Topics in Burns and Life Care Planning
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Editor’s Note

Welcome to the Fall 2011 issue of the Fall 2011 issue of the Journal of Nurse Life Care Planning. Our focus is on Life Care Planning in Burns. We believe that this issue will offer you insights into this topic, with resources and links. First, we offer a glimpse into the lives of a few people who have survived catastrophic burn injuries. Their words are sure to touch your hearts. Our authors are very experienced in burn life care planning and also always willing to help you succeed; contact information for each is in the articles.

Thanks to all of our readers who participated in our annual survey. We are heartened by your praises, grateful for your suggestions, and inspired to improve. One feature receiving consistently high marks was the suggested nursing diagnoses accompanying each clinical article. For this issue, these will be found all together beginning on page 454.

We also offer the latest installment of Technology Corner.

We hope to see you at the conference in dynamic and exciting Kansas City MO on October 21-24, 2011. As we go to press, our conference committee is putting together another excellent program; you may view the schedule, register for the conference, and find booking information for hotel rooms on the website at www.aanlcp.org/conference/.

Some of the presenters have offered us brief essays about topics of interest to them; you will find them beginning on page 467. Do approach them to say hello and thank them for their dedication to nurse life care planning and willingness to share their expertise with us. Nursing is such a collaborative profession!

Cordially,

Wendie Howland

Editor, Journal of Nurse Life Care Planning

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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 within the medical-legal community. Submitted material must be original. Manuscripts and queries may be addressed to the Editorial Committee. 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 only (.doc)
- 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)
- Set 1-inch margins
- Use Times, Times New Roman, or Ariel font, 12 point
- Use double-spacing, using the Word formatting feature
- Place author name, contact information, and article title on a separate title page, so author name can be blinded for editorial review
- Use APA style (Publication Manual of the American Psychological Association)

Art and Figures

All photos, figures, and artwork should be in JPG or PDF format (JPG preferred for photos). Line art should 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 should be on a separate page, 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, 2003).

Editing and Permissions

The author must accompany the submission with written release from:

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- any copyright holder, for copyrighted materials including illustrations, photographs, tables, etc.

- All authors must disclose any relationship with facilities, institutions, organizations, or companies mentioned in their work.
- 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 articlename.doc, e.g., wheelchairs.doc

All manuscripts published become the property of the Journal. Manuscripts not published will be returned to the author. Queries may be addressed to the care of the Editor at: whowland@howlandhealthconsulting.com

Manuscript Review Process

Submitted articles are peer reviewed by Nurse Life Care Planners with diverse backgrounds in life care planning, case management, rehabilitation, and the nursing profession. 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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Great source of information

I wanted to let you know that the AANCLP Journal has been a great source of information for my life care planning. I recently had to research amputation and found the Winter 2009 Journal very helpful.

Peggie Nielson BSN RN CNLCP

Conference Committee Update

Greetings from the conference committee! We have been pulling together the conference and securing speakers and vendors. Below is a sampling of what we will be offering this year at the conference. The full agenda and registration will be posted on the web page at www.aanlcp.org click on Conference information.

No trip to Kansas City is complete without a visit to the Plaza and that is right where we will be staying while attending the AANLCP Annual Conference October 21-24, 2011. This 14-square-block outdoor shopping and entertainment district is filled with romantic Spanish architecture, European art and dazzling fountains. Designed in 1922, the Plaza features boutiques and fashionable national stores as well as distinctive restaurants, outdoor cafes and nightlife hotspots. Two nationally renowned art museums are located nearby, The Nelson-Atkins Museum of Art and the Kemper Museum of Contemporary Art.

Pack your bags and get ready for some great nursing education and networking at the AANLCP Annual Conference held in Kansas City, Missouri, October 21st through the 24th at the Intercontinental Hotel.

April Pettengill, BSN RN CRN CDMS CNLCP MSCC
AANLCP 2011 Conference Chair

CNLCPs publishing

I am honored to be able to announce that our 54-chapter text has been born. The fourth edition of Nursing Malpractice has been released. It is much like giving birth.

Pat Iyer, Barbara Levin, and Kathleen Ashton joined me as coeditors of this text.

Victoria Powell, RN CCM LNCC CNLCP MSCC CEAS
Benton AR
Victoria@VP-Medical.com

Congratulations to the new parents! For a complete review and description, see page 436. Ed.

Correction: Dual Sensory Loss

I was just reviewing the Summer 2011 publication with my contribution in it. It is quite a fine piece of work when you see all of the articles together. Obviously, much work went into this. I’m sure these publications are greatly appreciated by your readers. Upon review of my article I have to say I was disappointed to see some of the language changed. One very obviously example is the use of “dual-loss children” on P. 404. I am planning on referring this publication to my colleagues in deaf-blindness across the country but am embarrassed by this wording because I would never refer to children in such a way, nor does the field. As in my original drafts I wrote using different wording such as “children with dual sensory loss” or “dual sensory impairment.” I’m sorry that I missed that on the final final review. Regardless, I am very thankful for the opportunity and hope that this information sheds light on your large membership.

Susanne Morgan Morrow MA CI CT
Project Coordinator
New York Deaf-Blind Collaborative

Letters on any topic are welcome and may be sent to the Editor at whowland@howlandhealthconsulting.com. Letters may be edited for brevity.
Contributing To this Issue

Shelene Giles ("Major Burns and Considerations for Life Care Plans") is President of FIG Services, Inc. an independent corporation providing services directed at determining/understanding future cost of care as well as coordinating care for the elderly and those with catastrophic medical conditions. For the past several years, her focus has been on providing Life Care Plans for catastrophic burn survivors. She has completed over 100 Nurse Life Care Plans as an Expert Witness and has consulted on hundreds of major burn cases. Shelene has authored articles and provides education concerning Nurse Life Care Planning, Medicare Set-Asides, and catastrophic burns. Shelene has also spoken nationally among nurse, medical providers, insurance carriers, employers, attorneys, and families regarding issues surrounding catastrophic injuries/illnesses. She was elected to serve on the American Association of Nurse Life Care Planners (AANLCP) Executive Board (President Elect – 2007, President – 2008, and Past President – 2009).

Wendie Howland ("In Their Own Words") is a former critical care specialist and nursing faculty. She is a life care planner doing life care plans for clients in many states across the US, case manager, and an in-house legal nurse consultant for a med-mal plaintiff firm. She also serves as the JNLCP Editor. She has spoken on writing for publication at several conferences and recently gave the Distinguished Nursing Lecture at Elms College in Massachusetts focusing on the nursing basis for autonomous practice entitled, “How Do You Know Where You’re Going If You Don’t Know Where You’ve Been?” She lives on Cape Cod in an old farmhouse with a tolerant husband, five cats, an indeterminate number of rodents, and a black snake in the cellar.

Shelly Kinney ("Getting Your Best Healthcare") provides Life Care Planning services across the country and case management services in Nebraska and surrounding states through her own consulting company in Ralston NE. She chairs the AANLCP Editorial Committee and frequently speaks at conferences for life care planners, case managers, and vocational specialists on life care planning and long term needs for individuals with traumatic injuries.

Regina A. Pepin ("Burns and Development of the Life Care Plan: Case Review Using a Standardized Checklist") holds a Bachelor of Science in Nursing from Fitchburg State University and became a Certified Life Care Planner (CLCP) in 2009. She continues attending conferences and seminars related to her fields of practice, license and certifications. In addition to her life care planning practice, she continues to practice part-time as an expert staff nurse at a leading Boston teaching hospital, with expertise in burns, plastic surgery, gynecology/oncology, general surgery, intermediate care, and GI surgery. She earned her Progressive Care Certified Nurse (PCCN) certification in 2011.

