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In order to make safe and effective judgments using NANDA-I nursing diagnoses it is essential that nurses refer to the definitions and defining characteristics of the diagnoses listed in this work.
Congratulations, all. You have, at the time of this writing, probably seen the last snow melt in your yards and streets, and should be enjoying the promise of spring with grateful hearts. As Charlotte says in E.B. White’s classic, Charlotte’s Web, “Winter will pass, the days will lengthen, the ice will melt in the pasture pond. The sparrow will return and sing, the frogs will awake, the warm wind will blow again. All these sights and sounds and smells will be yours to enjoy, Wilbur—this lovely world, these precious days…”

You have in front of you one of the largest issues the JNLCP has published in the last seven years, with the theme of spinal cord injury. It includes a number of important topics you might not expect to see, like a detailed case study of pregnancy and delivery, an article on breastfeeding, some surprising findings about pressure injury, some good information on travel, the skinny on adaptive driving evaluations, and a number of novel mobility technologies. You’ll also see a first for the JNLCP: a cartoon! And since we depend so much on communication in life care planning, we also have a column on staying connected to keep your business humming.

We have reached the enviable position of receiving increasing numbers of unsolicited manuscripts for consideration. This is flattering but honestly, some are school papers and don’t meet our needs at all. Suggestion: If you want to see your name in print, the first thing to do is look at the end of this issue to see what our upcoming topics are. Then flip to the Information for Authors page, and start thinking about what you want to say and how you want to say it.

Now, I know that some of you have some good articles in you, but what’s holding you back is the nagging feeling that you can’t write well. Surprise: Not one of these articles looked like this when it came in over the transom. I want to take this opportunity to thank the many people who serve as volunteer reviewers for your Journal—the ones who worked on this issue are listed on the Information for Authors page. When you submit an article, I blind it and then they get it, and they send kudos, suggestions for improvement, and ideas about related resources that then make their way back to you. It’s part of our job to make your writing look great, friends, because, well, then the Journal looks great, and then the Association looks great. We like to think we do a pretty good job of making all that happen.

“It is not often that someone comes along who is a true friend and a good writer. Charlotte was both.” Let us hear from you!

Wendie A. Howland MN RN-BC CRRN CCM CNLCP LNCC
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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 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)
- Use Times, Times New Roman, or Ariel font, 12 point
- 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, Figures, Links
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) Live links are encouraged. Please include the full URL for each.

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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 article-name.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: whohowland@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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A CORE CURRICULUM
for
NURSE LIFE CARE PLANNING

American Association of Nurse Life Care Planners

Dorajane Apuna-Grummer
Wendie A. Howland
Editors
A Message from the President

In the past, the Executive Board held a strategic planning meeting every January to determine the organization’s major goals. Typically, the incoming President would have a list of goals to accomplish while in office that developed while serving as President-elect over the previous year. Collectively, the Board would determine which were most important to direct the organization’s efforts for the year.

This January, seven leaders received a reading assignment and took a personality inventory. We then met in a home in San Antonio where we were held captive for several days. We discussed and later signed confidentiality/conflict of interest/code of conduct statements. We developed an emergency protocol. We went over policies and procedures and began developing and updating missing, incomplete, or outdated ones. We outlined Board member responsibilities and roles for the next 24 months. We developed and approved an annual budget.

We then began to develop a three-year strategic plan. We have met some goals already, including:
- Inaugurated the new look and feel for the Journal of Nurse Life Care Planning
- Launched the Mastermind educational series which has been well attended thus far
- Developed and posted a Call for Speakers/Presentations that has already resulted in some welcome proposals for our Conference
- Conducted site visits and negotiated contracts for the February 2016 Conference in San Antonio
- Updated the Association website scope and content – and we anticipate more growth and further upgrades next year

- Offered the first two Webinar Wednesdays and scheduled several more
- Launched the all-new electronic newsletter with all the latest news and information is posted. Find it on the home page or at http://aanlcp.blogspot.com
- Revised our Scope and Standards and submitted them to the ANA/CNPE in April
- Outlined four research projects we would like developed in the next year
- Initiated steps towards updating our Core Curriculum for 2017 publication
- Held monthly Executive Board meetings and included Committee Chairs every other month
- Developed more member benefits and discounts such as ASA Crosswalk, Medical Fees, Crash Cart, Word Rake, and My Computer Works. We are in negotiations with NANDA-I
- Exhibited at AALNC and CMSA conferences
- Marketed life care planning by board members and volunteers presenting on various topics to other groups
- Launched Crash Cart, containing all kinds of resource data specific to life care planning as well as sample letters, templates, contracts, etc.

Moving our annual conference from the fall to earlier in the year gives the executive board the opportunity to allow incoming board members to sit in on a strategic planning session in the fall to outline the following year’s goals. This will help the Board hit the ground running at the beginning of the year rather than later at the end of the first quarter.

My goals have been to increase membership. I am spearheading a project to get our life care planning students involved. This Student Track will be launching soon.

A member survey is coming soon. Your feedback is critical to our Association. We are also looking for leaders: step into a volunteer or leadership position. Nominations are open. And as a bonus, those who have 85% or greater participation receive participation points that can be used towards recertification.

I have to say that getting involved is the best use of your time as a life care planner. I can’t begin to describe how much I’ve learned and the personal and professional growth I have had in the last 18 months. I have changed significant things about my plans, my testimony, and own professional goals. By being intimately involved in the day-to-day activities of the association, I have a better understanding of our scope and standards, how we have evolved, how we continue to improve, and how we are meeting a need in the nursing community that has never been developed before.

The ANA and NANDA-I are very much aware of us and are excited to see what has developed in the past several years. We are continually applauded for the intense work we have put in and people are finally “getting it!” We are so close to an explosion of growth and it is just a matter of time before it all comes to fruition. It’s an exciting time!

Victoria Powell RN CCM LNCC CNLCP MSCC CEAS CBIS
President, AANLCP
victoria@vp-medical.com
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Contributors

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Dawn Cook has been a Health Care professional for three decades. She worked as a Registered Nurse in hospitals, home care, and life care planning and she is fully qualified as a Certified Nurse Life Care Planner, Registered Nurse, and Lifetime Nurse Care Planner. She has testified at depositions and at court. She is sought after for her high quality Expert Reports and her strength of testifying. She runs her own business from Las Vegas NV, and can be reached by phone at 702-544-2159 or 916-704-9424 or by email: Dawn@DawnRN.com.

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DAVID DILLARD
David Dillard BA MLS has degrees in history and library science. He has worked at Temple University Libraries since 1970, first in the Business Library; he moved to Reference and concurrently began to learn bibliographic database searching. He now does collection development for Tourism, Hospitality, Sports Management, Recreation, Therapeutic Recreation, Public Health, Kinesiology, Disabilities, Social Work and Communication Disorders. Dave started sharing information sources and answers to questions on internet discussion groups around 1998 and that has grown to a cottage business. He started a network of public search engine indexed discussion groups and archives for sharing of posts of good websites, bibliographies of sources on a wide variety of topics, and news story summaries with source citations and links to those sources. He is a regular on several nursing specialty lists and is very open to contact from anyone to help with searches on any topic.
to this Issue

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Clare Hartigan, PT, MPT is the Program Manager for Lower Extremity Robotics at the Virginia C. Crawford Research Institute, Shepherd Center, Atlanta GA. She is the Clinical Research Coordinator for Shepherd Center clinical trials of the Ekso™, ReWalk™ and Indego® Exoskeleton systems and participates in a variety of research projects for persons with SCI, MS, and stroke. She has presented at multiple national and international conferences on the topics of locomotor training and lower extremity exoskeletons. She continues to participate in a variety of research projects for persons with SCI, MS and stroke. She has co-authored peer reviewed publications on the Indego® Exoskeleton and has presented at multiple national and international conferences on the topics of locomotor training and lower extremity exoskeletons. She can be contacted at Clare.Hartigan@shepherd.org.

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Debra Morehead RN LNCP-C, CLC is the president of the Morehead Group of SC, offering research and outlining of expected medical costs for persons with accident, illness, injury, or disability. She may be contacted at 864-324-1412, deb@rnlifeplan.com.

JOANNE SMITH B.A., BRT Dip, CNP
Joanne Smith B.A., BRT Dip, CNP has lived with SCI for over twenty-five years. She holds degrees in holistic nutrition and psychology and a diploma in broadcasting. As a Certified Nutritional Practitioner, she specializes in providing optimal nutritional health for people spinal cord and brain injuries, speaking at conferences across Canada and the US. She co-authored Eat Well Live Well with Spinal Cord Injury, the first nutrition book dedicated to addressing the unique needs of people with SCI. She writes nutrition columns for New Mobility, PN, Sports n’ Spokes and Outspoken magazines in Canada and the USA. Her website is http://www.eatwelllivewell-withsci.com/. She may be contacted at fruitful- elements@gmail.com.
Organ transplantation

The organ transplant patients (heart, lung, liver, etc.) that we admit have been some of the easiest patients since they have been very well managed from a medical standpoint and are highly motivated to participate in rehab. We do not have specific protocols just request that the referring physicians clearly identify specific parameters for cardiac precautions, sternal precautions, etc. Often the transplant surgeons don’t specify METs, but they do limit lifting to 10 pounds, no manual wheelchair propulsion, use of arms in bed mobility or sit-to-stand activities. We also have to be sure that the many anti-rejection meds that the patient is on are available through our pharmacy- sometimes that could be come an issue if they are non-formulary and the patient’s family has to obtain them from the facility that did the transplant, bring them to us and have our pharmacy identify and label them so we can administer using our electronic scanning system. In general, the heart transplant patients have done very well- usual LOS has been approximately 3 weeks.

Karen Smith MSN, RN, CRRN
CNS, Rehabilitation Institute of Michigan

CBIS Feedback

I want to open up this discussion and in response to the letter published in our journal this quarter (JNLCP XIV.1). I agree that we need to be careful what initials we, as professional, licensed, and registered nurses, and certified life care planners, are putting behind our name. After reading the letter (I am hoping all of you read it), I went to the ACBIS website and found this disclaimer (excerpted).

“The Academy of Certified Brain Injury Specialists provides a certification program that intends for individuals to become familiar with a broad range of issues relevant to the care of people with acquired brain injuries. The training material and testing requirement was developed for unlicensed, non-professional staff to help raise their skill level and contribution as an integral part of interdisciplinary rehabilitation teams. … However, it does not confer or imply the acquisition of advanced training or expertise in brain injury rehabilitation. As such, this certification does not inherently expand a professional’s scope of practice … Certification as a Brain Injury Specialist or Brain Injury Specialist Trainer neither implies nor warrants: That the certificant is an expert in brain injury rehabilitation.”

As one can clearly see, this certification was developed for UNLICENSED, NON PROFESSIONAL STAFF. It would seem that this would be similar to leaving our CNA, LPN license, or maybe BCLS behind our name. Additionally, it appears that those placing these initials behind their name are being somewhat joked about in the professional arena by attorneys that are hiring life care planners.

