed that existing ASRA anticoagulation guidelines for regional anesthesia were insufficient for their needs. Those surveyed agreed that procedure-specific and patient-specific factors required separate guidelines for pain and spine procedures. In response, a guidelines committee was formed. After preliminary review of published complications reports and studies, the committee stratified interventional spine and pain procedures according to potential bleeding risk: low-, intermediate-, and high-risk procedures. The ASRA regional anesthesia anticoagulation guidelines were largely deemed appropriate for the low- and intermediate-risk categories, but the high-risk category required further investigation. The first guidelines specific to interventional spine and pain procedures were published in 2015. Recent reviews evaluating bleeding complications in patients undergoing specific interventional pain procedures, the development of new regional anesthesia and acute pain guidelines, and the development of new anticoagulants and antiplatelet medications necessitated complementary updated guidelines. The authors desired coordination with the authors of the recently updated regional and acute pain anticoagulation guidelines. The latest evidence was sought through extensive database search strategies and the recommendations were evidence based when available and pharmacology driven otherwise. We could not provide strength and grading of these recommendations because there are not enough well-designed large studies concerning interventional pain procedures to support such grading. Although the guidelines could not always be based on randomized studies or on large numbers of patients from pooled databases, it is hoped that they will provide sound recommendations and the evidentiary basis for such recommendations. This publication is intended as a living document to be updated periodically with consideration of new evidence.”

4) MANAGING CHRONIC PAIN IN OLDER ADULTS: A LONG-TERM CARE PERSPECTIVE

Abstract: “Chronic pain is a common problem among nursing home residents that is often difficult to manage, mismanaged, or not managed at all. Yet uncontrolled pain or suboptimal pain management can decrease residents’ quality of life and lead to worsening of other medical conditions and increase the risk of immobility, falls, and other complications. Every resident deserves appropriate pain management, and healthcare providers must be adequately prepared with the knowledge and information to meet their residents’ needs. This review presents information on common types of pain in older adults, describes how to assess pain, and discusses options for management, including nonpharmacologic therapies and medication management with mild analgesics and opioid-based therapies.”
Pain in Elders Continued

1) Overview of Persistent Pain in Older Adults

Abstract: “With the shifting age demographics of the U.S. population, more psychologists will be asked to provide clinical services to older adults. Given the high prevalence of persistent pain in aging, in many cases this will mean providing empirically supported interventions for pain and the interference it creates. The purpose of this review is to provide a broad overview of the scope and impact of persistent pain in older people and to discuss mechanisms by which persistent geriatric pain can lead to suffering and disability. We consider the unique context of pain in older adulthood and review differences between older and younger people in terms of pain perception, the social network, beliefs about pain, pain-related coping, and adherence to pain medication. Finally, we discuss special issues affecting pain management in older adults, including dementia, polypharmacy, and barriers to accessing adequate pain care. This review also highlights a need for greater provider training in pain management to meet the needs of a changing U.S.”

2) Pain in Older People
Reflections and experiences from an older person’s perspective

3) Pain Management and the Elderly
https://www.practicalpainmanagement.com/treatments/pain-management-elderly

Abstract: “The elderly pain population presents many challenges for pain practitioners, including comorbid medical conditions, polypharmacy, and barriers to accessing adequate pain care. This review also highlights a need for greater provider training in pain management to meet the needs of a changing age group.”

Opioids and Aging

1) Adverse cardiac events associated with incident opioid drug use among older adults with COPD.

Keywords: COPD; Cardiac; Drug safety; Opioids; Pharmacoepidemiology

2) Acetaminophen Versus IV Hydromorphone for Pain in the Elderly in the ED
https://clinicaltrials.gov/ct2/show/NCT03521102

Abstract: “Intravenous opioids are the mainstay of acute, severe pain treatment in Emergency Departments (ED) across the country. Acetaminophen, given orally, has also been used for treatment of mild to moderate pain. The more potent intravenous (IV) form of acetaminophen has been widely used in Europe for more than 20 years as post-surgical analgesia and received full FDA approval in the USA in 2010. As part of a continuing set of studies whose goal is to optimize treatment of pain among elderly ED patients, this randomized study will compare efficacy and safety of IV acetaminophen to IV hydromorphone.”