Keith Sofka ("Technology Corner") is a principal of Caragonne and Associates, Ajijic, Jalisco, MX. He has practiced the provision of assistive technology services for the past 30 years. Mr. Sofka provides consultation to hundreds of companies, schools, Government Agencies and individuals. A major focus of Mr. Sofka’s work has been to provide recommendations for and implementation of school and workplace reasonable accommodation recommendations for individuals and organizations. This work typically includes housing and commercial building access as well as transportation, mobility and completion of daily living needs as well as modifications to the individual worksite. He has also taken training and practiced in other areas of assistive technology including custom seating and positioning for individuals with severe orthopedic involvement. His work has always been focused on ways to use technology to increase the independence of the individual.
Nursing Malpractice, Fourth Edition is an outstanding reference for the attorney, legal nurse consultant, nursing expert witnesses, insurance claim adjuster, healthcare risk manager, or healthcare facility leader involved in a nursing malpractice claim.

This newly revised edition is designed to give a comprehensive overview of nursing malpractice litigation. This extensively revised and updated edition of a classic covers the spectrum of the nursing process— from the neonate to the oldest nursing home resident. It gives a comprehensive overview of nursing responsibilities. This text provides the help necessary to screen nursing malpractice cases, prepare expert witness reports, and workup and litigate cases involving nurses.

Nursing Malpractice, Fourth Edition consists of two separate books: Volume 1 and Volume 2. Volume 1, Foundations of Nursing Malpractice Claims, covers broad range topics such as patient safety, nursing practice, damages, and litigation of nursing malpractice claims. Included are new chapters on the view of the actuary and e-discovery.

Volume 1 also includes a newly updated chapter on Nurse Life Care Planning written by Mona Yudkoff, Alisa Dayanim, and Victoria Powell. It includes a description of a life care plan, the history of life care planning, how to choose a life care planning expert witness, the components of a plan, and much more.

Volume 2, Roots of Nursing Malpractice, takes a closer look at more specific nursing roles, with detailed chapters on obstetrics, critical care, psychiatric, medical surgical, orthopaedic, managed care and emergency nursing, among many others.

Included in the text are brand new chapters on respiratory care, school nursing, dialysis therapy, telephone triage, nurse practitioners, healthcare-acquired conditions, and falls and their consequences.

A unique blend of attorneys, nurse attorneys, nurse expert witnesses, legal nurse consultants, physicians, pharmacists, toxicologists, jury consultants, actuaries and legal photographers contributed chapters for this book. This text remains the only one on...
The healthcare system in the U.S. is a complex web of medical specialists, ancillary providers, and insurance requirements. This book is an essential tool for anyone who is dealing with personal or family health care issues.

In *Getting Your Best Healthcare: Real-World Stories for Patient Empowerment*, Ken Farbstein partners with the Professional Patient Advocate Institute to present real-life medical tragedies, successes, and best practices. These accounts provide a solid knowledge base that can help individuals, family members, physicians, and patient advocates avoid bad healthcare outcomes.

The book shows how to find physicians to fit an individual’s personality and healthcare needs, and how to interact with them so they can do the best job of providing care in the often-limited amount of available time. It discusses hospital and surgery experiences, both good and bad, and how to advocate for the safest care proactively, BEFORE admission. Matter-of-fact stories of inappropriate treatment, chronic illness, dealing with medical errors, and terminal conditions, while unsettling, nevertheless add a realistic and compassionate perspective and add value for both lay readers and healthcare personnel.

This is a perfect text to share with any health care consumer or someone who does not have a good understanding of the role of a patient advocate. I plan to share my marked up, highlighted and sticky-noted copy with my parents who are aging with chronic illness. I may just give a copy to their physician.

*Shelly Kinney RN, MSN, CCM, CNLCP*
This edition’s topic is ramps.
Ramps can provide a simple means of access for a person in a wheelchair or they can be a dangerous hazard and obstacle. A ramp’s usefulness depends upon how it is designed and built. Since there is a great deal of material available on the Internet about the design and fabrication of ramps for public places, I am going to focus on ramps designed and built for a specific user at their home. For information about ADA (Americans with Disabilities Act)-compliant ramps located in public places, try looking here:
http://www.a1-wheelchair-ramps.com/info/ada-wheelchair-ramps-html
A Google search for “ADA wheelchair ramps” should get at least an evening’s worth of reading, complete with drawings, specifications, and all the background information you would need to execute an ADA-compliant ramp. Why I still encounter “pinball chute” ramps in public places – well, I really don’t have an answer for that.

Those who read the Tech Corner article in the last edition about grab bars will remember that the ADA has no jurisdiction in private dwellings. As long as you are not building a ramp for the public, you can build it any way that works best for the individual user, as long as safety comes first. Let’s start there.

General safety information
It seems obvious but it needs to be said: Never build a ramp that would permit a user to exit from anywhere but the top or the bottom. Side rails must be at least high enough to prevent the chair or scooter from rolling over an edge and into oblivion. Since the person will be traveling parallel to the edge, the most likely accident will be that one side will roll off, tipping the chair or scooter and spilling the user to the ground. To prevent this, always have a barrier that will stop the tire from rolling past the edge of the ramp.

Usually this is some kind of hand rail with the space below it enclosed with horizontal or vertical boards. The barrier should strike the tire of the mobility de-

Keith Sofka ATP (retired)

From Technology Corner

It’s all downhill...

Please forward your comments and requests for other topics related to assistive technology to Mr. Sofka c/o the Editor.

Keith Sofka has practiced the provision of assistive technology services for the past 30 years. Mr. Sofka provides consultation to hundreds of companies, schools, Government Agencies and individuals. He can be contacted at ksofka@gmail.com
vice at or above the mid point of the tire. If the barrier is too low, the device could just roll right over it, thrusting the mobility device up and then over and down to whatever is below the ramp.

Not everyone can use a ramp. Be sure that it doesn’t create an obstacle for someone else by blocking stairs that could be safely used. Anyone with balance or gait difficulties, general weakness, or who uses a cane or walker is likely to be at risk using a ramp.

Weather can make ramps a hazard for any user. If there is snow, ice, or constant high humidity that might cause a surface to grow slippery green slime, include a plan for treating these problems before they create a hazard.

Any ramp should be inspected frequently for these and other hazards and for general fitness of use by someone who can spot problems and at least alert someone who can correct the obstacle or hazard.

General design issues
The first issue is the pitch: how steep the ramp can be and still be usable. Pitch is defined as the ratio of the rise over the run. The ubiquitous 1:12 ADA standard pitch simply means that for every foot the ramp goes up, it must go forward 12 feet. So a 24 inch rise into a house will require a 24 foot long ramp.

This can add up quickly. Soon you are faced with a ramp that is impossibly long for the space available. Even a 24 foot ramp should probably have a level area at the midpoint to allow the user a little bit of rest before continuing.

I never build a ramp longer than 36 feet. Even with relatively inexpensive wood, the cost of materials adds up quickly; over 36 feet, it becomes feasible to install a power lift for about the same cost. The pitch should be what is useful for the user. The 1:12 standard was developed by using World War II veterans who were wheelchair users. This causes considerable controversy about what is the most appropriate pitch for public ramps, as this is not a representative sample of today’s users.

I have designed ramps somewhat steeper than 1:12 for a strong user with limited space. I folded the ramp so that his van fit in a two car garage and he

continued next page
could exit the van lift onto the bottom of the ramp and then travel up switchbacks into the house. In places, the side of the ramp abutting each other formed part of the safety edge that prevented rolling off the side. I also designed and built a ramp that was 1:200 for an older woman with MS. We were only going up a few inches but it was a long and very gentle sloping ramp.

**Grade-Aids (right)** are another way to assure that a particular individual can use a ramp even though it may be a bit steep. They only work on manual wheelchairs. They’re like brakes that only work in one direction, preventing the wheelchair from rolling backwards. Grade-Aids users can stop pushing anytime they feel tired and the Grade-Aids keep the chair from rolling backwards. Most of the manual wheelchair users that I know really like the safety that Grade-Aids introduce when climbing any ramp. They cost about $180 at LiveWell Medical [http://www.livewellmedical.com/index.php?main_page=product_info&products_id=1298](http://www.livewellmedical.com/index.php?main_page=product_info&products_id=1298) and others.