I personally do not care what initials people choose to put behind their names. However, if the opportunity arises, I will help attorneys discredit these certifications in deposition and trial.

Lora White, RN
Phoenix, AZ

Travis Roy Update

For those of you who may remember, Travis Roy was our Keynote Speaker at the AANLCP conference in 2010/Boston. I was happy to read that he is going to receive the Christopher Reeve Spirit of Courage Award. Travis was a young man who suffered a serious spinal cord injury during the first 11 seconds of his first college hockey game. He founded the Travis Roy Foundation, which is dedicated to assisting individuals with spinal cord injuries by providing adaptive equipment and to finding a cure through increased funding of research.

http://www.travisroyfoundation.org
You can read the article at: http://www.pressherald.com/2014/11/20/inspiring-selfless-travis-roy-to-receive-prestigious-spirit-of-courage-award/

Barbara Bate RN-BC, CCM, CRRN, CNLCP, LNCC, MSCC, CBIS
Holden, ME 04429

RN: Join the AANLCP!

Recently I had the privilege of networking with experienced life care planners who were all nurses. What a powerful, diverse, and passionate group! It struck me that while many RNs use the nursing process as their foundation, it is AANLCP that promotes and recognizes the nursing process as a separate expertise/foundation in the field of life care planning. Therefore it is from this perspective that I invite all nurses, regardless of the initials after their names, to join AANLCP. Together, we will build and expand our expertise and our specialty practice.

Becky Czarnik RN, MS, CLNC, NLCP-C, CMSP
AANLCP Board Secretary 2015-2017

Research Update

I am planning in the very near future to post about the coming full text online to the AALNC Journal and the already existing full text of the AANLCP Journal to my ten or so lists and to relevant library-related lists.

I think it is wonderful to have both of these journals available at no cost to all readers. My lists are public and search engine indexed. I will also list these journals in my Social Work and Public Health Research Guides on the Temple University research guide website as well as my own copies of these guides on Google Sites.

Sincerely,
David Dillard
Temple University
### Clinical pharmacy services and solid organ transplantation: a literature review
Author: Stemer, G.
Journal: Pharmacy world and science
ISSN: 0928-1231
Date: 02/2010 Volume: 32 Issue: 1 Page: 7 – 18 DOI: 10.1007/s11096-009-9351-7

### Cardiac transplantation in adult patients with mental retardation: Do outcomes support consensus guidelines?
Author: Samelson-Jones, Emma
Journal: Psychosomatics (Washington, D.C.)
ISSN: 0033-3182

### Psychological stress in transplantation: a unified concept? What is measured and how: a literature review.

### Role of socioeconomic conditions on outcome in kidney transplant recipients
Author: Mistrutta, A.
Journal: Transplantation proceedings
ISSN: 0041-1345
Date: 05/2009 Volume: 41 Issue: 4 Page: 1162 - 1167 DOI: 10.1016/j.transproceed.2009.03.017

### Constantly responsible, constantly worried, constantly blessed: parenting after pediatric heart transplant.

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**TRANSPANTATION AND LONG TERM CARE BIBLIOGRAPHIES AND LITERATURE REVIEWS**

**BY David Dillard**

Successful transplantation results in long term care needs for the special health, physical and mental problems patients face after surgery. This selective list of bibliographic sources will help to lead health care professionals to sources that help fill these knowledge needs.

**Primary care of the renal transplant patient**
Author: Gupta, Gaurav
Journal: Journal of general internal medicine : JGIM
ISSN: 0884-8734

**Clinical pharmacy activities in chronic kidney disease and end-stage renal disease patients: a systematic literature review.**

**Medical care costs and survival associated with hepatocellular carcinoma among the elderly.**

**Delivery patterns of recommended chronic kidney disease care in clinical practice: administrative claims-based analysis and systematic literature review**
Author: Philipneri, Marie D.
Journal: Clinical and experimental nephrology
ISSN: 1342-1751
Date: 02/2008 Volume: 12 Issue: 1 Page: 41 - 52 DOI: 10.1007/s10157-007-0016-3

**Liver transplantation for quality as well as quantity of life**
Author: B Lankarani, Kamran
Journal: Hepatitis monthly
ISSN: 1735-143X
Date: 10/2013 Volume: 13 Issue: 10 DOI: 10.5812/hepatmon.14890

**Impact of a pharmaceutical care program on liver transplant patients' compliance with immunosuppressive medication: a prospective, randomized, controlled trial using electronic monitoring**
Author: Klein, A
Journal: Transplantation
ISSN: 0041-1337

**Key concepts relevant to quality of complex and shared decision-making in health care: a literature review**
Author: Dy, Sydney M. View Author Profile
Journal: Social science and medicine (1982)
ISSN: 0277-9536
Date: 02/2012 Volume: 74 Issue: 4 Page: 582 - 587 DOI: 10.1016/j.soscimed.2011.11.015

**Development and validation of a French patient-based health-related quality of life instrument in kidney transplant: the ReTransQoL**
Author: Gentile, S
Journal: Health and quality of life outcomes
ISSN: 1477-7525
Date: 10/13/2008 Volume: 6 Issue: 1 Page: 78 PMID: 18851730 DOI: 10.1186/1477-7525-6-78

**A personalized follow-up of kidney transplant recipients using video conferencing based on a 1-year scoring system predictive of long term graft failure (TELEGRAFT study): protocol for a randomized controlled trial**
Author: Foucher, Y
Journal: BMC nephrology
ISSN: 1471-2369
Date: 2015 Volume: 16 Issue: 1 Page: 6

**Impact of islet cell transplantation on diabetic retinopathy in type 1 diabetes.**
I have been a workaholic and traveler all of my life! When I got into the life care planning business, I worried about traditional offices and especially about phone service. Here’s what works well for me in my travels.

**The Phone’s The Thing**

The very most important thing you need when you are away from your home office is reliable phone service. Consider using a cell phone as your primary business phone. Even when I am at home in Las Vegas, my cell phone is my primary business phone. I seem to get about half of my business calls while I’m shopping for groceries or at some other errand. I hate to think of the business that I’d lose by only counting on a landline.

You should consider using a cell phone for your business and always keeping it with you. It should have the local area code of the city where you do most of your business, so you don’t mislead your clients. Law firms won’t see you as someone from out of town. When you are calling locally for costs, the physician’s office or hospital will be more inclined to return a local call.

**Use Call Forwarding**

If you like having a landline, or if this is already your business line, get set up for call forwarding. You can have your calls forwarded to any cell phone. See if your cell provider uses the same directions as many phone systems:

- Key in *72, then add the forward-to phone number (think: 2 = TO)
- Key in *73 to remove call forwarding (think: 3 = FREE)

**Have Two Cell Phones**

I use a smart phone for personal use and Internet access. I have a “dumb” phone for business. I may upgrade to a smart phone for business, but I like having two phones all the time. I don’t think a landline is necessary, and I don’t have one. When I am out of town on business or pleasure, my clients don’t even realize that I am out of the office unless I tell them.

**Service Coverage**

You’ll benefit by studying the coverage maps for all the major providers of cell phone service. Some are very good if you are in certain cities but are not that good in smaller cities and towns. If you look at any of the cell phone carriers’ maps, you’ll see that...
it looks like Nevada has hardly any service at all. Nevertheless, I find that there are only a few spots on the highways between Las Vegas in the south and Reno in the northwest where I might not have a signal for a few minutes. But that’s all.

I’ve used the same service in California, Oregon, Washington, British Columbia, Alaska and Hawaii. I’ve used this service as I drive from Las Vegas to Denver, to Chicago and New York City. I’ve used it down the east coast from Pennsylvania to Georgia, on the Gulf Coast, and all the way across Texas. Recently my cell phone worked well in Key West, where I spent a marvelous week working at life care planning at the beach! There were no problems in Hawaii, but some in very rural Alaska.

Even when I can’t talk on the phone due to a poor signal, I can still send and receive texts.

Charging
When you travel, be sure to have cell phone recharging cables for home and car. I have one for each cell phone because occasionally I forget to charge and suddenly both cell phones are almost dead! The last thing you want while conducting a professional business is to not be able to immediately call out or receive phone calls! You can also get cell cases that include batteries that can increase your battery life by over 100%.

International Service
If you plan travel to Mexico or Canada, ask if your carrier has a plan to make calls while traveling out of the US. I have a special Canada plan with Verizon. I have no roaming charges anywhere in the US or Canada. I can receive calls in Canada without roaming charges. I recently spent a week in Mexico and my phone was already “global equipped.” If your cell phone is “global enabled” you will be able to receive and make calls from anywhere that has cell phone service. My provider insisted that my “basic phone” couldn’t be used in Mexico, saying that only “smart phones” are “global enabled.” But since I have used it in Canada, she double checked and discovered that it was “global enabled” too. All around, my charges were $.99 per minute and my service was very good.

Local Phone Numbers
I found that when I moved from rural Nevada and changed my cell phone number to the Las Vegas area code, I got a lot busier as a life care planner. If you should decide to be away from your home for any length of time, you might want to get a cell phone with a “big city” area code. If you are a “snow bird” life care planner, living in the north in the summer and the south in the winter, you may want a cell phone number for each locale.

Services like Grasshopper and others can give you an 800- or 866- number for a small charge, and include other services like answering and multiple lines.

Apps
A handy app for coverage is called, well, “Coverage.” It’s $5, is updated regularly, and shows where strong cellular signals are. To obtain good coverage, some serious travelers have one cell phone from one carrier and another cell phone from another carrier. You might find this works for you but you will probably still need to have just one business phone number and that one should have good coverage. Don’t forget that you may be traveling by air and ground to visit people for a home interview. You might find yourself far away from your usual carrier area and you’d be wise to be sure you can get coverage wherever you are.

Travel
If you’re traveling internationally, check out the latest in international cell phones. You can get a phone from most carriers that is “local” where you are going. You can have all of your calls forwarded to this phone and the charges are usually not nearly as high as using your cell while roaming in China or Europe. You might also want to consider having a temporary answering service while you are out of the country.

Call all of your current clients and let them know your plans. Agree to check your email once or twice day and maybe you can resolve all of your business concerns without having to use the phone, for the duration of your trip. You voice mail message can give your email and tell the prospective client that your will check and respond to email twice a day.

Cruise Ships
This is also a good strategy for travel with a cruise ship. It is very expensive to use the phone or Internet while on the cruise. But you could take care of a lot of business in a few minutes if you plan carefully and do all your emailing twice a day.