3) Epidemiological characteristics, safety and efficacy of medical cannabis in the elderly.

Keywords: Aged; Elderly; Medical cannabis; Medical marijuana; Opioids

4) New opioid use in older adults with COPD associated with increased risk of death

5) Opioids for muscle and joint pain in older people may be harmful

Abstract: “A new study has shown that opioids offer older people with muscle and joint pain little benefit, whilst significantly increasing the risk of serious negative side effects.”

6) Opioids and Older Adults: Poll Finds Support for Prescribing Limits, and Need for Better Counseling and Disposal Options
https://www.newswise.com/articles/view/697918/

Abstract: “74 percent support prescription restrictions, but many keep unused pills and don’t get information on risks, U-M/AARP National Poll on Healthy Aging finds.”

7) Trends in abuse and misuse of prescription opioids among older adults
https://www.drugandalcoholdependence.com/article/S0376-8716%2815%2900047-2/abstract

Abstract: “Dramatic increases in the prescriptive use of opioid analgesics during the past two decades have been paralleled by alarming increases in rates of the abuse and intentional misuse of these drugs. We examined recent trends in the abuse and misuse and associated fatal outcomes among older adults (60+ years) and compared these to trends among younger adults (20–59 years).”
Guardianships and Conservatorships in the Nurse Life Care Plan

by Andrea Goicoechea, MSN, RN

Keywords: Guardianship, conservator, fiduciary, capacity, deficient knowledge, special needs trust

Introduction

In the United States, all persons 18 years of age and older are presumed competent and capable of handling their own affairs unless a judge determines otherwise. An adult who cannot make personal or business decisions may need a guardian or conservator to make them legally. Once determined by the court that the individual lacks capacity, considerable rights are given to the court-appointed guardian/conservator. Guardianship should be a last resort and be established in cases where lesser restrictive means of intervention are not possible (National Guardianship Association, 2017).

The nurse life care planner may encounter clients of all ages who must anticipate guardianship or conservatorship due to illness or incapacity. This article introduces the process of guardianship/conservatorship and selected applications in a life care plan.

Definitions and Terminology

Generally, guardianship protects children and adults who cannot care for themselves, make decisions that are in their best interests, or manage their assets. A probate court, after being petitioned, must determine that an individual is incapable of handling such affairs, and will then appoint a guardian or conservator.

Procedures differ somewhat between states, and
terminology varies; there are no national uniform definitions of guardianship or conservatorship. The Uniform Law Commission’s Uniform Guardianship, Conservatorship, and Other Protective Arrangements Act of 2017 urges states to adopt consistent language and clarifies terminology, and their (UGCOPAA) language will be used throughout this article. (Uniform Law Commission, 2018).

A guardian of the estate (guardian) can protect an individual from being exposed to financial abuses. A guardian of the person (conservator) may be needed to ensure adequate healthcare and to make personal arrangements for a disabled person (Dussault, 2010, p. 945). A parent must petition for guardianship and/or conservatorship in the probate court before an incapacitated child reaches the age of 18, the legal age of adulthood. (Juvenile court guardianships of minors removed from the home, or proceedings in a family law court will not be addressed in this article. Also, individuals with serious, life-threatening mental health conditions may require court intervention if they cannot or will not agree to treatment. These procedures and protections vary between states, and are referred to as mental health guardianships. It is beyond the scope of this article to discuss the needs of individuals requiring court intervention to insure extensive mental health treatment.)

The Nurse Life Care Planner (NLCP) may recognize the need for specialized legal support for an incapacitated client. The NLCP should be familiar with local jurisdiction procedures in when recommending advocacy or guardianship/conservatorships. State government websites offer valuable guidance. Collaboration with those experienced in this area include:

- special needs attorneys
- elder law attorneys
- estate attorneys
- professional guardians
- fiduciaries
- trust officers

Limited guardianship/conservatorships assist persons with intellectual or developmental disabilities who cannot fully care for themselves or their finances, yet do not need a general guardianship/conservatorship. These are designed to help persons with intellectual or developmental disabilities lead independent, productive lives. The disabled person retains all legal and civil rights except for those the court specifically grants to the conservator.