No ramp or any other wheelchair-accessible area should have any noticeable bump or rise that is greater than about 1/4 inch. Doorway thresholds are notoriously impassible. The other common barrier is at the start of a ramp, particularly a wooden one. If the horizontal surface is 3/4 of an inch thick, then some additional material must be used to make the rise at the start of the ramp as gradual as the rest of the ramp. Steel or aluminum or even concrete can be used to eliminate an abrupt rise and assure access.

 khô Look for Part II of ramps in the next edition of the Tech Corner.

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**Nursing Diagnoses to Consider**  NANDA International Nursing Diagnosis, 2009-2011

- **Impaired Physical Mobility**  *Limitation in independent purposeful physical movement of one or more extremities (Domain 4, Activity/Rest; Class 2: Activity/Exercise)*
- **Fatigue**: *An overwhelming sense of exhaustion and decreased capacity for physical and mental work at the usual level (Domain 4, Activity/rest; Class 3: Energy Balance)*

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"Nursing Diagnoses to Consider" box with NANDA International Nursing Diagnosis, 2009-2011 information. It contains the following diagnoses:

- **Impaired Physical Mobility** - Limitation in independent purposeful physical movement of one or more extremities (Domain 4, Activity/Rest; Class 2: Activity/Exercise)
- **Fatigue** - An overwhelming sense of exhaustion and decreased capacity for physical and mental work at the usual level (Domain 4, Activity/rest; Class 3: Energy Balance)

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"Look for Part II of ramps in the next edition of the Tech Corner."
In Their Own Words

Wendie Howland RN-BC MN CRRN CCM CNLCP NLCP-C

In preparing this issue, I asked several burn survivors, family members, and nurses about their injury, treatment, recovery, and present status and memories. These are their words.

Wife of man, 39, with 87% TBSA burn in garage fire when water heater pilot light ignited gasoline fumes; sister of a man, 44, with 98% TBSA burn in a work injury: “Fourteen years ago our doctor told us my husband had a less than 1% chance of survival but he thought (trying to save him) was worth a shot. My brother was burned 98% and 90% was third degree, in 2005. He had the same doctor. They both lived.

“Whether or not they have family support is so important. Now life couldn’t be better; there are two babies on the way.

“In my brother’s case, he still has Medicare, Medicaid, and worker’s comp. In my husband’s case, they took him off and he has no insurance. He’s good, he gets up every day and lives life like a regular guy.

He owns his own business but he can’t afford to buy health insurance, so we don’t have any.

“We had, and have, no other help. We don’t really know what the long-term repercussions are of such a large burn.”

Woman burned in a catastrophic house fire, 55% TBSA, lost a child in the fire and three other children were also burned:

“I had a case manager, a social worker, who set things up for me. It was a year and a half to have all my surgeries done; I had in-home health services for quite awhile. First I had to learn to stand up and sit down, and I had a very strong hand therapist. He was one tough cookie. You could take a long as you want, but you did those ten reps. He knew how to push and how to use com-

Wendie Howland is the Editor of the Journal of Nurse Life Care Planning. She is the owner and principal of Howland Health Consulting, Inc., providing life care planning, case management, Medicare set-asides, and editing for health professionals. She may be reached at whowland@howlandhealthconsulting.com
passion. ... The therapist knows what it takes to get better, you don’t. Do what he says.

“Remember it is a long term situation. We’re a very impatient society, and (with a burn) it takes whatever it takes. I remember sitting home with no memory of family visits for four months (in the hospital). They were there for me but then they had to go home. When I came home my church family took care of me, one would make lunch, one would do the laundry, like that. I’ll never forget my friend used to help me in the restroom. Dignity is so important.

“The thing that turned out to be surprisingly helpful was the company I kept. It’s so important to have positive and real people around you. You have great mountains and low valleys and someone who can be really with you on that journey is very helpful.

“I learned so much that now I help others with their lives, I have a nonprofit for that, not just burned people but anyone with a bad situation. I’ve been very busy with victims of natural disasters recently.”

Woman, 27, 3rd & 4th degree burns on entire leg at age 9 in a backyard fire: “Emotionally, I think therapy should be a part of recovery, family therapy; there are still issues about this in my family and we can’t ever talk about it together. My mother can’t look at my leg so I keep it covered when I visit her; she cries when it’s mentioned. She won’t talk about it with a therapist. My brother still blames himself because he was in charge of me when it happened, but it wasn’t his fault.

“I felt so alone as a kid because I couldn’t talk about it. I have friends from high school who still don’t know I was burned because I covered it up. Even today it hurts to talk about my experience with friends. I’ve gotten to the point where I’m ok with my body, my boyfriend encourages me to wear shorts, but I still go out of my way to cover up the burns.

“I still have vivid dreams of the hospital today, when they used to take me to a room and scrub me. It was so terribly painful, I screamed and fought, I can never forget that.

continued next page
“I am planning on volunteering at a burn camp in the next few years. I feel like it’s extremely important for young victims to know that they’re not alone. Kids need language to deal with the questions they’ll get, they need to know about dealing with the staring.

“I would want to tell burn victims that if people stare at you, it’s not because they think you’re ugly. I took a lot of time to grasp that. It’s because there’s something different and they’re curious. I get a lot of sympathy looks, which I still find uncomfortable, but I’ve realized that I don’t have to be ashamed.

“I went through a horrible experience, but I got through it. I have a good life now, a good boyfriend, a good job. I try to be optimistic and think about all the good I have in my life ... It’s easy to play the “woe is me” card -- it takes more strength to be proud of what you’ve accomplished.”

Man, 36, two years post injury when his work truck was rolled by a tornado, gas tank exploded, 38% TBSA 3rd degree burns on arms and hands. We spoke with the help of a caregiver due to a language barrier: “I was in the hospital for a long time, I had skin grafts and surgery. I live in a hot dry place so it is hard for me to go outside or to ride in a hot car. I need to be in air conditioning all the time.

“I had broken bones in my hand. I am going to have surgery for it because it wasn’t fixed before. The doctor doesn’t know if he can make it work better.

“I had terrible pain and became addicted to my medicines. It is very hard for me because I lost my memory from the medications and I am nervous about this. I still have a lot of pain. I do not sleep well. I have bad dreams. My pain doctor is helping me get away from the medicines.

“I am alone. I have a helper in my house eight hours per day because I cannot do very much with my hands. I cannot drive because I can use just one hand and arm. Nobody has helped me with any special equipment, I do not have a case manager.

“I am scared all the time; I wish I could have my old life back. My work insurance only gave me eight visits with a counselor a long time ago.

“Can you help me?”
According to statistics from the National Burn Repository (1999 – 2008), there are over one million documented burn cases per year. The majority of these burns cases being less than 10% total body surface area (TBSA) (National Burn Repository, 2009). The mean age for these cases was 32 years old and consisted mainly of Caucasian males. The American Burn Association (ABA) noted most burn cases were thermal, with scalds being a close second and occurred in the home (American Burn Association Fact Sheet, 2009). Statistics showed approximately 40,000 hospitalizations per year for treatment of burns and 25,000 admissions per year to specialized burn centers. Only 10% of the documented burn cases were considered major burns. There was a 95% survival rate among major burns due to advanced technology. The ABA has developed these burn center referral criteria for admission:

- 2nd or 3rd degree burns >10% TBSA (under 10 years and over 50 years of age)
- 2nd or 3rd degree burns >20% TBSA (in other age groups)
- 2nd or 3rd degree burns involving face/ hands/feet/genitalia/perineum/major joints
- 3rd degree burns >5% TBSA (any age group)
- Electrical burns, including lightning injury
- Chemical burns
- Inhalation injury (smoke or chemicals)
- Pre-existing medical disorders that could complicate management, prolong recovery, or affect mortality
- Concomitant trauma where burn injury poses greatest risk of morbidity or mortality
- Children in hospitals without specialized pediatric unit
- Patients requiring special social, emotional, or long-term rehabilitation support

(American Burn Association)

If the burn size is larger than a quarter, epithelial cells will not regenerate in the epidermis, but from the dermis. However, if the dermis is damaged (second degree, or partial thickness, burn), independent epithelial cell growth cannot occur, and burn wound excision/debridement and grafting is required for healing and re-epithelialization.