These hints will address most issues of phone service you’ll encounter as a life care planner, wherever you are. Travel within North America is a little easier and cheaper than travel to Europe and Russia, but you can still manage phone service to meet your needs at home and abroad. If you research the best plans and coverage for cell phone service, you’ll never have to be without effective phone service. Your responsibilities to your business, clients and prospective clients can be managed, whether you’re grocery shopping near home or hiking the Rocky Mountains. The only time you should ever hear, “Can you hear me now?” is in the commercials.
Free Searches for SCI and Life Care Planning

BY DAVID DILLARD

Fields like life care planning and legal nurse consulting need information from a variety of subject fields. No database designed for a specific field covers its entire field, maybe not even most of it. Subscribing to specialized databases is expensive; independent or small group practices cannot afford to purchase even the most important set of databases containing listings of important articles and books they need.

However, the literature in subject fields you seek is out there, scattered throughout many different databases. Critically, in contrast to the familiar proprietary or publishers’ databases, access to much of it is free or very inexpensive. This is because there are many thousands of articles that are not found in the core databases for their fields but can be found in databases of other disciplines. You just have to know that they all do different things and should be used in conjunction with each other.

As an example, here’s an article that explains how to find social work citations in unexpected places. Finding citations: the relative benefits of using Web of Science, Scopus, or Google Scholar. Journal of Academic Librarianship, v 38, n 6, p 370-9, Nov. 2012.

This article is a very important source for how to do research in social work. Curiously, however, the journal in which it appears is not indexed in the two core databases of Social Work, but it is indexed in an engineering (!) database, Compendex, which covers journal publications in computer science and information science.

The highly regarded international medical database Embase costs millions of dollars per year. The bad news is that individual practitioners
cannot afford this database, but there is some balancing very good news: It has coverage is comparable to that of PubMed, and PubMed is available to all at no cost to everyone on the Internet, as is Google Scholar.

To demonstrate this, I searched the titles of the first 26 titles found in an Embase search looking for information on life care planning and longterm care. I excluded animal studies, because there are not many mice registered for nursing home care, though in poorly run nursing homes it is possible that the mice may get some pantry therapy. Of those 26 articles, I found 23 cited for free in Google Scholar. One of the two sources not found was a study of a hepatitis treatment in Changzhou China.

Another citation not found in Google Scholar turned up in Google web search as a poster presentation at a conference held in Turkey. The Embase link to the full text of this conference gives a listing that costs $39.95. I seriously doubt that anyone reading would feel serious loss at not seeing it.

Now let’s look at some ways to get the most out of your free search capabilities.

Google Scholar will provide access to extensive bodies of literature in a very wide range of subject disciplines. Consider a search of spinal cord injuries and long term care or life care planning executed in Google Scholar. (“life care” OR “long term care” OR “end of life” OR “nursing home”) AND “spinal cord” (http://tinyurl.com/qhy-q4vd)

This search lists 17,000 sources found in Google Scholar, but plain Google searches never show more than 1,000 results.

All of the first 100 sources in the results of this search are cited by more recent publications, which is a Google Scholar link “cited by…” at the bottom left of the information provided about the source. Links at the top of the Google Scholar citation usually either lead to the fee-based source of the article or to the free full text of the article on the internet. Searching the article title in quotation marks in Google web search can lead to the full text of the article on the web. The “cited by” feature is extremely important. If the citing author’s interest in the article is the same as your interest, you have probably found another article you can use.

Some of the titles found in this search include:
- Carbohydrate and lipid metabolism in chronic spinal cord injury. (Cited by 126)
- A rational approach to long-term care: comparing the independent living model with agency-based care for persons with high spinal cord injuries. (Cited by 35)
- Long-term survival, prognosis, and life-care planning for 29 patients with chronic locked-in syndrome (Cited by 80)
- Spinal cord injury medicine. 6. Economic and societal issues in spinal cord injury (Cited by 69)
- Direct health care costs after traumatic spinal cord injury (Cited by 58)
- Follow-up care for persons with spinal cord injury living in the community: a systematic review of interventions and their evaluation (Cited by 32)
- Utilization of health services following spinal cord injury: a 6-year follow-up study (Cited by 118)

Any citing articles are probably also themselves cited, so as long as the resulting sources are relevant, you can keep building up your results. The “cite” link also provides citations in MLA, APA, and Chicago formats.

If the issue is legal and you need to see law cases, simply click on “case law” at the top of the left sidebar. This search finds 228 law cases having to do with long term care and spinal cord injuries.

Google Books is another free source of tremendous value. It can find on-topic content buried in books that appear to be too general or hopelessly off-topic. Here are a few book citations found with this search topic. (http://tinyurl.com/paxqata2)

- Spinal Cord Injury Desk Reference: Guidelines for Life Care Planning and Case Management
- Life Care Planning and Case Management Handbook
- Pediatric Life Care Planning and Case Management
- A Core Curriculum for Nurse Life Care Planning

The Summon database is available to users free from a large number of colleges and universities worldwide and all its findings can be added to search results by simply clicking an icon box at the top of the search screen. You can limit to specific dates in a date range search. This and other valuable tools are found on the left side bar of the result pages.

Summon lets you limit a search to journals and peer reviewed sources. You can also find a large variety of source types using this database including popular magazines, trade journals, newspaper articles, and books. The sidebar shows the types of information found about spinal cord injuries and long term care in this database. (See Figure 1.)

(It certainly would be interesting to know how sheet music could be written regarding the spinal cord and, say, nursing home care, or what kind of painting results from this search.)

How to choose?
If you need to find popular quality information on the web while avoiding the iffy medical content Google Web Search finds so efficiently, consider using PogoFrog. Some of these sources will be full text articles or documents on the internet at no cost. http://tinyurl.com/nrapnnj will
lead to sources such as:

- Major medical conditions and VA healthcare costs near end of life
- Long-term care services needs for spinal-cord injury patients in Taiwan
- Life care planning projections for individuals with motor incomplete spinal cord injury before and after locomotor training intervention: a case series.
- Spinal cord injury desk reference. Guidelines for life care planning and case management

The PubMed database from the National Library of Medicine will provide scholarly research resources on the topics searched in this government database and on this topic, returning 192 at tinyurl.com/kescnab

To expand this result and weed out less productive ones from good sources, you can specify your search source: ("life care" OR "long term care" OR "end of life" OR "nursing home") AND "spinal cord" AND SITE: PUBMED (http://tinyurl.com/l6skd8m) (About 854,000 results)

If for legal or other reasons, there is a requirement to find evidence based sources, our topic may be searched in the TRIP database. You will get 8,087 results for "("life care" OR "long term care" OR "end of life" OR "nursing home") AND "spinal cord""

by quality at tinyurl.com/o5b29j5 including sources like these:

- Family Perceptions of End-of-Life Care for Long-Term Care Residents with Dementia: Differences Between the United States and the Netherlands.

Mixed methods study: End-of-life care in two Norwegian nursing homes: family perspectives

- Place of death and end-of-life care in nursing home residents after implementing Germany’s first regional advance care planning programme: a controlled trial (study protocol).

- The effect of policy on end-of-life care practice within nursing care homes: a systematic review

- The role of healthcare support workers in providing palliative and end-of-life care in the community: a systematic literature review

These are powerful and free tools that can save you major costs compared to buying specialized fee-based databases. You can apply what you save toward the purchase of specialized articles. It is easier to expense costs of specific articles to a client than to try to figure out a percent cost of a whole database.

Database Links

- Google Scholar: http://scholar.google.com
- Google Books: http://books.google.com
- Temple Summon Search: http://library.temple.edu/summon
- TRIP Database: http://www.tripdatabase.com
- PogoFrog: http://www.pogofrog.com/index.html

David Dillard

BA MLS has degrees in history and library science. David does collection development for Tourism, Hospitality, Sports Management, Recreation, Therapeutic Recreation, Public Health, Kinesiology, Disabilities, Social Work and Communication Disorders. He is a regular on several nursing specialty lists and is very open to contact from anyone to help with searches on any topic. He can be contacted at JWNE@TEMPLE.EDU.
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- Customize Narrative headings or use default
- Create “options” in LCP, MSA or MCP
- Upload files into template
- Submitter cover letter for MSA
- Calculates “Seed” money
- MSA template for WC and Liability files
- Limited use “User” available for certain sections
- LCP Narrative Section
- LCP Tables Section
- Customize Cover Pages
- Customize Company Logo or Customer Logo
- Footer information
- Admin. section to assign users
- Group files by customer on “Dashboard”
- Custom Data Lists reduces data entry
- Screen lock on “non-usage” for security
- Calculates age
- Calculates life expectancy
- Inflation factor built into template tables
- Calculates tables
- Customize table headings
- Create custom text tables
- Tables Summary with inflation numbers
- End notes section
- Notes section
- LCP Supportive information reference page
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Recently, two documents on pressure ulcers (PUs) of significance for Nurse Life Care Planners (NLCPs) have been published. This article will briefly review the two documents and discuss their significance for NLCPs, especially as they relate to spinal cord injury (SCI). The documents are:


The Quick Reference Guide is downloadable free; the full version costs $75.00 plus shipping and handling. Go to [www.npuap.org](http://www.npuap.org) for further details.

The NPUAP Unavoidable Pressure Injury Document
This twenty-two page article presents a state of the science paper on unavoidable pressure injury (PI) and the results of the NPUAP’s February 2014
A consensus conference on the subject. They define pressure injury, unmodifiable risk factors, intrinsic risk factors, and extrinsic risk factors. (See Table 1)

One section of the article specifically addresses SCI (page 321) and reviews recent literature on PUs and SCI. Post injury hypotension has been identified as a key risk factor for PUs in SCI patients in several studies. Recent publications suggest that microcirculatory dysfunction or impaired vascular response may contribute to PU development in SCI patients. 30% to 50% of all SCI patients develop a PU during the first month post injury, regardless of their acuity level. (Black, 2011)

Fifteen Consensus Statements received 80% or more agreement by the representatives of the participating organizations at the conference. Four of the fifteen statements can be directly related to SCI patients, either in the acute or the chronic phase. The four statements are:

1. Immobility can increase the likelihood of developing an unavoidable PU
2. When life-sustaining, vascular access, or other medical devices preclude turning and/or repositioning, the likelihood that an unavoidable PU can occur increases
3. An unstable pelvic fracture or spinal cord injury that precludes turning an individual increases the likelihood of an unavoidable pressure ulcer
4. Unavoidable pressure ulcers do occur

Other Consensus Statements may be applicable for specific individuals.

**NPUAP/EPUAP/PPPIA Prevention and Treatment of Pressure Ulcers: Clinical Practice Guideline**

This update of the clinical practice guidelines (CPG) is 308 pages in the long version and 136 pages in the Quick Reference Guide. Major sections of the guideline include:

- Prevention and Treatment
- Treatment, Special Population
- Implementation

Dozens of articles are cited in each section. The long version of the CPG includes a 13 page Glossary and Appendices. The International NPUAP/
Implications for NLCPs
NLCPs will find the terms “pressure injury” and “unmodifiable intrinsic and extrinsic risk factors” useful for explaining the acute and chronic conditions that people with SCI face. Focusing on the most common risk factors and comorbidities that can cause PUs in this patient population – immobility and post-injury hypotension – can provide a framework for assessing SCI patient needs.