General guardianship/conservatorship is for individuals who cannot care for themselves or their finances and must be deemed incapacitated by a judge through legal petition. A guardian:

- Provides for proper food, clothing, shelter, transportation, recreation, and health care
- Makes important medical choices for the individual after obtaining approval from the court for certain medical decisions (sterilization or other life-altering interventions)
- Reports regularly to the court

The guardian is not required to contribute personal assets to support the person.

The conservator handles the individual’s financial matters, and has a fiduciary duty to act in the best interests of the individual. The conservator:

- Manages the conservatee's finances
- Locates and takes control of all assets
- Collects the conservatee's income
- Makes a budget to show what the conservatee can afford
- Pays the conservatee's bills
- Responsibly invests the conservatee's money
- Protects the conservatee's assets
- Accounts to the court and to the conservatee for the management of the conservatee's assets on a regular basis, often biennially or triennially

Temporary guardianship/conservatorship may be appointed for 60-90 days until a general guardian/conservator is identified.

Establishing a permanent guardianship/conservatorship can take six months or more (https://www.caregiver.org/resource/conservatorship). Although costly and time-consuming, guardianship/conservatorship offers a high degree of protection to the individual. The conservator has a fiduciary duty to the individual and must file an inventory of all the property of the conservatee and routinely file accountancy with the court that reflects all transactions involving the conservatee’s assets. The conservatorship provides structure to assist a conservatee who may be reluctant to accept advice. The guardian/conservator can remain a neutral party whose only concern is the best interests of the individual, particularly when family members have trouble agreeing.
Arranging Guardianship/Conservatorship

Setting up a conservatorship is a long, expensive, and complex process involving steps to determine capacity and establish a guardian/conservatorship.

- **Starting the conservatorship** by the proposed conservator, the proposed conservatee, the spouse, domestic partner, a relative, or a friend of the proposed conservatee, another interested person or an interested state or local agency. The process starts once all the necessary paperwork is filed with the court.

- **Completing the petition** to include information about the proposed conservator and conservatee, relatives, and the petitioner and the reasons why a conservatorship is necessary. It must also explain why the possible alternatives to a conservatorship are not available in this case.

- **Filing the petition** with the court clerk. The filing fee must be paid, plus a court investigator fee.

- **Informing the proposed conservatee**. Someone other than the petitioner must personally deliver a citation and a copy of the petition to the proposed conservatee.

- **Informing the proposed conservatee’s relatives**. Someone other than the petitioner must mail a written notice about the court hearing on the petition, with a copy of the petition, to the conservatee’s spouse or domestic partner and close relatives.

- **Investigation by a court investigator or designated committee** to talk to the proposed conservatee and others who may be familiar with the conservatee’s condition. A report is made to the court.

- **Hearing.** The proposed conservatee must go to the hearing unless excused because of illness. A judge will determine if everyone has been properly notified and whether a lawyer should be appointed to represent the proposed conservatee. If the judge grants the petition, an order appointing the conservator will be filed and Letters of Conservatorship will be issued. If there is an estate, a surety bond must usually be filed.

This process involves loss of privacy, since court proceedings are part of the public record. If approved, the conservator can then assume the powers authorized under the law. The conservator/guardian often attends training for conservators offered by the court. Each guardian/conservator will have the ongoing duty to report regularly to the court.

A conservator may be required to obtain a probate bond to protect the interests and affairs of the conservatee in accordance with the applicable state law. The cost of a fiduciary bond is a percentage of the whole amount of the bond. The amount of the bond is directly linked to the value of the estate or assets that the fiduciary has to take care of, between 1%-3% of the total amount of the bond (https://www.suretybonds.org/probate-bonds).

The guardian’s authority is defined by the court and the guardian may not exceed it. If family members seek the job of guardian/conservator, a judge will follow preferences established by state law. Most states give preference to the spouse, registered domestic partner, adult children, adult siblings, or other blood relatives. If no relative or acquaintance is suitable to act as guardian/conservator a judge will select an appropriate candidate, or assign a professional attorney, guardian, board certified patient advocate, fiduciary, or public guardian.