Shelene Giles has made her focus on providing Life Care Plans for catastrophic burn survivors. She is the only Nurse Life Care Planner in the nation with a specialty in catastrophic burn cases. She has completed over 100 Nurse Life Care Plans as an Expert Witness and has consulted on hundreds of major burn cases. Shelene has authored articles and provides education concerning Nurse Life Care Planning, Medicare Set-Asides, and catastrophic burns. She may be contacted at shelene@figservices.com
Burns greater than 30% TBSA can be life threatening or fatal and require emergency medical intervention. The American Burn Association defines a major burn as greater than 40% TBSA. However, the definition of a major burn varies among sources. Some define a major burn as any referral to a specialized burn center. The initial TBSA listed on the admission note can be misleading. Often, the initial TBSA is revised upwards during hospitalization due to burn progression, non-healing, infection, expanding excision/debridement/grafting, and inclusion of donor sites wounds (American Burn Association White Paper: Surgical Management of the Burn Wound and Use of Skin Substitutes, 2009).

**Complications**

The risk of complications from major burns increases with the size of the TBSA, age (elderly or young), polytrauma, inhalation injury, respiratory failure with ventilator support (>4 days), infections, or comorbidities (National Burn Repository, 2009).

The healing/recovery/rehabilitation phase can be lengthy depending on the TBSA, acute complications, and comorbidities. Survivors of major burns need extensive medical care, including wound care and dressing changes, splinting, interim and customized compression garments, symptom management, scar management, therapeutic modalities, and specialty burn care.

**Scar maturation** can occur within 12 to 24 months and can be symptomatic (itching, open wounds, infection, and limited range of motion/functioning/strength), especially with the growth and development in young children. The thickness and pliability of a mature scar can be deceiving as healed scars are 20% weaker than the skin they replaced. Loss of skin strength places the scarred skin at high risk for fragility, skin breakdown, ulcerations, and infection. Partial thickness or full thickness burns make permanent changes in the integumentary system. These can include:

- loss of sebaceous glands (inability to moisturize or perspire, impaired temperature regulation, dryness, and itching),
- loss of melanocytes (pigmentation changes),
- loss of elastin (poorly organized collagen, fragile skin, ulcerations/open wounds, and infection),
- altered hair growth patterns (alopecia and ingrown hairs)
- nerve damage (altered sensations, hypersensitivity, and hyposensitivity)

There are approximately 40,000 hospitalizations per year for treatment of burns and 25,000 admissions per year to specialized burn centers.
• loss of eccrine glands and subcutaneous fat (poor temperature regulation, and heat/cold intolerance)
• loss of vitamin D absorption/production
• loss of or severe alterations in personal identity

Secondary diagnoses and complications may not occur until months or years postburn and are not always due to poor care or noncompliance of the burn survivor. Scar maturation outcome can be frustratingly uncertain.

**Reconstructive Surgeries**

Reconstructive surgeries and procedures are typically begun within 12 months following discharge from the burn center (note, not 12 months from incident) (Barrett-Nerin & Herndon, 2005). Physicians will closely monitor the scar maturation phase and begin the reconstructive phase once scar maturation has plateaued. It is understood that reconstructive surgeries are elective and not reasonable and medically necessary to save an individual’s life. However, when conservative treatment is no longer effective, reconstructive surgeries become reasonable and medically necessary to return the burn survivor as close to an appearance as the day before the incident. The purposes of reconstructive surgeries/procedures are many. They can lessen symptoms (pain, numbness, tingling, itching, tightness), improve function (range of motion, lifting, pushing, pulling, strength), improve quality of life, improve appearance of disfigurement (reduce scarring, pigmentation), or prevent complications (contractures, scar bands, infection). Reconstructive surgeries and procedures can be necessary at any time in life expectancy due to natural or unforeseen changes in the skin, such as aging, injury to scars and graft sites, breakdown of graft sites over joints, infection, changes in body structure with weight loss or gain or growth and development in young children, and recurring contractures or scar bands. Keep in mind that reconstructive surgeries, including split thickness or full thickness skin grafts, cannot eliminate the permanent changes to the skin. (Klein, Donelan, & Spence, 2007).

**Associated Polytrauma, Complications, and Secondary Diagnoses**

These can extend hospitalization time for burns, prolong healing/recovery/rehabilitation, and be devastating to the burn survivor as well as family members.

**Polytrauma** can involve internal organ, musculoskeletal, and neurological systems. Complications result from the trauma (direct or indirect), sequelae of burns, or subsequent medical care.

**Secondary diagnoses** may include vascular compromise (compartment syndrome; venous insufficiency, edema, ulcerations from impaired lymphatic system), cardiac arrhythmias, respiratory distress or failure from inhalation injury (Acute Respiratory Distress Syndrome, pneumonia), renal dysfunction or failure from rhabdomyolysis (myoglobinuria), musculoskeletal diagnoses (heterotopic ossification, degen-
erative disease, arthritis, muscle contractures, spine deformity with growth and development), and integumentary diagnoses (syndactyly, contracture, skin cancer, epidermal inclusion cysts, Marjolin’s ulcers). Major burns can cause lifelong symptoms and limitations in multiple body systems. (Herndon, 2002) (Holavanahalli, Helm, & Kowalske, 2010).

**Integumentary symptoms** may include scarring (hypertrophic or keloid), scar contractures or bands; pigmentation changes; altered perspiration; altered hair growth pattern; skin sensitivities and allergies; heat, humidity, and cold intolerance; sun exposure intolerance with higher risk of sunburn; loss of stamina/endurance with fatigue; pruritis triggered by dry skin, environment (heat and cold, clothing, soaps, detergent), physical activity, or stress; fragile skin with ulcerations, open wounds, infection, unstable skin grafts, and delayed healing; and lack of vitamin D absorption.

**Musculoskeletal symptoms** may include pain, contractures, limited mobility, and limited functioning. Musculoskeletal symptoms can lead to hygiene deficits and impaired self-care.

**Pulmonary symptoms** due to inhalation injury may be progressive. These include shortness of breath, wheezing, congestion, productive cough, and snoring.

**Cognitive symptoms** may include memory loss and poor concentration/focus.

**Psychosocial symptoms** may include sadness, anxiety, frustration, loss of privacy, loss of independence, hopelessness, flashbacks, nightmares, insomnia, and intimacy and sexual dysfunction (Falvo, 2009). Do not forget emotional trauma experienced by the family or significant others.

Society has not been kind to burn survivors. Physical appearances of characters in horror stories and bad guys in a superhero movie are patterned after severely burned or disfigured males.

Psychosocial symptoms also create educational and vocational barriers. Psychological diagnoses can include anxiety, depression, adjustment disorder, acute stress disorder, and Post Traumatic Stress Disorder.
(PTSD). Early detection and intervention of psychological symptoms can improve the burn survivor’s outcome (Wallis, Renneberg, Ripper, Germann, Wind, & Jester, 2006; Blakeney, Rosenberg, & Faber; Martz & Livneh, 2007).

**Life Care Planning Considerations**
The purpose of a Nurse Life Care Plan is to address future medical and non-medical needs as well as associated costs which are related to the major burns. Considerations are based on a reasonable degree of certainty to manage symptoms, reduce complications and secondary diagnoses, maintain function, and optimize independence throughout the client’s life span. The *Clinical Practice Guidelines for Burn Care* were published in the *Journal of Burn Care & Research* in 2001. The *Model Systems Knowledge Translation Center for Burns* also offers practice guidelines and research findings specific to major burns. However, these publications focus on the acute care and complications of catastrophic burns.

Research specific to outcomes, chronic complications, and considerations for long term care can be found in the *Journal of Burn Care & Research, Burns Journal*, burn center research department publications, and from related associations and organizations that promote education, networking, and support of burn survivors and families. Treating providers at a specialized burn center are also an invaluable resource when considering outcomes for the Life Care Plan.

Considerations for life care planning of a major burns case may include, but are not limited to:

**Medical care** This is dependent upon the severity of the major burns and complications. Examples include but are not limited to: burn care and plastic surgery, dermatology, physiatry, pain management, primary care, musculoskeletal, neurology, pulmonary, cardiovascular, genitourinary, gastroenterology, endocrinology, vascular, otolaryngology, and psychiatry.