The cornerstones of PU prevention and treatment for SCI patients remain the same:
- Plan of Care addressing immobility and PU Prevention
- Support surfaces, including seating and bed surfaces
- Topical treatment, including cleansing and dressings if PUs develop
- Nutritional support
- Blood pressure monitoring
- Labs for monitoring ongoing status
- Referrals to wound specialists, if PUs or other wounds develop
- Education of the SCI patient and caregivers

Details regarding best practices for each of these topic areas can be found in the full version of the CPG.

Conclusion
Taken together, these two new documents provide the best evidence base to date for PU prevention and treatment for all people and for patients with SCI in particular. NLCPs who assist the SCI patient population will find the details presented in both of these documents essential for advocating for the best prevention and treatment products and services for their clients.

EDITOR’S NOTE: Dr. Krasner presented information from the CPG at the AALNC conference in April 2015. I was struck by the implications for life care planning for SCI regarding the unavoidability of PUs in many cases. So often we have heard that PUs are preventable, signs of poor care by others or self-care by the individual. This document makes it clear that if the individual meets one or more of these criteria, it would be wise to add provisions for more PU treatment to the preventative measures and monitoring.

REFERENCES
Certified Nurse Life Care Planner (CNLCP®) Certification Board
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CNLCP® Handbook & Applications for Candidates
Application by Exam: http://www.ptcny.com/PDF/CNLCP.pdf
Application by Reciprocity: http://www.ptcny.com/pdf/CNLCP-Reciprocity.pdf

A MULTIDISCIPLINARY APPROACH FOR CARE OF PREGNANT WOMAN WITH SCI:
Keeping the Patient as the Center of Care

PATRICIA J. KLASSA, MSN, RN, IBCLC
JUNE MURPHY, DO, FACOOG
This family-centered Birthing Center in a 191 bed suburban hospital has developed a “Culture of Caring” philosophy of patient care where providers keep the patient as the center of all care provided. It involves taking the time to understand the patient’s backstory (past life experiences they are bringing with them) and truly listen to their desires. Caring becomes a fundamental attitude and shows our ability to treat patients and one another kindly, compassionately and with respect. In the maternity setting, we meet with our identified high-risk patients prenatally to promote a collaborative approach to their care. The goal is to maximize the patient’s input in her care and the possibility that her birth will be as normalized as possible, minimizing intervention and maximizing safety and quality of care. As the Clinical Nurse Specialist, I (PJK) received a request for consultation from the maternal-fetal medicine (MFM) clinic for a pregnant woman with quadriplegia. And so our relationship began.

Rebecca is a 36-year-old small business owner who suffered a spinal cord injury at C6-7 when she was 23 years old. She and her husband David were thrilled to find out she was pregnant 13 years later and looked forward to the healthy birth of their baby boy.

Developing the individualized plan of care began with a careful review of Rebecca’s medical history. The purpose of our initial consultation with Rebecca and David was to get acquainted and to gather information about how they visualized their birth. Identifying the expectant mother’s priorities and concerns, gathering educational materials and answering questions would ease the patient/family’s anxiety. We continued meeting throughout the pregnancy via emails, calls, or in-person visits that coincided with regular prenatal visits.

The next step was to organize a multidisciplinary meeting to sit together to discuss the best and safest care options for her, her unborn baby, and medical plan of care and the patient/family plan of care.

In 30 years of practicing in obstetric nursing, this was the first time I was involved in caring for a pregnant mother with SCI. It was an opportunity to learn about this population, to educate the LDRP (labor, delivery, recovery, postpartum) staff and to assist with this family’s care. However, reviewing the literature, I found limited current information available on pregnancy, labor, birth, and lactation in SCI. The American College of Obstetricians and Gynecologists (ACOG) last formulated a Committee Opinion on this subject in 2002 (ACOG, 2002) and it was apparent we needed to do more research.

According to the National SCI statistics (Burns, O’Connell, Burns & O’Connell, 2013) the annual incidence of SCI in the US is approximately 12,000 new cases each year, with an average age of 42.6 years; about
80.7% of these injuries are to males. Unlike in males, female fertility is not usually affected by SCI. With modern technology many women with SCI are becoming pregnant and having successful pregnancies and births (Tebbett & Kennedy, 2012). Thus, it is imperative to educate providers in the obstetric community on how to best care for this population. According to Camune (2013), a family-centered approach along with an interprofessional team can allow the couple to have a safe and optimal birth experience.

THE PLAN OF CARE
The most important component of these plans is the patient/family plan of care that describes how a couple envisions their birth as seen through their eyes. Most women have dreamt about what labor and birth would look like since they were young girls. Regardless of details, those dreams probably didn’t include a high-risk condition such as pregnancy with quadriplegia.

Most women find that once they conceive, they have very little control over their bodies, even for common conditions like nausea and vomiting or gestational diabetes. Most diagnoses that place women at high risk certainly remain out of their control as well. Thus, the goal with our team meetings with Rebecca and David was to normalize pregnancy as much as possible and help our staff learn to provide them the birth experience they’d always imagined. As you can appreciate, along with the powerlessness that accompanies pregnancy, a pregnant woman with quadriplegia has less control of even more aspects of her body. In this population, it’s about giving back as much control as possible with birth. In fact, according to Simkin, a nationally renowned childbirth education specialist, every birth has the potential for lifelong satisfaction and many mothers felt it had to do with being in control or accomplishing a goal which enhances self-confidence and self-esteem (1991).

During the multidisciplinary meeting, the obstetrician/midwife provide recommendations related to the pregnancy, labor, and birth processes. Rebecca’s physical medicine and urology specialists shared suggestions for medications and physical care in LDRP. Anesthesia made recommendations regarding analgesia/anesthesia during labor and birth and types of specialized monitoring not usually done in the LDRP area.

OUR TEAM’S GOAL WAS TO NORMALIZE PREGNANCY AS MUCH AS POSSIBLE TO PROVIDE THEM WITH THE BIRTH EXPERIENCE THEY’D ALWAYS IMAGINED.

These included an arterial line and continuous cardiac monitoring by the ICU team. Pharmacy and dietetics discussed issues related to medications and special dietary concerns. Lactation reviewed the literature and made recommendations to ensure breastfeeding success.

The team’s goal was to combine the medical care necessary for a safe birth with the patient/family’s request for the birth they desired. Most planning occurred during the antepartum period.

From the initial consult with Rebecca, it was apparent that since the day of the accident, her dreams of becoming a mother changed drastically. Her body was no longer wholly hers and becoming pregnant, as well as every other aspect of labor, birth and motherhood, would be different than she originally imagined. She was the leader of the team. The goal was to write a plan of care through her eyes. Some of the items important were:

Antepartum Period:
- Regular visits with the multidisciplinary team throughout pregnancy including not only OB providers but all members of her care team.
- Her current physical medicine and urology providers were not from this organization. Therefore she met this system’s providers, who joined the multidisciplinary care team.
- Quadriplegia alone increases risk for deep venous thrombosis in the lower extremities. This is exacerbated with pregnancy due to a hyper-estrogen state and risk for venous stasis. Thus, prophylactic enoxaparin (Lovenox) or heparin may be indicated along with a sequential compression device (ACOG, 2002). Rebecca’s plan of care included both.
- Chronic urinary tract infections are common in SCI. Thus, prophylactic antibiotics are often a component of care in consultation with the urologist or infectious disease specialist (ACOG, 2002). This was not done in her case. However, she did have a course of antibiotics at 28 weeks to treat preterm contractions that were thought to be caused by a urinary tract infection.
- Antenatal testing with nonstress testing and biophysical profile in the third trimester may provide fetal reassurance when movement after 28 weeks cannot be reliably felt. This was done along with monthly ultrasounds to assess fetal interval growth, which allayed the couple’s anxiety.
- Women with spinal cord injuries above T10 have painless labors, increasing the risk of having unexpected birth at home. Both Rebecca and her spouse were taught how to palpate for contractions. We considered home uterine contraction monitoring, which was not done. Also, serial
cervical length measurements (every 2 weeks in the 2nd and 3rd trimesters) as well as cervical examinations every 1-2 weeks are advisable (Lee & Hickenbottom, 2015). These were also done.

- An anesthesia consult is highly recommended in the late third trimester to discuss early epidurals to prevent/treat autonomic dysreflexia (AD). AD is the most significant medical complication occurring with SCI. The release of hormones leads to vasoconstriction which is associated with nasal congestion, sweating, and severe hypertension, with the potential for respiratory, cardiac, or placental complications (ACOG, 2002). Continuous cardiac and invasive hemodynamic monitoring were suggested during labor, and an ICU nurse was present in LDRP during Rebecca’s labor for this purpose (Kuczkowski, 2006).

- Rebecca’s skin condition was impeccable, so a consult from a wound care nurse was not needed. However, the wound care nurse provided staff education on skin breakdown prevention, since this was new information to the LDRP nurses.

- Occupational therapy was offered, but Rebecca and David felt her own therapists would address this.

- Rebecca’s primary LDRP nurses met with the family during prenatally, alleviating some labor anxiety with seeing familiar faces coming in for labor/birth. A prenatal LRDP tour was also done for the same reason.

- Rebecca and David wanted to attend childbirth education classes but realized that much of the information presented there might not be relevant. Thus, the primary LDRP staff nurse provided them with individualized childbirth classes.

Intrapartum and Postpartum:
- Patient Plan: Staff were encouraged to truly listen to her, her primary caregiver (her spouse), and her primary nurse, and her aide. This in-
involved simple items such as not only knocking before entering the room but waiting for a response that it was acceptable to enter. When you are undergoing catheterizations at least every 2 hours, privacy is appreciated. Multidisciplinary/Medical: The team provided necessary privacy and used communication that created an environment where the family felt safe.

- **Patient Plan:** Since there was a great connection with her primary caregivers, Rebecca requested that her own staff provide care during her hospitalization for items not related to the pregnancy/labor/birth. She also requested to continue straight catheterizations with her own familiar supplies every two hours, not a Foley catheter; position changes every 2 hours; bowel regimen; and other familiar routine care. Multidisciplinary/Medical: The LDRP staff honored these wishes and performed only those aspects of labor and birth care such as full assessments, fetal monitoring, etc.

- **Patient Plan:** Rebecca requested a gluten and dairy-free diet and her routine dietary supplements to prevent any gastrointestinal issues while hospitalized. Multidisciplinary/Medical: A consultation with a dietitian and pharmacy arranged support for her taking medications brought from home, though this is usually discouraged at this institution.

- **Patient Plan:** Rebecca wanted to have her baby placed skin-to-skin immediately after birth. Breastfeeding with involvement from the lactation team was also extremely important to her. Multidisciplinary/Medical: Immediately placing babies skin-to-skin was the usual practice at this facility. Lactation support continued throughout the entire hospital stay with home visits following discharge.