**Children**

Parents are the natural guardians of children under 18. If a child is deemed incapacitated, the natural guardian(s) may petition the court to become the legal guardian and/or conservator. This process should be started well before
the 18th birthday. When parents are unable or unwilling, the judge will appoint a professional conservator.

**Estate Planning and Settlements; Special Needs Trust**

A settlement must be expertly organized and managed in order for the individual to remain eligible for public benefits and avoid tax consequences. A bank or professional trustee creates and manages a special needs trust. The special needs attorney, elder law attorney, or estate attorney provide appropriate oversight and asset structuring. Costs include set-up fees, mandated reporting to the courts, and updating the financial plan. Although attorney fees vary and can be many hundreds of dollars, the investment in correctly structured estate plans is warranted. These costs can be provided as a line item in a LCP with attorney approval, or the attorney may prefer to submit them separately to the court (see Life care planning considerations below).

The court, family, or guardian may employ a professional fiduciary, professional guardian/conservator, or board-certified patient advocate to oversee personal and/or estate management once the petition has been granted. These professionals provide services to seniors, persons with disabilities, and children. They manage matters for clients including daily care, housing and medical needs, and also offer financial management services ranging from basic bill paying to estate and investment management (https://www.fiduciary.ca.gov). Select states require education and licensing of professional fiduciaries and guardians. The fiduciary will work together with an attorney when legal support is required for reporting or trust management.

**Other Considerations: Advance Directives**

Importantly, if an individual has advance directives in place, including powers of attorney for finance and healthcare directives, conservatorship/guardianship can be avoided. Unlike guardianship, advance directives do not involve the surrendering of any rights and can be dissolved at will. Powers of attorney are valid only if set up before a person becomes incapacitated. Without a detailed power of attorney, the spouse, parent or other interested party must go through the guardianship/conservatorship process.

Each state has templates for advance health care directives, living wills, and five types of powers of attorney. The National Institute on Aging recommends reviewing advance planning documents no less than every ten years (https://www.nia.nih.gov/health/advance-care-planning-health-care-directive). Individuals should confer with a specialized attorney to craft these important directives before incapacity from any cause. The NLCP should know if and what kind of powers of attorney/advance directives exist for a client before recommending court proceedings or fiduciary assistance.

According to the National Guardianship Association, alternatives to guardianship/conservatorship include designating a representative payee to accept public funds, use of case management, trusts, joint checking accounts, community advocacy systems, and supported decision-making networks (https://www.guardianship.org/advocacy/positionstatements).

**Looking Ahead**

Reforms to the conventional court-appointed guardianship system focus on rights of the individual and are increasingly person- and family-centered. Supported decision-making models have been described where the disabled individual is the ultimate decision maker and is supported by a chosen team of trusted persons who explain and interpret issues. It is the position of the National Guardianship Association, among other relevant entities, that supported decision-making should be considered before guardianship and the supported decision-making process should be incorporated as part of a guardianship.

According to the Uniform Law Commission, the 2017 UGCOPAA is “a guardianship law suitable for the twenty-first century and should be adopted in every state.” The UGCOPAA, created by guardianship experts, promotes person-centered planning and independence and protects the evaluee’s procedural rights, provides clear guidance to guardians and conservators, and helps conserve court resources (ncpj.files.wordpress.com/2019/05/ugcopaa-summary.pdf).

UGCOPAA introduces the term “protective arrangement instead of guardianship or conservatorship” to describe a less-restrictive alternative to guardianship or conservatorship. Instead of imposing a guardianship or conservatorship for a person who would otherwise need one, a court can instead enter a limited order to address a specific need. A number of states have adopted language from the UGCOPAA to modernize perspectives in the probate courts.

**Life Care Planning Considerations**

Individual needs change over the lifespan, perhaps including disabling conditions that warrant provisions for legal or fiduciary assistance in the life care plan. Such situations the NLCP may encounter include, but are not limited to:
A traumatic brain injured client with altered consciousness, post-concussion syndrome, cognitive deficits, or advancing dementia

Aging individuals with physical, social, and cognitive decline

Disabled youth who will need oversight by a guardian/conservator upon reaching 18

Death of a caretaker or parent.

Settlement award with no previous estate planning

An incapacitated individual with no advance directives in place.