**Reconstructive surgeries and procedures** These depend upon the severity of scarring, symptoms, and functioning. Examples include, but are not limited to: excision, complex closure, Z-plasty, advancement flap, tissue expander, split thickness skin graft, full thickness skin graft, removal of lesions and neuromas, dermabrasion, laser resurfacing, and orthopedic repair. Reconstructive surgeries should include recovery and rehabilitation phases for scar healing and maturation. Reconstructive surgery outcome also relies on proper postoperative care: wound care/dressing changes, scar management, occupational therapy (OT), physical therapy (PT), compression garments, and specialty followup.

**Therapeutic evaluations & modalities** Scarring location, severity, symptoms, and effect on function have considerable influence on life care planning choices. These can include PT, OT, speech therapy, nutritional therapy, therapeutic counseling.
(individual and family), cognitive therapy, recreational therapy, audiology evaluation, ophthalmology evaluation, and home modalities. Burn survivors and family members should be educated on the important of long term skin care, scar management, precautions, environmental limitations, complications, and secondary diagnoses (Helm, Herndon, & deLateur, 2007) (Fauerbach, Pruzinsky, & Saxe, 2007).

**Diagnostic studies** Typically, major burns do not themselves require diagnostic studies over the long term. However, secondary diagnoses such as contractures, nerve impingement, neuropathy, vascular compromise, osteoporosis, or degenerative disease may. Diagnostic imaging (e.g., x-rays, MRI, CT), nerve studies, bone density scans, and lower extremity venous Doppler studies are some of the evaluations that could be indicated.

**Laboratory studies** Long-term followup of major burns, complications, secondary diagnoses, and long term medications could require comprehensive metabolic panel (including hepatic and renal function), sedimentation rate, rheumatoid factor, thyroid panel, calcium levels, hemoglobin A1C, cortisol levels, and electrolyte panel. (Frontera, Silver, & Rizzo, 2008).

**Medications** These will be symptom-based and can include prescription and over-the-counter drugs: analgesic, anti-inflammatory, anti-itch, anti-depressant, anti-anxiety, sexual dysfunction, antibiotic, multivitamins, and vitamin D supplement are common.

**Scar management** Depending on the severity of hypertrophic/keloid scarring, this could include wound care supplies, interim and/or customized compression garments, scar massage, moisturizer, sunscreen, alternative bandages, silicone gel and silicone gel sheets, UV protectant clothing, thermoregulated clothing, allergen-free products, and others. Consider replacement costs and intervals for specialty-order or customized items, such as compression garments.

**Durable medical equipment and aids for independent function** Requirements can vary widely depending on mobility level, activities of daily living (ADLs), and safety needs. Examples can include specialized bedding, bathroom aids, kitchen aids, household aids, communication and

continued next page
writing aids, assistive technology, and adaptive clothing. Consideration should be given to provide for initial and periodic home occupational therapy evaluations to assess use, functioning, maintenance, and replacement.

**Orthoses/Prostheses** Burns can result in amputation or limb deformity. Consider need for splints, braces, orthoses, prostheses, customized shoes, or other items. Occupational therapy evaluations should be included for special order or customized products, and for information on maintenance and replacement.

**Home care and living arrangements** Needs will depend on severity of limitations with ADLs. Examples can include climate-controlled environment; home safety, handicap accessible and barrier free modifications; home maintenance, lawn care, snow removal, and homemaking; vehicle maintenance; assistance with ADL; and changing level of skilled nursing care. Remember that it is not reasonable to assume that family will be willing or able to meet these needs. Consider increased assistance necessary as the burn survivor ages and complications arise.

**Mobility** Depending on severity of limitations with mobility, needed equipment and services could include cane, walker, scooter, or manual or power wheelchair. Remember replacement and maintenance intervals and costs. Equipment needs should be evaluated initially and periodically by qualified therapists. Consideration should be given for mobility aids as the burn survivor ages and complications arise.

**Transportation** Independence will depend on upper and lower extremity functioning. Consider need for travel expenses for specialty burn care, certified driving rehabilitation specialist (CDRS) evaluation, permit for handicap-accessible public transportation, handicap-accessible vehicle, handicap parking permit, tinted windows, climate controlled vehicle, and accessories to transport wheelchair or scooter.

**Educational and Vocational** Survivors of major burns have difficulty with temperature regulation and exposure to sun, heat, and cold. Take these limitations into account when looking at educational and vocational settings. Children with major burns can have delayed growth and development. These children may have lost considerable time from school; when they return, they may have impaired ability due to chronic symptoms, physical limitations, or fatigue. They may meet with intrusive or disturbing classmate and peer ridicule or curiosity. For adults and children, consideration should be given to environmental (temperature controlled environment, allergen free, limited dust particles, limited sun exposure, limited outdoors and heat), physical (lifting, pushing, pulling, carrying, reaching, altered sensations, avoiding repetitive motion/vibration, pro-
longed standing and walking, and fatigue), and psychological limitations (disturbed body image and societal reaction) as related to the major burns.

**Other** Every case is different. The Nurse Life Care Planner should include adjunct resources tailored to individual needs, such as case management, burn support group, burn association conferences, burn camp, climate-controlled environment for physical fitness, avocational and leisure modifications, cosmetics (BEST program, Angel Faces), and family support.

**Life expectancy** for a major burns case is similar to that of the general population with the exception of organ involvement and co-morbidities (Herndon, 2002). Outcomes in the Nurse Life Care Plan should be focused on physical impairments, psychosocial issues, and community reintegration (Blakeney, Partridge, & Rumsey, Community Integration, 2007). A proactive approach with prevention and early detection of complications and secondary diagnoses and aggressive symptom management will improve outcome. Research shows the more positive the support system and available resources, the better the outcome for the burn survivor (Rosenbach & Renneberg, 2008).

**A Final Note**

As you view this picture, ask yourself, “Is this paradise?” The obvious answer seems be, “Yes.” But during the last family vacation to the beach, this Nurse Life Care Planner gained a different perspective of paradise. Realizing most of us spend our vacations relaxing at the beach, pool, or hanging out in the back yard, this Nurse Life Care Planner began to inquire from burn survivors of their idea of paradise. After testimonies from hundreds of burn survivors/family members, the answer to the question is now, “That depends.”

**References**

American Burn Association [www.ameriburn.org](http://www.ameriburn.org)


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Nursing Diagnoses to Consider

- **Ineffective Health Maintenance**: Inability to identify, manage, and/or seek out help to maintain health (Domain 1, Health Promotion; Class 2: Health Management)

- **Ineffective Family Therapeutic Regimen Management**: Pattern of regulating and integrating into family living a program for treatment of illness and its sequelae that is unsatisfactory for meeting specific health goals (Domain 1, Health Promotion; Class 2, Health Management)

- **Ineffective Self-Health Management**: Pattern of regulating and integrating into daily living a therapeutic regimen for treatment of illness and its sequelae that is unsatisfactory for meeting specific health goals (Domain 1, Health Promotion; Class 2, Health Management)

- **Risk for Imbalanced Fluid Volume**: At risk for decrease, increase, or rapid shift from one to another of intravascular, interstitial, and/or intracellular fluid (Domain 2, Nutrition; Class 5, Hydration)

- **Impaired Gas Exchange**: (Domain 3, Elimination and Exchange; Class 4, Respiratory Function)

- **Deficient Diversional Activity**: (Domain 4, Activity/Rest; Class 2, Activity/Exercise)

- **Sedentary lifestyle**: (Domain 4, Activity/Rest, Class 2 Activity/Exercise)

- **Impaired Walking**: (Domain 4, Activity/Rest Class 2: Activity/Exercise)

- **Impaired Physical Mobility**: Limitation in independent purposeful physical movement of one or more extremities (Domain 4, Activity/Rest Class 2: Activity/Exercise)