- **Patient:** Rebecca and her husband both desired the midwifery philosophy of care and a vaginal birth vs. Cesarean section (C/S). According to ACOG, women with SCI may deliver vaginally and those with an injury above T10 may even have a painless labor (ACOG, 2002). Rebecca also preferred forceps over vacuum birth. Multidisciplinary/Medical: Midwife consult was done prenatally and a midwife provided support during her labor/birth as well. All Rebecca’s desires became the team’s goals. Because there was a slight chance a C/S would be needed, those details were discussed in the meeting and written in the plan as well.

Our team quickly learned to truly listen to Rebecca and her team who knew her best. In fact, during active labor, there was a time when Rebecca had a frightened look in her eyes accompanied by acute hypertension as her body was beginning to experience AD. The anesthesiologist came to the room and immediately wanted to administer more narcotic medication into the epidural to treat AD, but Rebecca’s primary nurse/caregiver suggested that the obstetrician evaluate labor progress as she thought it was possible that this was a sign of further labor progression. She was absolutely correct: Rebecca was completely dilated and the baby was crowning. The AD was due to the rapid descent of her newborn. Not one of her LDRP staff, including myself, identified that. Thus, only a small amount of lidocaine was administered in the epidural and birth ensued.

Delivery at 36-37 weeks is typical with early epidural during induction of labor. Rebecca’s labor was augmented, as she was already in early labor on the day of induction at 37 weeks. After a very short, uneventful labor, she gave birth to a beautiful son who descended on his own and was gently assisted to meet his parents via forceps. He came out crying but immediately stopped after hearing his parents’ voices and after being placed skin-to-skin (with not a dry eye in the room).

**SUMMARY**

In conclusion, childbirth can be a very empowering and a positive experience for women with SCI. Although there are risks for complications, many risks can be managed with early prenatal care and a team approach (Pregnancy with women with spinal cord injury, 2004). The key to Rebecca’s successful birth was early multidisciplinary planning using the LDRP’s Culture of Caring philosophy, truly listening to her desires for birth. The medical decisions made incorporated her wishes and birth was safe and satisfying. The lessons we learned from Rebecca and her team made a lasting impact on all of us that we will carry with us while caring for pregnant mothers with SCI in the future. We thank them for that.

---

**JUNE C. MURPHY, DO, FACOOG**

Dr. Murphy is a maternal fetal medicine specialist with 16 years experience. MFM specialists are obstetricians who complete a 3 year fellowship post residency concentrating on all aspects of high risk pregnancy care.
Patients with spinal cord injuries (SCI) present many challenges for the obstetrical team. The key word to overcome these challenges in prenatal care and labor and delivery is “team.”

In many areas of obstetrics we look to the OB care provider as the quarterback. In Rebecca’s case I think the foundation for her successful outcome was because our “team” listened so well to our patient “quarterback.” The medical aspects may be more straightforward, but psychosocial aspects and coordination of care are key to success. In this area our “quarterback” taught us all the level of care we needed to provide.

The key components Rebecca and David wanted were consultation and discussion, good accessibility, and communication with her providers from infectious disease, physical therapy, OB, nursing, and maternal-fetal monitoring. As providers we should encourage patients with SCI to set the bar high for accessibility, multidisciplinary discussion, and communication. Many patients may not have the experience or may feel too shy to ask for that level of care, or more than typical. Requesting privacy, waiting after knocking, and having one’s own caregivers during admission all facilitate a positive birth experience. After caring for Rebecca, I have made it a point to tell all of my patients with SCI that they should expect and request the above elements, plus 24-hour accessibility to providers that know her well.

The medical aspects of care are more straightforward. Since many SCI patients, depending on the level of the injury, cannot appreciate uterine contractions or fetal movement, serial cervical length evaluation in the second and third trimester may help stratify preterm birth risk. Antenatal testing with non-stress testing and or biophysical profile, depending on clinical circumstances in the third trimester, may provide fetal reassurance when the patient cannot reliably document movement after 28 weeks.

Physical therapy should continue if at all possible throughout the pregnancy. Increased risk for thrombosis should all be considered with SCI patients in pregnancy given the hyperestrogen state of pregnancy. Prophylactic lovenox or heparin may be indicated. Delivery at 36-37 weeks is typical. Anesthesia plays a large role in preventing autonomic dysreflexia in labor with epidural management.

Straightforward medical aspects of obstetrical care of a patient with SCI can be found in “Up to Date” or various case series. However, our patient educated our team in truly patient centered care. This will be the lasting gift we can bring to future patients with SCI.

LESSONS LEARNED: DR. MURPHY

REFERENCES


Breastfeeding Experience of a Mother with a Spinal Cord Injury at C6/7

A CASE REVIEW

Published data that defines limitations of a woman’s ability to breastfeed based upon her injury site needs to be challenged and more research done to find ways to support and enhance a mother’s experience, thereby increasing breastfeeding satisfaction, duration, and exclusivity.

BY JULIA GRAGG, BSN, RN, IBCLC

KEY WORDS: Breastfeeding with SCI, newborn nutrition

Much of the literature reinforces an understanding that a woman with an injury above T6 may have difficulty maintaining milk production after 4-6 weeks post partum. Initial information placed the cause of this fact on the lack of neurological response needed for the release of prolactin, the hormone that stimulates milk production in the breast, and resulting decreased...
prolactin levels at 4-6 weeks after delivery (Halbert, 1998).

In a mother with an intact nervous system, prolactin levels have been found to increase in the circulation during the first 4-6 weeks after delivery, peaking during nipple stimulation. After this initial period of lactation, basal and nursing-induced prolactin levels both decrease, but lactation continues. The full explanation for this change in hormonal response is not known (Becker, 2001).

Oxytocin is the hormone that causes ejection of milk from the alveoli in the breast (let-down reflex). Oxytocin release continues to occur with each feeding throughout the period of lactation. Prolactin and oxytocin release by the pituitary gland are controlled by both hormonal and sensory input.

This is only part of the story of how milk production occurs. The breast is an active glandular organ. After the initial increase in milk production, occurring usually within 100 hours after delivery, the breast itself controls the amount of milk produced. This is referred to as autocrine control. Milk production becomes dependent upon milk removal. Breast fullness signals the body to decrease milk production. Increased frequency of breast emptying will increase milk production (Riordan, 1999).

More recent literature explains that women with an injury at or above T6 may have a reduction in milk production after 6 weeks due to lack of nipple stimulation. This may be due to poor latching, and resulting poor milk removal, as a result of upper arm impairment and spasticity making positioning for feeding difficult (Spinal Outreach Team, 2014). In addition, there continues to be controversy about whether women with tetraplegia can experience the let-down response. Reyes’ case study showed that mental imaging, relaxation, and/or oxytocin nasal spray enabled women with SCI at T4 and above to nurse successfully (Reyes, 2005). Case studies indicate that women with tetraplegia can successfully maintain lactation and breastfeed for several months to a year postpartum (Cowley, 2014). Because each woman with SCI experiences an individualized neurological deficit, it is important that we approach her breastfeeding potential with enthusiasm and support that she can achieve her feeding goals. To assume that any woman’s milk supply will be inadequate is a self-fulfilling prophecy. The influence of a woman’s spouse, family, caregivers, and support systems is an important factor for any woman in optimizing her success at breastfeeding. This support team would be of utmost importance for the breastfeeding (Baby Friendly USA). She, her husband, and care providers had created an interdisciplinary birth and postpartum plan of care, including hospital processes and procedures to support her plan to breastfeed. The newborn son remained skin-to-skin with mother right after birth for two hours and roomed in with her 24 hours per day. He successfully latched numerous times during their hospitalization and received his mother’s copious supply of colostrum. Rebecca felt something happening deep within the breast during feedings. She and her husband learned how to position, latch, and evaluate milk transfer. They used no supplementation with formula

**UNTIL MATERNAL/CHILD CARE PROFESSIONALS DO EVERYTHING POSSIBLE TO SUPPORT THE BREASTFEEDING EXPERIENCE OF A WOMEN WITH A SCI, WE CANNOT CONCLUDE THAT AN INSUFFICIENT SUPPLY IS DUE TO ANYTHING OTHER THAN LACK OF ADEQUATE SUPPORT.**

**Recommendation:** It may have been beneficial for a lactation consultant and occupational therapist to be involved during the prenatal interdisciplinary planning. Prenatal lactation education could have gone beyond the traditional topics to include establishing an intimate breastfeeding support team and acquiring and using a breast pump, due to the known potential vulnerability of this mother’s milk supply. OT’s assistance with evaluating the home environment and creative positioning for feeding would have been very helpful. A mother’s ability to

**REBECCA'S BREASTFEEDING CARE IN THE HOSPITAL SETTING:**

**Support:** Rebecca delivered her baby at 37 weeks gestation in a hospital that had implemented the Baby Friendly 10 Steps to Successful Breastfeeding or pacifier. They learned how to do manual expression and use a breast pump to promote milk supply, and how to collect expressed breast milk for supplementation to their son. They fed their son this expressed milk using alternative feeding methods with a syringe and a spoon to avoid use of artificial nipples.

**Recommendation:** It may have been helpful to have a lactation consultant and occupational therapist involved during the prenatal interdisciplinary planning. Prenatal lactation education could have gone beyond the traditional topics to include establishing an intimate breastfeeding support team and acquiring and using a breast pump, due to the known potential vulnerability of this mother’s milk supply. OT’s assistance with evaluating the home environment and creative positioning for feeding would have been very helpful. A mother’s ability to
The family was discharged from the hospital two days after birth.

Support: Rebecca’s husband was trained how to assist with positioning and latching the baby. He demonstrated competency of these skills and latching the baby. He demonstrated how to assist with positioning and latching the baby. The infant was in good position, but he did not latch. The infant was in good position, but he did not latch.

Recommendation: A lactation consultant plan for home care developed prenatally and modified as needed would have been beneficial, with the first visit made within the first 24 hours after discharge and visits continued regularly until the family latched with consistent success. Ninety-two percent of mothers with concerns about breastfeeding expressed breast milk and learned to pace feed so as not to overfeed. Rebecca used a double electric, hospital grade pump with appropriate-sized flanges. She wore a sports bra with back support.

A FULL DISCUSSION AND PLAN OF HOW TO INCORPORATE BREASTFEEDING INTO THE MOTHER’S DAILY ROUTINE OF PERSONAL CARE WOULD HAVE HELPED TO GIVE THE PARENTS GUIDELINES TO ADAPT.

A team of support people trained in assisting the mother to latch would give the mother and father a pool of rested and renewed support when her own exhaustion challenged her resolve to continue breastfeeding.