An individual with no willing or able persons to provide care

The NLCP may recommend guardianship, conservatorship, or special needs counsel without attaching detailed fee schedules in the life care plan. Collaboration with an existing legal team and healthcare providers is part of NLCP practice.

Reforms to the conventional court-appointed guardianship system focus on rights of the individual and are increasingly person- and family-centered.

The referral source (attorney) must support probate-oriented recommendations and may prefer that the interventions or costs be listed in an addendum to the life care tables as a probable need.

Professional fees and court costs are regional; communications with preferred or local vendors will reveal pricing. Costs include probate court filing fees, attorney fees for evaluee and surrogate lawyers in probate court, attorney fees for managing a guardianship/conservatorship petition, submission of routine reports to the court, bonding of the conservator, and hourly fees for professional oversight throughout the life expectancy or term of the life care plan. Funding sources differ depending on the unique case and income source.

Case examples

Case Example #1. Moderate-to-Severe Traumatic Brain Injury

At 19 years of age, A.B. was injured in a motor vehicle accident. At the emergency department he denied loss of consciousness. His Glasgow Coma Score was 15. He had a superficial scalp wound. Head CT revealed a small subarachnoid hematoma and no further neurosurgical intervention was recommended. One month later, he reported headaches, lower back pain, dizziness, impaired concentration interfering with work and recreation, and difficulties with mood and sleep. He was diagnosed with moderate-to-severe traumatic brain injury, post-concussion syndrome, labyrinthine trauma, post-traumatic stress disorder, and anxiety.

A.B.’s life care plan included a lifetime fiduciary to assist with management of finances and financial decisions. The nurse life care planner based her recommendations upon the medical diagnoses and supporting literature, her direct client assessment of A.B.’s abilities, nursing diagnoses, and anticipation of a financial settlement requiring expert administration.

Related nursing diagnoses to consider: Impaired memory, chronic confusion, ineffective coping, impaired verbal communication.

Case Example #2: Cerebral palsy, dependent upon grandmother for support

A life care plan was requested for 17-year-old C.D. in response to the accidental death of his maternal grandmother, R., who substantially provided his physical, emotional, mental, and financial care. At seven days of age, C.D. suffered Group B Streptococcus neonatal meningitis, resulting in spastic cerebral palsy, seizure disorder, developmental delay, severe cognitive dysfunction, speech and swallowing problems, and aggressive behaviors. His reported mental equivalency was of a 18–20-month-old child. It was anticipated that he would require personal care assistance with all basic activities of daily living throughout his lifetime.

R. and C.D.’s mother chose to keep C.D. at home, rather than in an institutional setting, with additional siblings and an infant grandchild. The grandmother lived nearby and arrived daily to bathe, feed, dress C.D. while L. prepared the family for the day. Both women held jobs. The family used few public resources, as C.D. had been lost to follow up by social services and the family was not informed of available support.
C.D. will require a legal guardian when he turns 18. His mother could become a paid caregiver for C.D. under Medicaid, but then would not be able to function as his guardian. In the absence of R. there is no one to act in the guardian role. The court would have to be petitioned to establish guardianship for C.D. and a professional or public guardian would likely be appointed. Since there is no settlement or estate, a conservator was not included.

C.D.’s life care plan included a surrogate guardian at age 18. The nurse life care planner supported her recommendations based upon the legal need for guardianship of an incapacitated adult, attention to eligibility for public assistance, and medical diagnoses.

Related nursing diagnosis to consider: Risk for caregiver role strain, stress overload.

Summary
Guardianship and conservatorship statutes allow appointment of persons or entities to provide fiduciary and/or personal support to those that are deemed incapable of making decisions in their own best interests. Or, in the case of the incapacitated minor child, need supervision upon reaching adult age. A client’s situation will alert the NLCP to the possible need for intervention to provide oversight of an individual’s financial or personal wellbeing.