- **Fatigue**: An overwhelming sense of exhaustion and decreased capacity for physical and mental work at the usual

continued next page
- **Deficient Diversional Activity**: (Domain 4, Activity/Rest; Class 2, Activity/Exercise)
- **Self-Care Deficit**: (bathing, dressing, feeding, toileting) (Domain 4, Activity/Rest; Class 5: Self-Care)
- **Risk for Compromised Human Dignity**: At risk for perceived loss of respect and honor (Domain 6, Self-Perception; Class 1: Self-Concept)
- **Hopelessness**: Subjective state in which an individual see limited or no alternatives or personal choices available and is unable to mobilize energy on his own behalf (Domain 6, Self-Perception; Class 1: Self-Concept)
- **Powerlessness**: Perception that one’s own action will not significantly affect an outcome; perceived lack of control over current situation or immediate happening (Domain 6, Self-Perception; Class 1: Self-Concept)
- **Risk for/ Situational Low Self-Esteem**: Development of a negative perception of self-worth in response to a current situation (specify) (Domain 6, Self-Perception; Class 2: Self-Esteem)
- **Chronic Low Self-Esteem**: Long-standing negative self-evaluating/feelings about self or self capabilities (Domain 6, Self-Perception; Class 2: Self-Esteem)
- **Disturbed Body Image**: Confusion in mental picture of one’s physical self (Domain 6, Perception/cognition; Class 3, Body Image)
- **Caregiver Role Strain**: Difficulty in performing family caregiver role (Domain 7, Role Relationships; Class 1: Caregiving Roles)
- **Interrupted Family Processes**: Change in family relationships or functioning (Domain 7, Role Relationships; Class 2: Family Relationships)
- **Ineffective Role Performance** (Domain 7, Role Relationships; Class 3, Role Performance)
- **Impaired Social Interaction** (Domain 7, Role Relationships; Class 3, Role Performance)
- **Grieving** (Domain 9: Coping/Stress tolerance Class 2: Coping responses)
- **Post Trauma Syndrome**: Sustained maladaptive response to a traumatic, overwhelming event (Domain 9, Coping/Stress Tolerance; Class 1: Post Trauma Responses)

- **Risk for Post Trauma Syndrome**: At risk for sustained maladaptive response to traumatic, overwhelming event (Domain 9, Coping/Stress Tolerance; Class 1: Post Trauma Responses)

- **Anxiety**: Vague uneasy feeling of discomfort or dread accompanied by an autonomic response, source often non-specific or unknown to the patient; feeling of apprehension caused by anticipation of danger (Domain 9, Coping/Stress Tolerance; Class 2: Coping Responses)

- **Ineffective Community Coping** (Domain 9, Coping/Stress Tolerance; Class 2, Coping Responses)

- **Risk for Infection**: At increased risk for being invaded by pathogenic organisms (Domain 11: Safety/Protection, Class 1: Infection)

- **Risk for Injury**: At risk of injury as a result of environmental conditions interacting with the individual's adaptive and defensive resources (Domain 11: Safety/Protection, Class 2: Physical Injury)

- **Risk for Imbalanced Body Temperature**: At risk for failure to maintain body temperature within normal range (Domain 11: Safety/Protection, Class 6: Thermoregulation) related to burn: clothing, inability to perspire, metabolic requirements

- **Impaired Tissue Integrity**: Damage to mucous membrane, corneal, integumentary, or subcutaneous tissues (Domain 11: Safety/Protection, Class 2: Physical Injury)

- **Social Isolation** (Domain 12, Comfort; Class 3, Social Comfort)

- **Impaired Comfort**: Perceived lack of ease, relief, and transcendence in physical psychospiritual, environmental, and social dimensions (Domain 12: Safety/Protection, Class 1: Physical comfort; Class 2, Environmental comfort; Class 3, Social comfort)

[http://www.burn-recovery.org/burn-centers.htm](http://www.burn-recovery.org/burn-centers.htm)
The Burn Model Systems
National Institute on Disability and Rehabilitation Research

An estimated one million Americans sustain a burn injury each year, out of which 45,000 are hospitalized. Severe burns are one of the most complex forms of trauma injury and often require long-term rehabilitation. A person with a burn injury often suffers from a wide range of physical and psychosocial problems that can affect their ability to function.

The Burn Model Systems (BMS) Program began in 1994 with funding from the National Institute on Disability and Rehabilitation Research (NIDRR), U.S. Department of Education, to improve care and outcomes for individuals with burn injuries. Currently, there are four BMS centers: University of Washington, Johns Hopkins University, University of Texas Medical Branch - Galveston, and University of Texas Southwestern Medical Center. Each center provides a coordinated and multidisciplinary system of rehabilitation care including emergency medical, acute medical, post-acute, and long-term follow-up services to persons with burn injuries. In addition to providing direct services, these centers play a pivotal role in building the national capacity for high quality research and treatment to improve physical, functional and psychosocial outcomes for persons with burn injuries. For BMS contact information and resources go to: http://burnmodelsystems.org/.

Research
Each BMS center conducts research and contributes follow-up data to the BMS Data Coordination Center (http://bms-dcc.ucdenver.edu) located at the University of Colorado, Denver.

- The BMS Data Coordination Center collects and analyzes data on the course of recovery and outcomes of individuals who were admitted to BMS centers for medical care. This database has information on over 4,000 individuals with burn injuries including data on pre-injury, injury, acute care, rehabilitation, and outcomes at 6, 12, and 24 months post burn injury.

- Eight site-specific and one multi-center studies are currently underway. Examples include long-term survivor needs, efficacy of innovative exercise programs, children with acute and/or post traumatic stress disorder, and biomechanical properties of burn scars.
Mr. A is a 40-year-old married construction worker who was on his way home from work when entrapped in a car fire. His medical history included intermittent asthma and hypertension. After extrication from his vehicle, Mr. A was airlifted to a verified burn center* (see next page) in Boston MA. He was unconscious, with smoke inhalation airway burn with lung edema and 2nd and 3rd degree burns to 40% total body surface area (TBSA): burns to bilateral upper arms including his left elbow, left hand, chest, lower back, and bilateral thighs. He had scattered small burn wounds on his lower legs. He was immediately intubated to protect his airway.

During his acute hospitalization, Mr. A required escharotomies to his bilateral upper extremities and chest. He required fasciotomies to his left hand and arm for signs of compartment syndrome. His hospital course was prolonged due to respiratory failure; he required a tracheostomy due to airway swelling and inability to wean from the ventilator. His burn injuries were treated with daily dressing changes to debride eschar and protect the open wounds, surgical excision of eschar, and periodic skin grafting.

He had some visual changes with slightly blurred vision since the accident. He suffered from body image disturbance in addition to his physical problems. Disfigurement can affect self-concept, body image, comfort in interpersonal situations, and acceptance in the workplace (Herndon 2007). According to the American Burn Association, the average length of stay in the acute care hospital for burn survivors is slightly greater than one day per percent TBSA burned (ABA 2009), but Mr. A’s...
complications led to a longer hospital stay. After seven weeks in the acute care hospital, he was transferred to a rehabilitation facility; six weeks later, he was ready for discharge home. It was evident that his future care needs would require extensive planning. His hospital case manager recommended he seek the services of a life care planner to help him organize a comprehensive plan for future care needs.

According to the American Association of Nurse Life Care Planners, “the Nurse Life Care Planner utilizes the nursing process in the collection and analysis of comprehensive client specific data in the preparation of a dynamic document. This document provides an organized, concise plan of estimated reasonable and necessary, (and reasonably certain to be necessary), current and future healthcare needs with the associated costs and frequencies of goods and services. The Nurse Life Care Plan is developed for individuals who have experienced an injury or have chronic healthcare issues. Nurse Life Care Planners function within their individual professional scope of practice and, when applicable, incorporate opinions arrived at collaboratively with various health care providers. The Nurse Life Care Plan is considered a flexible document and is evaluated and updated as needed.” (AANLCP, 2011)

A solid foundation for planning future care is critical. Without an appropriate roadmap, individuals who suffer from burn injuries can lose sight of their abilities and lose hope for their future. The Life Care Plan can be invaluable to help burn patients find purpose and be productive members of their communities while dealing daily with the tragic consequences of their burn injury.