REBECCA’S BREASTFEEDING CARE AT HOME:

Support: A lactation consultant (family friend) made informal visits to the family on days two and nine post discharge. She assisted with a feeding, reviewed effective latching and positioning, demonstrated alternative feeding techniques to supplement the infant, reviewed signs of adequate intake, and assessed the home set-up. The family had a custom built raised crib that allowed Rebecca to wheel right up to it (Figure 1). They experimented with her ability to bring the infant to her breast if she lifted her breast onto the crib and scooped the infant close to her. She was able to do this independently. The infant was in good position, but he did not latch.

Recommendation: A lactation consultant plan for home care developed prenatally and modified as needed would have been beneficial, with the first visit made within the first 24 hours after discharge and visits continued regularly until the family latched with consistent success. Ninety-two percent of mothers with concerns about breastfeeding expressed breast milk and learned to pace feed so as not to overfeed. Rebecca used a double electric, hospital grade pump with appropriate-sized flanges. She wore a sports bra with back support.

Support: The home environment was well set up for the mother to function from her chair in caring for the infant: use of the stroller to move the baby around the house, raised crib, counter surfaces at chair height.

Support: Rebecca had full time care for herself to assist in her activities of daily life and her husband was able to take leave from his job.

Challenge: There are however only 24 hours in a day. The mother’s own daily care and PT time commitment is comparable to a part time job. Any woman who has a baby and within 3 days goes back to work part time is going to find breastfeeding significantly challenging!

Recommendation: A full discussion/plan of how to incorporate breastfeeding into the mother’s daily routine of personal care (bladder and bowel program, personal hygiene, physical therapy) would have helped to give the parents guidelines to adapt to having a demanding baby in the home. Increasing the number of people involved in the care of the infant both day and night would have allowed the parents less stress. Peer support specifically for women with SCI needs to be developed. The Internet allows women all over the world to share creative solutions to the challenges of mothering. A chat room for mothers with SCI facilitated by a LC/OT team would be an amazing asset.

Support: Both parents were committed to breastfeeding, but were flexible and responded well to their baby’s needs and their own concerns if the baby’s intake was adequate. Rebecca’s baby was exclusively breast milk fed for 7-8 weeks. Supplementation at night began due to decreased milk supply. (He continued to receive his mother’s milk until 10 weeks, and donated human milk until 12 weeks of age.) They began bottle-feeding with expressed breast milk and learned to pace feed so as not to overfeed. Rebecca used a double electric, hospital grade pump with appropriate-sized flanges. She wore a sports bra with back support.

A team of support people trained in assisting the mother to latch would give the mother and father a pool of rested and renewed support when her own exhaustion challenged her resolve to continue breastfeeding.
slits cut at nipple site so that the flange of the pump could be passed through the bra and held hands free in place. This allowed her some independence when pumping and allowed her to apply compressions to the breasts during pumping to promote milk flow (Jane Morton).

**Challenge:** The additional time requirements of pumping added to the stress of time management. Intruding supplementation frequently leads to decreasing milk supply (Walker, 2015).

**Support:** Rebecca had a copious supply of colostrum and her mature milk came in by the fifth day postpartum. She has everted nipples and never experienced nipple breakdown.

**Challenge:** The baby did not consistently open his mouth widely. He would easily latch directly on the nipple. It was difficult for the parents to determine if the latch was effective and frequently the infant had a shallow, less effective latch as noted by the compressed shape of the nipple after feeding. A shallow latch decreases milk removal from the breast and decrease let-down. Both will eventually result in a decreasing milk supply.

**Recommendation:** More frequent and more consistent lactation consultant involvement (or visiting peer support) to evaluate latch; prenatal and postpartum occupational therapy referral to assist with upper body positioning and latching techniques; oxytocin nasal spray may have aided in letdown (Reyes, 2005).

**CONCLUSION**

Rebecca continued to give her baby her breast milk and continued to latch until the infant was 10 weeks of age. The challenges of this mother’s immobility and the need for someone to help her attach herself to her obviously hungry baby were her greatest obstacles to breastfeeding and maintaining milk supply. She experienced let-down, she fed her infant the best nutrition, and passed to him her immunity via her colostrum and mature milk in the first 10 weeks of his life. This is a story of success. But we can learn from it to provide expanded help to breastfeeding mothers with SCI to make the next story one of even greater success.

__JULIA GRAGG RN, BSN, IBCLC__

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Can Insurers Save Money By Providing Permanent Housing For Renter Claimants?

You receive a case file for a renter claimant and you are wondering what to do about long-term living arrangements? Modifications? Costs? Best options? How do we modify a rental property? What do I do and how do I do it?

Rental properties are an added problem to tackle when planning accessibility modifications for a claimant. More planning and coordination are involved. More approvals are needed and costs may be higher in the end. Modifying a rental property for wheelchair occupancy requires preapproval of all modifications by the landlord/property owner. Approvals may often be accompanied by a requirement that some or all preapproved modifications be removed and the property restored to its pre-modification condition if and when the claimant moves out – all at the owner’s discretion. So…how does one plan for and cost this? How do I know if or when the claimant might move? How do I know what modifications the landlord may want removed and what areas restored to their pre-approved condition? The US Census Bureau’s most recent American Community Housing Survey shows that the average renter remains in the same residence for a period of 2-5 years. The length of time the average single family home buyer remains in their home is over 15 years. Over half of all home buyers remain in their homes for a period of over 20 years. Each time a renter claimant moves, new rental home modification costs are paid by the insurer – pre-settlement. Additionally, some landlords may require that some modifications constructed be restored to pre-modified condition as well to attract new disabled renters new non-disabled renters. This requirement leads to added modification construction and restorative costs for the insurer client.

So…what are the other options I might consider? What else can I do? In open and unsettled claimant cases, a permanent housing solution may be the answer to successfully manage long-term home modification exposure and costs. Depending upon the client’s exposure and their cost con-
trol strategy in a given case, a cost analysis for a permanent housing solution should be considered. In some cases, the client may save a considerable amount of long-term costs. In more difficult and contentious cases, providing permanent accessible housing for the claimant may also remove this area of dispute and result in bringing both parties closer together and moving more expeditiously toward settlement. An expedient and comprehensive settlement eliminates the potential for unknown and or escalating future costs for the insurer.

Here is an actual case cost analysis example of potential future costs that can occur in such renter claimant cases and associated savings opportunities:

**EXAMPLE 1:**
- Renter Claimant life expectancy: 44 years/12.5 moves
- Average home modification cost: $52,000 x 12.5 = $650,000
- Property pre-accessible restoration cost: $325,000*
- Estimated total lifetime cost: $975,000
- Homeowner Claimant life expectancy: 44 years/No moves
- Estimated home purchase cost: $325,000-$380,000**
- Estimated total lifetime cost: $352,500
- Total homeowner lifetime cost savings - $649,500

**EXAMPLE 2:**
- Renter Claimant life expectancy: 28 years/8 moves
- Average home modification cost: $52,000 x 8 = $416,000
- Property pre-accessible restoration cost: $208,000*
- Estimated total lifetime cost: $624,000
- Homeowner Claimant life expectancy: 28 years/No moves
- Estimated home purchase cost: $325,000-$380,000**
- Estimated total lifetime cost: $352,500
- Total homeowner lifetime cost savings - $271,500

**EXAMPLE 3:**
- Renter Claimant life expectancy: 12 years/4 moves
- Average home modification cost: $52,000 x 4 = $208,000
- Property pre-accessible restoration cost: $104,000*
- Estimated total lifetime cost: $312,000
- Homeowner claimant life expectancy: 17 years/No moves
- Estimated home purchase cost: $325,000-$380,000**
- Estimated total lifetime cost: $352,500
- Total lifetime cost savings - ($40,500)

* 50% reduction allowed for some modifications to remain after claimant departure
** Cost includes all average necessary modifications for standard paraplegic occupancy
Claimant case located in Northern California

The three cases above demonstrate that there is significant potential cost savings to be obtained when comparing rental claimant lifetime costs for home modifications versus those modification costs for permanent housing. These comparative numbers also provide evidence that the longer the estimated life expectancy of the renter claimant, the greater the potential savings to the insurer client. So...the resulting questions here are: 1) Are Life Care Planners looking at long-term move issues and costs regarding renter claimant cases? And 2) If not, should you be factoring in those average costs to compensate for such potential moves in renter claimant cases?

The lives of others are in our hands every day.

**BARRY JONES**
President
ADA Home services

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INTRODUCTION
Complementary and preventative approaches to conventional health care are on the rise. Alternative medicine is the most rapidly growing field in health care today as more people realize the need to take more responsibility for their own health. However, trying to find fully wheelchair-accessible health facilities with adapted fitness equipment, or even information that caters to the unique health care needs of individuals with spinal cord injuries (SCI) - the people who in many cases need this alternative and preventative health care the most - is extremely difficult.

After SCI, not only is the body suddenly forced to cope with the direct impact of paralysis, but it must also deal with psychological stress, physical pain, biochemical changes, and hormonal imbalances. Together these factors can contribute to the development of many common, recurring, and potentially life-threatening secondary health complications, such as pressure injuries, arthritis, osteoporosis, pain, fatigue, impaired respiratory and immune function, bladder infections, altered bowel function, type 2 diabetes, cardiovascular disease, and obesity.

It is also common for individuals with SCI to experience multiple nutrient deficiencies, and then these secondary health complications place additional demands on the body for increased calories, vitamins, and minerals. Therefore, it is essential that people living with SCI educate and empower themselves in order to protect their health. One of the key ways individuals with SCI can practice preventative health care and attain optimal health is through nutrition.

Food is a powerful medicine. Unlike traditional allopathic medicine, which fights disease and treats symptoms, nutrition has the ability to address the underlying cause of what’s going on in the body, help restore balance and boost overall health through the intake of correct nutrients. Furthermore, what many health care providers, life care planners, and insurers are recognizing is that incorporating nutrition into clients’ rehabilitation and long term health care plans not
only complements other traditional therapies, but is also cost-effective. Managing secondary health conditions with a nutrient-dense diet geared to an individual's specific needs can be less expensive than consuming prescription medications on a long term basis. It also helps avoid negative side effects often associated with medications, which in turn can lead to the intake of additional prescriptions.

The risk of developing many secondary health conditions, such as pressure injury and bowel dysfunction, increases as individuals with SCI age. Making healthy eating a part of an individual's regular lifestyle significantly reduces these risks, as well as re-hospitalizations and the potential cost of medical supplies and/or home care.

Changing eating habits is not easy and people with SCI face added challenges such as:

- Knowing which foods are best for their health concern(s)
- Dealing with budgetary constraints
- Difficulty organizing and preparing healthy meals due to limited function/dexterity
- Difficulty with adequate intake due to dysphagia

To address these issues, I recommend that individuals be referred to a dietitian or nutritionist for a personalized nutritional evaluation (including weekly meal plans with food and nutritional supplement recommendations) and receive monthly counseling sessions to work on meal planning and program adjustments for at least four to six months.