Guardianship issues are managed in each state’s probate court. An individual, parent, family member, or interested entity may petition the court to become another’s guardian of the person and/or conservator of the estate. A judge must proclaim the evaluatee incapacitated; the process is lengthy and costly. Conservators and guardians are held to strict routine reporting to the court and have a significant fiduciary duty to act in the best interest of the conservatee in all affairs. Contemporary approaches to legal guardianship are increasingly person-centered. Efforts to retain autonomy and personal rights through supported decision-making teams and full estimation of an evaluatee’s abilities are being adopted by many states. Special needs, elder, and estate attorneys, along with professional guardians, patient advocates, and fiduciaries are integral partners in the life care planning process.

REFERENCES


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Introduction
Certified Nurse Life Care Planners (CNLCP®) have the skills and knowledge for preparing and reviewing Medicare Set-Asides (MSA). We are experts in identifying the needs of the injured and know what should be included in a Nurse Life Care Plan regarding future care and costs. This article will provide basic MSA knowledge and how CNLCPs® could add MSAs to their business. Discussing MSA history, requirements, rules, or all of the information and documents that are required for submission is beyond the scope of this brief review. You should learn this in the course you take before certification.

What is a Medicare Set-Aside?
A Medicare Set-Aside (MSA) is a specific report outlining future care and costs that are covered by Medicare, suggesting that a certain amount of money be “set aside” after a settlement to satisfy Medicare’s Secondary Payor (MSP) requirements.


By law, Medicare cannot pay for a beneficiary’s medical expenses when payment “has been made or can be reasonably be expected to be made under a workers compensation plan…” If responsibility for the workers compensation claim is in dispute and workers compensation will not pay “promptly” then the provider may bill Medicare as the primary payer. If the treatment is reimbursable under Medicare rules, Medicare may pay conditionally, but this payment is subject to later recovery if there is a subsequent settlement, judgment, award or other payment in the workers compensation case.

CMS.gov states, “Prior to settling a workers’ compensation case, parties to the settlement should consider Medicare’s interest related to future medical services and whether the settlement is to include a Workers’ Compensation Medicare Set-aside Arrangement (WCMSA).”

The best way to protect Medicare’s future interest is to create a Workers Compensation Medicare Set-Aside Allocation (WCMSA). However, the law does not mandate that an MSA is required to settle a case. The law requires that you must protect Medicare’s interest when settling. However, how you do that is not mandated by law. In workers compensation claims a Medicare Set Aside is the CMS recommended method for protecting Medicare against future medical payments.

Professional Requirements, Education and Certification
There is no requirement to be certified in order to provide the services related to MSAs. However, if you want to be able to advise your clients appropriately about MSA requirements,
certification is recommended. The Medicare Set-aside Certified Consultant™ (MSCC™) credential has achieved specific pre-approved training in MSA arrangements and has demonstrated knowledge regarding the development and application of the MSA process (International Commission on Health Care Certification (ICHCC), 2021). In order to qualify for the MSCC™ designation, one must be a qualified health care professional as defined by ICHCC, have a minimum of twelve months of acceptable full-time professional employment in the past three years, and have a minimum of an associate degree (with the exception of diploma Registered Nurses).

The MSCC™ requires 30 hours of training through a course approved by ICHCC. A minimum of 25 hours must address basic orientation, methodology, and practice standards for developing and applying MSA allocations (International Commission on Health Care Certification, 2020). ICHCC has an approved list of programs on their website. The cost varies according to the program and ranges from $450.00 to $1,000.00.

**Nurses can expand their business by adding Medicare Set-Asides (MSA) for workers compensation or liability cases. Referrals can come from defense attorneys, plaintiff attorneys, or insurance adjustors.**

The application to apply to sit for the MSCC™ examination requires a copy of the certificate from the completed course, your curriculum vitae (CV), an MSA work sample, a copy of the peer review critique of your MSA work sample, and a test fee of $445.

**The Business of Medicare Set-Asides**

Nurses can expand their business by adding Medicare Set-Asides (MSA) for workers compensation or liability cases. Referrals can come from defense attorneys, plaintiff attorneys, or insurance adjustors. Referrals can be received anytime during the litigation process, but typically when at or nearing the time of settlement.

When you get a referral for an MSA, there is a tremendous amount of information that you will need to collect, including the claimant, the compensable injuries, the jurisdiction, and the names of all parties involved (e.g., claimant’s attorney, defense attorney, workers’ compensation adjuster, employer, etc.). Create an intake form or checklist to make sure you have all information available to you. Share it with your referral source right from the beginning, because it may take some time to collect it all.