Mr. A’s Life Care Plan was organized systematically to address the significant number of details and com-

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**What is Burn Center verification?**

Verification of burn centers is a joint program of the American Burn Association (ABA) and the American College of Surgeons (ACS). It is a rigorous review program designed to verify a burn center’s resources required for the provision of optimal care to burn patients from the time of injury through rehabilitation. Elements of this voluntary program include application, pre-review questionnaire, in-depth on-site review by the ABA Verification Committee and senior members of the ABA. A written report of the site visit team is reviewed by the ABA Verification Committee and by the Committee on Trauma of the ACS.

Burn Center verification provides a true mark of distinction for a burn center. It is an indicator to government, third-party payers, patients, families, and accreditation organizations that the center provides high-quality patient care meeting the demanding standards for organizational structure, personnel qualifications, facilities resources, and medical care services set out in the ABA chapter on Guidelines for the Operation of Burn Centers in the ACS publication on Resources For Optimal Care Of The Injured Patient 2006.

http://www.ameriburn.org/verification_verifiedcenters.php
plexities. According to Atul Gawande (2009), “the volume and complexity of what we know has exceeded our individual ability to deliver its benefits correctly, safely or reliably” (p. 13). There is so much information that it becomes difficult to get it right. We need a strategy to take advantage of knowledge and experience that is often lost due to human inadequacies, and a checklist is a simple solution (Gawande 2009). Checklists are used increasingly to reduce errors in many professions; for our purposes, they are a simple but effective method of ensuring a comprehensive and consistent approach to a Life Care Plan.

The Nurse Life Care Planner (NLCP) used Roger Weed’s Life Care Plan checklist (Table 1, next page) for Mr. A’s Life Care Plan, recommending items and services based on her expertise, consultation with individual experts, review of the literature, and established standards of care. This approach using a standardized format is an established process that ensures development of a consistent and comprehensive plan to address future care needs. (Ed. note: Some suggested nursing diagnoses are highlighted in blue; also please see page 454.)

**Projected Evaluations** The Nurse Life Care Planner recommended the following evaluations:

**Driving evaluation** by an occupational therapist trained in disability management with a certification in driving evaluations, for clinical assessment and road assessment to follow if the clinical assessment confirmed functional skills needed to drive a vehicle (Risk for injury; Social isolation)

**Neuro-optometrist:** Evaluate neurological visual changes related to his burn injuries and make necessary recommendations for therapy (Disturbed visual perception)

**Neurologist:** Identify neurological damage from his burn injuries and airway injury and make medication or treatment recommendations (Impaired comfort)

**Neuropsychology:** Evaluate cognitive status and psychological conditions to guide treatment (Impaired Memory, Disturbed Sensory Perception)

**Occupational therapy:** Assess contractures before and after plastic surgery, to assess ability to participate in ADLs, and to make treatment recommendations (Impaired Physical Mobility; Self-care Deficit)

**Physical therapy:** Treatment recommendations to maintain functional mobility, prevent contractures, and recover after plastic surgery (Impaired Physical Mobility; Self-care Deficit)

**Ophthalmology:** Evaluate for retinal damage (Disturbed Visual Perception)

**Otolaryngology:** Assess for upper airway changes from inhalation injury (Impaired Communication; Impaired Tissue Integrity)

**Pain Clinic:** Assess issues, make treatment recommendations. (Impaired Comfort)

*continued page XX*
Table 1. Life Care Planning Checklist

Projected Evaluations: Have you planned for different types of non-physician evaluations (for example; physical therapy, speech therapy, recreational therapy, occupational therapy, music therapy, dietary assessment, audiology, vision screening, swallow studies, etc.)?

Projected Therapeutic Modalities: What therapies will be needed (based on the evaluations above)? Will a case manager help control costs and reduce complications? Is a behavior management, or rehab psychologist, pastoral counseling or family education appropriate?

Diagnostic Testing/Educational Assessment: What testing is necessary and at what ages? Vocational evaluation? Neuropsychological? Educational levels? Educational consultant to maximize IDEA?


Wheelchair Accessories and Maintenance: Has each chair been listed separately for maintenance and accessories (bags, cushions, trays, etc.)? Have you considered the client's activity level?

Aids for Independent Functioning: What can this individual use to help him or herself? environmental controls? adaptive aids? omni-reachers?

Orthotics/Prosthetics: Will the client need braces? Have you planned for replacement and maintenance?

Home Furnishings and Accessories: Will the client need a specialty bed? portable ramps? Hoyer or other lift?

Drug/Supply Needs: Have prescription and non-prescription drugs been listed including size, quantity and rate at which to be consumed? All supplies such as bladder and bowel program, skin care, etc.?

Home Care/Facility Care: Is it possible for the client to live at home? How about specialty programs such as yearly camps? What level of care will he/she require?


Transportation: Are hand controls sufficient or is a specialty van needed? Can local transportation companies be used?

Health and Strength Maintenance: What specialty recreation is needed? blow darts? adapted games? Rowcycle? annual dues for specialty magazines? (Specialty wheelchairs should be placed on wheelchair page.)

Architectural Renovations: Have you considered ramps, hallways, kitchen, fire protection, alternative heating/cooling, floor coverings, bath, attendant room, equipment storage, etc?

Future Medical Care/Surgical Intervention or Aggressive Treatment: Are there plans for aggressive treatment? Or additional surgeries such as reconstruction?

Orthopedic Equipment Needs: Are walkers, standing tables, tilt tables, body support equipment needed?

Vocational/Educational Plan: What are the costs of vocational counseling, job coaching, tuition, fees, books, supplies, technology, etc.?

Potential Complications: Have you included a list of potential complications which can occur such as skin breakdown, infections, psychological trauma, contractures, etc.? (Usually “possible” rather than “probable.”)
Physiatry: Assess clinical status, make treatment recommendations (Impaired Physical Mobility; Self-care Deficit)

Psychiatry: Assess clinical status, make treatment recommendations (Social Isolation; Hopelessness; Powerlessness; Risk for Compromised Human Dignity; Disturbed Body Image; Risk for Post Trauma Syndrome; Grieving)

Pulmonology: Evaluate and treat post-inhalation injury (Impaired Tissue Integrity; Impaired Gas Exchange; Ineffective Breathing Pattern)

Psychology / social worker: Assess family dynamics, coping skills, educational needs, and counseling (Social Isolation; Hopelessness; Powerlessness; Risk for Compromised Human Dignity; Disturbed Body Image; Risk for Post Trauma Syndrome; Interrupted Family Processes)

Recreational therapy: Assess recreational needs and make recommendations to enhance quality of life (Deficient Diversional Activity, Sedentary lifestyle)

Assistive technology evaluations: Identify assistive technology needs and recommend for devices, equipment or software (Impaired Physical Mobility; Deficient Diversional Activity; Impaired Social Interaction)

Projected Therapeutic Modalities These were based on the recommended Projected Evaluations, interviews with Mr. A and his providers, and the life care planner’s nursing knowledge and experience.

Individual counseling, for body image disturbance, alteration in coping, anxiety, and depression since the accident, ongoing, with frequency decreasing over time based on the literature and recommendations by his psychotherapist.

Family counseling, for disability education and support for interrupted family processes.

Burn support group, to allow Mr. A. and his family to meet others who have survived burns

Massage therapy, to loosen muscles, increase flexibility, soften scarring, and help with relaxation

Case management services, to implement the Life Care Plan, facilitate, coordinate, and monitor

Physical and occupational therapy, ongoing, with increased frequency before and after plastic surgery procedures, to prevent contractures, maintain functional mobility, improve overall functioning, and facilitate increased independence with ADLs

Respiratory therapy, as needed to treat inhalation injury-related complications

Diagnostic Testing/Educational Assessment An annual computed tomography (CT scan) or magnetic resonance imaging (MRI) was included to assess bones and joints involved in the injury. X-
rays were also recommended once each year to assess bone status and lung status related to disability.