The overall combined cost of nutritional services and supplements over a person's lifetime can be relatively inexpensive compared to other traditional therapies, equipment, services or medications. Nutrition evaluations and protocols typically cost $750 CAD/$570 USD. One-hour monthly counseling sessions are $100 CAD/$85 USD (fees reflect average Canadian insurance rates and do not include travel or mileage). The average cost of supplements over an individual's lifetime can range from $70,000 to $155,000 CAD / $58,200 - $129,000 USD depending on onset of injury and specific secondary health complications being addressed.

As a nutritionist who specializes in working with people with SCI and has lived with a SCI for over 25 years, I'd like to provide some simple, yet vital strategies to help your clients overcome some of the challenges noted above, as well as offer food and nutritional supplement recommendations for five common SCI-related secondary health complications.

**DIGESTIVE DYSFUNCTION**

Good health starts with a healthy digestive system. After SCI, gastrointestinal peristalsis is affected, which can inhibit digestive and absorptive function, slow movement of food through the gastrointestinal tract.

**RECOMMENDATIONS**

To help support the digestion and absorption of nutrients, enhance peristalsis and alleviate gas and bloating I recommend the following:

1. **Drink 6-8 cups of fluids every day.** Drinking adequate amounts of fluid such as water with fresh lemon juice, herbal tea, or diluted juice helps produce essential digestive secretions needed for optimal digestion and is essential in helping move matter more easily through the digestive tract. Drinking fresh ginger root or peppermint tea will also help relieve gas and bloating.

2. **Take digestive enzyme supplements.** Made from pineapple and papaya, these natural supplements (often containing HCL and bile) help ensure proper digestion and absorption of food, reduce bloating, and decrease symptoms of indigestion. It is recommended to take 1-2 enzymes at every main meal.

3. **Eat small, frequent meals.** Eating stimulates the gastrocolic reflex and peristalsis, so consuming smaller, more frequent meals helps to naturally support movement through the digestive tract.

4. **Reduce/eliminate refined carbohydrates & processed foods.** Foods that are high in simple or refined carbohydrates (high glycemic index foods), such as white bread or bagels, white rice, white pasta, fiber-less processed cereals, baked white potatoes, French fries, cakes, donuts, pastries, cookies, soda, and candy can slow the motility of the intestinal tract. Specifically, when blood sugar levels raise too
rapidly, the duodenum and jejunum slow the propulsion of digested matter.

WEIGHT GAIN
Following SCI there are abrupt changes in body composition, including a loss of lean muscle mass and increase in fat mass. Coupled with reduced physical activity, hormonal changes, altered organ function, decreased carbohydrate metabolism, and unchanged dietary habits, this results in an imbalance between energy intake and energy expenditure leading to an accumulation of fat.

Over 65% of people with SCI are overweight. This increase in weight is strongly correlated with the development of other health conditions such as cardiovascular disease and type 2 diabetes. When most people think about losing weight and unwanted fat, they think less is more: fewer calories, fewer meals, and smaller portion sizes. While healthy weight loss is indeed about eating the right kinds of foods and in the right amounts, it’s also greatly affected by the balance and signaling of the hormones insulin and glucagon.

Eating a diet too high in processed carbohydrates and simple sugars (refined sugar/ flour, white bread/ pasta/ rice, soda, cakes, cookies, etc.) significantly affects insulin levels. These foods are very quickly digested and absorbed into the blood, causing a rapid increase in blood glucose. In response, the pancreas secretes insulin to transport glucose into the cells to be utilized as fuel.

However, when diets primarily consist of simple sugars, the pancreas has to continually pump out insulin. High insulin levels can not only lead to cells becoming insulin resistant, but it also sends messages to the body to store more fat. Furthermore, individuals with SCI have difficulties with carbohydrate metabolism, glucose intolerance and insulin resistance so it’s extremely important that they eliminate processed, high-glycemic foods from their diet.

Many people try to lose fat by skipping meals and/or drastically reducing calories. However, skipping meals or consuming too few calories causes the body to release glucagon, which causes muscle loss. Glucagon sends a message to the body to start breaking down muscle (protein) so it can be converted into energy. So the weight that will be lost by depriving oneself of food is good muscle, not fat, and individuals with SCI need to maintain all muscle they have. Here are 4 tips to help your clients lose weight and reduce fat while maintaining muscle without having to starve themselves:

1. **Stabilize blood sugar and insulin levels.** Consuming 4-5 small meals a day, consisting of low glycemic foods (e.g., proteins and complex carbohydrates - fruits, vegetables, whole grains, and legumes) will not cause blood glucose and insulin spikes. The added benefits of eating this way are more sustained energy throughout the day and improved bowel function.

2. **Reduce grains.** Only eat 1 serving (1 slice or 1 cup) of whole grain bread, whole grain pasta, or brown rice a day.

3. **Eat protein for breakfast.** Protein helps stabilize blood glucose. Studies show that people who eat protein for breakfast (e.g., yogurt, eggs, protein smoothies) lose more weight than individuals who eat carbohydrates (e.g., cereal, bread, bagels).

4. **Eat good fats.** Healthy fats help reduce inflammation, decrease cravings and suppress appetite. Consume salmon, sardines, halibut, olive oil, avocados, and walnuts on a regular weekly basis. I also recommend taking daily omega 3 essential fatty acid supplements. (Caution: essential fatty acids are natural anticoagulants. Always check with physician first before taking.)

*See Weight Wise Chicken Salsa Recipe at end of article

PRESSURE INJURY
After SCI the skin is much more susceptible to damage and breakdown due to loss of sensation, decreased muscle mass, altered blood circulation and collagen production, impaired immune function, spasms, and chronic pressure exerted over areas such as the buttocks, elbows, and heels. It’s estimated that 10-30% of people with SCI will develop a pressure injury within the first year post-SCI, and that 85-95% will develop one at some point. Research indicates that the risk of developing them increases with time since injury. These severe skin breakdowns can significantly hinder quality of life and in some cases be life-threatening. This high prevalence of pressure injury accounts for a large number of rehospitalizations.

The best way to treat pressure injury is to do everything to prevent them from developing in the first place by using proper seating devices and practicing pressure relief techniques. If clients experience them, I recommend the following:

1. **Increase protein.** Protein is essential for the growth and repair of new tissue. In the presence of a pressure injury, it is advised to consume 1.2-1.5 grams of protein per kg of body weight a day (Kirk 1996).

2. **Eat foods rich in vitamins A, C, E & Zinc.** These nutrients have immune-boosting and collagen-produc-
BOWEL DYSFUNCTION

It’s no revelation to anyone who has experienced a SCI that this type of neurological damage can significantly affect elimination function. In fact, constipation is the number one gastrointestinal complaint after SCI. Chronic constipation due to compromised peristalsis can contribute to prolonged, inefficient bowel routines, stomach pain, stress, fatigue, and autonomic dysreflexia. To help keep things moving follow these steps:

1. **Boost immune system.** Nutrient deficiency is the most common cause of low immune function. Studies show that bladder infections occur more frequently when the body’s immune system is low, so optimal immune function is vital in preventing and fighting bladder infections. Vitamins A, C and zinc are primary nutrients needed to enhance the body’s natural defense mechanism.

   * See nutrient chart for food sources and supplement dosages.

2. **Take Probiotics.** Probiotics are good bacteria that are very important in maintaining and boosting the immune system. Many people with SCI take antibiotics to fight infections. However, these disturb the normal internal flora and may actually increase recurrent infection by promoting antibiotic-resistant bacteria. Eating probiotic-rich foods such as yogurt, sauerkraut, miso, and kefir and taking a probiotic supplement every day can help protect a person with SCI from developing bladder infections.

3. **Drink Cranberry or Blueberry Juice.** These berries do not kill bacteria or inhibit bacterial growth. Instead they contain large amounts of compounds called tannins, which prevent E. coli from attaching to the wall of the urinary tract. Only drink pure or unsweetened cranberry or blueberry juice.

   * See Cranberry Cocktail Recipe at end of article.

4. **Take D-mannose.** D-mannose is a naturally occurring sugar, similar in structure to glucose. It can be very effective at preventing and addressing bladder infections. D-mannose can be purchased in supplement form in health food stores. Take as directed on the label.

5. **Avoid Caffeine, Alcohol & Sugar.** Caffeine (found in coffee, tea and chocolate) and alcohol can aggravate the urinary tract. Sugar feeds bacteria, thus making the infection stronger.

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**Bladder Infections**

It is estimated that 80% of people with SCI will develop bladder infections at some point. People with SCI are highly susceptible to bladder infections (often chronic) because of compromised immune function, the necessary practice of catheterization, and repeated use of antibiotics. Chronic urinary tract infections can contribute to other health concerns such as fatigue, autonomic dysreflexia, kidney infections, bladder/kidney stones, and sepsis. Therefore, a proactive approach to bladder health is imperative. Here are some ways nutrition can help:

1. **Drink 8 cups of water/fluid a day.** Water helps carry repair substances to the site of injury and helps fight infection as it is needed to eliminate waste.

2. **Eliminate junk food.** Refined and processed foods contribute to tissue inflammation, which inhibits the body’s ability to heal tissue.

   * See Skin Strengthening Smoothie Recipe at end of article.

3. **Eat healthy fats.** Good fats such as omega-3 are required for proper cell reproduction and have been shown to play a central role in skin health. The previous caution on omega-3 applies.

   * See chart for food sources and supplement dosages.

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**Table:**

<table>
<thead>
<tr>
<th>Nutrient</th>
<th>Skin / Immune Benefits</th>
<th>Source</th>
<th>Supplement Dose</th>
</tr>
</thead>
<tbody>
<tr>
<td>Vitamin A</td>
<td>immune boosting, skin reparative properties</td>
<td>orange/yellow vegetables, kale, spinach</td>
<td>5000 IU/day</td>
</tr>
<tr>
<td>Vitamin C</td>
<td>multiple immune, collagen and elastin-building functions</td>
<td>berries, red/green peppers, broccoli, kale</td>
<td>2-3000 mg/day</td>
</tr>
<tr>
<td>Vitamin E</td>
<td>powerful antioxidant that helps reduce tissue damaging free radicals</td>
<td>almonds, sunflower seeds, olives/olive oil, spinach</td>
<td>400 IU/day</td>
</tr>
<tr>
<td>Omega-3</td>
<td>helps reduce inflammation, assists in transporting nutrients, needed for the growth and support of cells and tissues</td>
<td>salmon, sardines, halibut</td>
<td>2-4, 1000 mg/day</td>
</tr>
<tr>
<td>Zinc</td>
<td>supports collagen production, increases production of white blood cells and enhances their function</td>
<td>pumpkin seeds, sesame seeds, beef, legumes, ginger root</td>
<td>50 mg/day (for 8-12 weeks)</td>
</tr>
</tbody>
</table>

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*Figure 1. Nutrient chart. Courtesy J. Smith, 2015.*

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**Notes:**

- Vitamin A: Immune boosting, skin reparative properties. *See nutrient chart for food sources and supplement dosages.*

- Vitamin C: Multiple immune, collagen and elastin-building functions. *See chart for food sources and supplement dosages.*

- Vitamin E: Powerful antioxidant that helps reduce tissue damaging free radicals. *See chart for food sources and supplement dosages.*

- Omega-3: Helps reduce inflammation, assists in transporting nutrients, needed for the growth and support of cells and tissues. *See chart for food sources and supplement dosages.*

- Zinc: Supports collagen production, increases production of white blood cells and enhances their function. *See chart for food sources and supplement dosages.*
1. Increase Fiber (19-30 grams of fiber/day). Fiber is critical for proper large intestinal function and can help prevent or reverse constipation. This is achieved by fiber’s ability to absorb water, provide bulk to the stool, and makes the stool more slippery, soft, and pliable. Increasing fiber in the diets of individuals with SCI helps improve bowel transit time, the amount of stool being passed during bowel care routines, and creates better stool consistency to help prevent bowel accidents. Fiber-rich foods include legumes, quinoa, fruits, and vegetables. If clients are not eating enough fiber-rich foods, consider taking a fiber supplement such as one tablespoon of whole husk psyllium in a large glass of warm water every day.