The MSA should be prepared exactly the same whether you are working for the claimant’s attorney, the defense, or the adjuster. In other words, if I were to review an MSA that was prepared by the defense, it would match very closely one that I prepared for the claimant.

So, you get a referral from a new (or existing) client who wants you to prepare a WCMSA allocation for a client. You have the basic information and have requested the necessary records to begin the process. Does your client want you to submit the WCMSA to CMS for approval? Or are you preparing this for settlement purposes only and will not be submitting for approval? You may ask, “Does it matter?”

Well, yes…and no.

No, because the MSA report must be prepared in the same manner and guidelines that have been established. Yes, because the submission process will take extra time and all of the required documents and information must be submitted before CMS will review it. If there are documents missing, this will delay the review process and can ultimately delay the settlement.

There are additional costs and services to consider when starting MSA consulting. Your business will need access to pharmacy costing database (Red Book Drug Reference https://www.micromedexsolutions.com ). You’ll need access to the workers’ compensation fee schedules for the states in which you will be preparing MSAs. Some states have public access for no charge, and some may charge to access other fee schedules.

How you submit the MSA is part of your business plan to be determined before receiving your first referral. You can submit a paper copy or CD to the Benefits Coordination & Recovery Center (BCRC), which then transfers it to the CMS computerized system and checks for errors. It is then reviewed by the Workers’ Compensation Review Contractor (WCRC). You can also submit the WCMSA online via the WCMSA Portal (WCMSAP), which goes directly to the WCRC for review.
“Why would I not want to submit via the portal?” you might ask. “What’s the catch?” You have to be approved to have access to the WCMSAP, and you can plan on this taking some time. The Workers’ Compensation Medicare Set-Aside Portal (WCMSAP) User Guide assists you in the application process.

Another option for your business could be reviewing MSAs that have already been prepared. For example, a third party (e.g., an adjuster) has prepared an MSA and your client (the claimants attorney) wants you to review it. Why? If it were prepared according to the guidelines, it should be “good to go.” You would want to review it for mathematical errors, incorrect charges, incorrect frequencies of services, or specific treatments were included that have been changed or discontinued.

Another reason the claimant’s attorney would want an independent review would be to advise on how the amount of the MSA can be reduced. For example, if the claimant has a medication that is noted to be prn, this medication must be included. However, if the claimant is not taking this medication, you can advise your client (and claimant) to have the treating physician discontinue this medication. Having knowledge in how to reduce an MSA can go a long way with your retaining attorney.

Conclusion
Adding Medicare Set-Aside consulting can help you grow your business. I recommend taking an approved MSA course and becoming certified. Additionally, develop a business plan that lays out everything that you will need to have in place prior to putting out your MSA shingle. You want to ensure that you have all of the available and needed resources when you take in your first MSA referral to deliver a credible product to your clients.

For further information, you can contact the author at shirley@daugherty-legalnurse.com, 765-215-7965

Fees for Taking a Course in Medicare Set Asides:
- https://www.aaaceus.com/MSCC-Training-Program.asp - $600.00
- https://phhp.ufl.edu/academics/certificate-programs/msa/ - $625.00
- Kelynco - $450.00
- NAMSAP - $850 + $350 (peer review)
- FIG - $600 to $1000

RESOURCES


For our 2022 Conference, AANLCP is asking its members to help recruit conference sponsors and vendors. If you have a sponsor or vendor you would like to see at our 2022 conference, and they have no prior affiliation with AANLCP, we are offering a discount toward your conference registration. Go to the AANLCP website

https://www.aanlcp.org/corporate-partnership/

and fill out the Partnership Referral Form. Next, have your potential sponsor or vendor go to

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and register. Whenever they are filling out the sponsor/vendor form, they must include your name on the referral form.

For each new sponsor/vendor you recruit, you will receive 10% of their sponsorship level (Platinum sponsorship $3500, you will receive $350 once they have registered and paid in full) toward your general conference session registration. You will accumulate up to the cost of the general conference registration. Your credit will be used toward your 2022 conference registration. There will be no refunds, and you will not be able to carry over the referral credit.
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