One to three electrocardiograms (EKGs) annually were included to monitor cardiac status and as needed before future operations. Pulmonary function testing (PFT) was recommended annually to monitor for changes due to respiratory injury.

Routine blood work, urine tests, and wound cultures were recommended at various intervals to monitor nutritional status, endocrine issues, possible infection, side effects of medications, and general response to disability.

The neurologist recommended electromyelogram (EMG) on an as-needed basis to assess development of any peripheral nerve dysfunction from peripheral burn injuries.

Educational assessment was not indicated as Mr. A had no plans for further education.

Wheelchair and Maintenance His physical therapist and physiatrist recommended a power scooter to allow him to conserve energy when out and about for long trips out of his home. His altered respiratory status due to his smoke inhalation injury and worsening of his asthma kept him from long walks and he did not have the stamina to go out to his favorite sporting events or on walking vacations without a device. The scooter would need to be replaced approximately every five to six years according to the manufacturer. Maintenance included an annual tune-up/check by the scooter company, with replacement wheels, battery, and belts.

Aids for Independent Function The items included in this area to address Mr. A’s self-care deficit included adaptive bathing, grooming and eating utensils to promote his independence. Other aids for independent function included a handheld shower and reacher/grabber. He would benefit from assistive computer technology, with an adaptive keyboard and stand as he was unable to sit comfortably, and Dragon Naturally Speaking software for voice activation when fatigued or after arm surgical contracture releases.

Orthotics/Prosthetics Given his altered mobility and potential for disuse syndrome, Mr. A’s occupational therapist recommended various splints to prevent contractures and maintain positioning.

Home Furnishings and Accessories A recliner/lift chair was included in the plan based on assess-
ment of Mr. A’s altered mobility and difficulty arising from sitting. A portable ramp was also included so that Mr. A could get his scooter into his vehicle and into his home when necessary. A small carport was included to allow the scooter to be left outside protected from cold and inclement weather since his home had no porch and not enough space to park the vehicle routinely.

Drug/Supply Needs  Mr. A’s medication list was based on input from his primary care physician, physiatrist, and burn surgeon. It included numerous vitamins, anxiolytics, anti-depressants, anti-itch medications, antibiotic ointments, vaccinations, antibiotics and pain medications for future surgical procedures. Specifically, they recommended Eucerin and Aquaphor cream to lubricate the skin given the loss of sweat and sebaceous glands, Dermablend cream to help cover scarring and reduce effects of disfigurement, sun block to protect fragile skin from effects of UVA and UVB rays, and wound care/dressing supplies to treat open wounds that are common with fragile burned skin. Two sets of pressure garments to prevent and manage hypertrophic scarring are needed at all times; replacement is annually or more often as they stretch or the patient loses or gains weight.

Home Care/Facility Care  A nurse and a home health aide daily were added for medical assessment, dressing changes, treatments, and to assist with personal care, with increased hours during postoperative periods.

Since family cannot be caregivers indefinitely and it is unreasonable to expect them to take on all care at the expense of their own physical and psychological well-being, homemaking services are vital. Therefore a homemaker was included for routine meal preparation, house cleaning, shopping, transport to and from appointments, and general companion care.

Some weekly hours for home maintenance and home repair were included for maintenance Mr. A was unable to perform due to his injuries.

Inpatient days were included as needed for acute rehabilitation after major surgeries. Assisted living was included should he become unable to live independently.

Routine Future Medical Care expected to include the following specialties:

- **Primary care** for general medical status related to his burns and resulting needs, quarterly plus annual physical examination
- **Ophthalmology** annually, to assess his vision given the retinal involvement
- **Orthopedist** annually to monitor orthopedic issues related to burns with loss of muscle mass and resulting complications.
- **Otolaryngology** evaluation every five years to address any upper respiratory issues.

continued next page
Pain Clinic visits up to 6 times per year to ensure adequate follow-up of chronic pain issues and repeated expected surgeries

Physiatry up to three times per year to assess physical functioning and recommendations though life expectancy

Plastic surgery, multiple visits to monitor injuries and follow-up after procedures for up to eight years, and then as needed through life expectancy.

Podiatry every six to eight weeks to cut toenails and assess feet

Pulmonology to monitor respiratory status pre- and postoperatively, and every five years to monitor and treat general pulmonary status

Transportation Vehicle modifications were included in the plan to allow him to drive safely, based on the driving evaluation. Should he be deemed unable to drive safely, a stipend for cab fare was included to get Mr. A to and from his medical appointments and on necessary errands.

Health and Strength Maintenance Membership in a local gym was included to provide a structured setting for Mr. A to work out, maintain strength, encourage him to be out of the home routinely, and socialize with others. Periodic physical therapy visits were included to instruct and evaluate an individualized home exercise program, and a treadmill was also included.

Architectural Renovations Architectural renovations included widening doorways, a walk-in shower, a ramp for his scooter, central air conditioning, and a closet to house his equipment and supplies.

Future Medical Care/Surgical Interventions or Aggressive Treatment Multiple surgical procedures, including hospitalizations and associated costs, were included in the plan to address multiple plastic surgery needs recommended by his plastic surgeon. These included contracture releases for hand, elbows and affected fingers; possible flap surgeries to release contractures and restore mobility; revisions of burn scars; and other unplanned procedures such as skin grafting for pressure or shearing injuries to his fragile burns.

Orthopedic Equipment Needs There were no orthopedic equipment needs identified.

Vocational/Educational Plan Vocational evaluation, counseling, and a job coach were included should Mr. A decide to return to work when ready.

Potential Complications Unexpected hospitalizations were included in the plan without associated costs, with a list of the significant number of possible complications typical in victims of burns.

Summary and Conclusion A comprehensive Life Care Plan comprised of appropriate medical care, therapeutic interventions, prevention of complications and quality of life is critical for any victim of a significant burn injury. Every individual’s needs and details needed to de-
velop the plan are different. However, use of a checklist along the way helps guide the nurse life care planner to account for the significant number of details involved.

Planning ideally should begin in the acute setting, immediately after injury. Many hospital and rehabilitation nurses and case managers are unaware of the field of Nurse Life Care Planning and its benefits to patients; with some knowledge of this discipline they would likely encourage this avenue for their patients. Nurse Life Care Planners could help by reaching out to hospital and rehabilitation nurses and nurse case managers with continuing education offerings on the role of life care planning.

References:

Whale pod
Off Cape Town, South Africa
Editor's note: For the last three AANLCP Annual Conferences, the JNLC has extended an invitation to all speakers to submit a brief essay on a topic of their choosing, with the objective of introducing themselves further. The only constraints were that these were not to be straight biographical statements and were not to be a repeat of their conference presentations. Two speakers responded this year. Please take the time to seek them out and engage them in conversation about Nurse Life Care Planning and its future.

**Conference Speakers**

**Kathie Allison, PT, MS, CLCP**

I guess what I want people to know about me, is how much I love the process of life care planning. It truly allow me to use all my skill sets. I taught PT at the University of Kansas; I love the research of life care planning. I was in management for about 7 years; I love the cost analysis. I have 39 year experience as a physical therapist; I love patients who are now clients. I get to do something I love!

**Terri Blackwelder, BSN, RN, CCM, CRRN**

I have worked with patients for years who told me about a moment—such as an accident—where in a few minutes or hours, everything in their lives completely changed and nothing was ever the same again. For me, this pivotal moment was a force of nature. My life was on course until a weekend at the end of August, 2005, when everything changed for us in the New Orleans area. We were told to evacuate and get ready for the biggest Hurricane since Betsy and Camille. We all initially had a “c’est la vie” type attitude, as we had heard all this before and nothing ever really happened. There was mass panic and hysteria. Phone lines were jammed. We decided as a family to batten down the hatches and weather the storm. We were above sea level, across the lake from the city and would get power back sooner. The other poor folks from New Orleans needed the hotel rooms and flights and gas more than we did. It was a life changing experience for all of us. After the storm and the events that followed, I remember thinking that I was back down to the basic needs of Maslow’s hierarchy. I realized that material things don’t really matter, only people do. This set my life on a whole different course than I ever could have planned...
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