*See Better Bowel Quinoa Recipe at end of article

2. Drink 6-8 cups of water/fluids/day. The large intestine is responsible for reabsorbing excess water out of the feces. When dehydrated, the body will remove more water from the colon in order to serve other body functions, resulting in more solid stools which are harder to pass.

3. Eat Good Fats. Healthy fats can help lubricate the bowel and soften hardened stools, acting as natural stool softeners. Be sure olive and coconut oils are included in the regular diet (e.g., use olive oil in salad dressing, add coconut oil to favorite dishes). I also recommend taking two to four 1000 mg capsules of omega-3 fish oil every day. The previous caution on omega-3 applies.

4. Take Probiotics - a healthy balance of good bacteria in the large intestine can enhance peristalsis and help prevent constipation. As noted in the Bladder section above, eat probiotic rich foods such as yogurt, sauerkraut, miso and kefir, and consider taking a probiotic supplement every day. Getting all the recommended amounts of nutrients and fiber mentioned above into a regular diet is a challenge for anyone, but even more so for individuals with decreased function who have difficulty preparing and/or consuming food. One of the easiest solutions to obtaining health-boosting nutrients and fiber is to drink them in the form of a juice or smoothie. These are a delicious way to pack nutrients into the diet and can be enjoyed as a breakfast or snack. There are many good-quality, inexpensive, easy-to-clean blenders on the market that can enable clients to mix their favorite fruits and vegetables together and retain all the fabulous fiber needed to support bowel function. I also suggest adding:
- Fish or flax seed oil to decrease joint pain
- Muscle-building whey protein powder
- Ginseng or wheat germ to boost energy and decrease stress levels.

**STAYING ON BUDGET**

One of the main concerns I hear from my clients with SCI is, “How can I eat well without spending more?” There are numerous ways to get healthy foods into a regular diet and stay within budget. Here’s how:

- **Build main meals from legumes/whole grains.** It’s healthier and cheaper to build main meals from grains and legumes instead of meat. For example, legumes such as chickpeas, navy, and kidney beans contain complex carbohydrates for energy, fiber for proper bowel function, protein for tissue repair and growth, and many other essential vitamins and minerals. Unlike animal proteins, these plant-based foods contain no saturated fats, so they help reduce the risk of cardiovascular disease and decrease toxic burden on the liver and kidneys.

- **Buy in bulk.** Whole grains and legumes can be bought in bulk inexpensively and there are endless ways to enjoy them. See sidebar for websites with recipes.

- **Organic is not necessary.** Not all fruits and vegetables are created and/or grown equally; some contain fewer pesticides than others. Besides spinach, bell peppers, potatoes, celery, peaches, strawberries, raspberries, apples, grapes, and pears most other vegetables and fruits are low in pesticides and don’t need to be purchased in the organic section. Just remember to always wash fresh produce well!

- **Skip the middle aisles of your grocery store.** This where the pro-
cessed foods are kept. Instead, shop on the outside edges where all the whole foods are located.

Avoid prepared products. Prepared foods, frozen meals and/or vegetables in sauces may save time but cost more. Even if they claim to be healthy and low in fat, they are usually chock full of salt, sugar, and preservatives that can contribute to high blood pressure, weight gain, and allergic reactions. Avoid buying prepared, cut raw vegetables because they cost more. Instead buy them whole and cut them yourself.

Buy local. Fruits and vegetables that are grown locally and in season are fresher, taste better, and are less expensive. Check the Internet for local farmers markets.

A FINAL WORD

Once individuals with SCI know what to eat, it’s important for them not to put pressure on themselves to try to change their entire diet all at once. This approach may result in feeling overwhelmed, frustrated, and could lead to self-defeat. The foods we eat and how we prepare them are habits that have developed over years, so it’s not realistic to expect that anyone will be able to transform them overnight. Furthermore, our bodies need time to adjust to new foods, higher nutrient levels and increased fiber intake. So I suggest starting with 1 meal at a time. For instance, work on changing breakfast foods over the course of a few weeks. Once this meal has been successfully modified, move on and tackle lunch or snack foods, and then move on to dinners.

Help your clients take a preventative approach to their health by making wise nutritional choices. Doing so will not only help them gain control of certain bodily functions, but control of their wellbeing, independence and life.

Weight Wise Chicken Salsa

<table>
<thead>
<tr>
<th>Ingredient</th>
<th>Quantity</th>
</tr>
</thead>
<tbody>
<tr>
<td>Baby spinach</td>
<td>4 cups</td>
</tr>
<tr>
<td>Chicken breasts</td>
<td>2</td>
</tr>
<tr>
<td>Sea salt</td>
<td>1 tsp</td>
</tr>
<tr>
<td>Butter, melted</td>
<td>3 tbs</td>
</tr>
<tr>
<td>Garlic, minced</td>
<td>1 tbs</td>
</tr>
<tr>
<td>Tomato, peeled</td>
<td>1 cup</td>
</tr>
<tr>
<td>Red pepper, diced</td>
<td>½</td>
</tr>
<tr>
<td>Green pepper, diced</td>
<td>½</td>
</tr>
<tr>
<td>White wine vinegar</td>
<td>3 tbs</td>
</tr>
<tr>
<td>Olive oil</td>
<td>4 tbs</td>
</tr>
<tr>
<td>Sesame seeds</td>
<td>4 Tbsp</td>
</tr>
<tr>
<td>Black pepper</td>
<td></td>
</tr>
</tbody>
</table>

1. Season chicken with salt
2. In small bowl, combine butter, garlic
3. Grill chicken 7 minutes per side and brush with garlic butter blend
4. While chicken is cooking, combine tomato, peppers, white wine vinegar, olive oil, salt and pepper in bowl and stir well
5. When chicken is cooked coat with sesame seeds and place on bed of spinach
6. Serve salsa over grilled chicken

Better Bowl Quinoa

<table>
<thead>
<tr>
<th>Ingredient</th>
<th>Quantity</th>
</tr>
</thead>
<tbody>
<tr>
<td>Quinoa</td>
<td>1 cup</td>
</tr>
<tr>
<td>Baby spinach leaves, washed,</td>
<td></td>
</tr>
<tr>
<td>Stemmed and cored, cut into</td>
<td></td>
</tr>
<tr>
<td>Pieces</td>
<td></td>
</tr>
<tr>
<td>Chickpeas, rinsed, drained</td>
<td></td>
</tr>
<tr>
<td>Fresh chopped parsley</td>
<td></td>
</tr>
<tr>
<td>Handful pecans</td>
<td></td>
</tr>
<tr>
<td>Sea salt and fresh ground pepper, to taste</td>
<td></td>
</tr>
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Maple Vinaigrette Dressing:

<table>
<thead>
<tr>
<th>Ingredient</th>
<th>Quantity</th>
</tr>
</thead>
<tbody>
<tr>
<td>Extra virgin olive oil</td>
<td>4 Tbsp</td>
</tr>
<tr>
<td>Balsamic vinegar</td>
<td>3 Tbsp</td>
</tr>
<tr>
<td>Pure maple syrup</td>
<td>2 Tbsp</td>
</tr>
</tbody>
</table>

1. Place the quinoa in a saucepan or a rice cooker. Add 2 cups fresh water, and a pinch of sea salt. Cover and cook on a low simmer until all the water is evaporated and the quinoa is tender, roughly 20 minutes. Fluff with a fork and put into a large bowl.
2. Add the baby spinach, pear, chickpeas, and chopped parsley to the quinoa and fluff.
3. Whisk together the vinaigrette; pour it over the quinoa salad and toss gently to coat. Season to taste with sea salt and ground pepper.
4. Just before serving, add the pecans and lightly combine.
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TO INDIVIDUALIZE TREATMENT PROGRAMS

INTRODUCTION
The human body is a complex machine, made up of several different systems that need to work together to keep us moving. As physical therapists, we find out what systems need improvement, especially when something does not go as planned. While this may seem like an overwhelming undertaking, there are many objective tools at our disposal. One of these modalities is electromyography (EMG). EMG can be performed on the surface (sEMG) or with fine wire instrumentation; at our facility, we use a wireless sEMG system. To appreciate how the sEMG can be used objectively during a treatment session, it is important to first understand how the body and sEMG work.

While the body is made up of several organ systems, the two that are the most important (in relation to sEMG) are the nervous and musculoskeletal systems (Criswell, 2011). For voluntary muscle activation to occur, the central nervous system (CNS) needs to send impulses to the peripheral nervous system (PNS), which in turn communicates with the muscles on a cellular level, the motor unit. The motor unit
contains the muscle fiber, and muscle fibers are excited by neurotransmitters to initiate movement. Once they have been excited over a certain threshold, it causes an electrical burst known as an action potential (Konrad, 2006). The sEMG signals are based on the recruitment of motor units in a muscle and their respective action potentials. The recording of this electrical signal emitted by a muscle during contraction is known as electromyography (EMG) (Gilmore, Meyers, 1983, pp.3-9).

Research-based advances in SCI/TBI call for an immediate paradigm shift in the clinical recovery process. Our goal is to provide a comprehensive and holistic approach to clients with spinal cord injuries (SCI) and traumatic brain injuries (TBI). We combine the expertise of physicians and physical therapists with experienced and knowledgeable physical therapist assistants, athletic trainers, and exercise physiologists. Together, we design an intense, activity-based, and goal-oriented recovery program focused on established principles of neurological rehabilitation and training. Our protocol is customized to address the individual needs of our clients while meeting their goals for recovery.

Most our clients present with a decrease in overall sensation and joint awareness during functional activities. The sEMG system allows us to validate specific exercises and activities for producing muscle activation and evaluating motor control. The sEMG system also lets us give the client auditory and/or visual biofeedback in real time. This article is intended to explain sEMG to life care planners who may recommend to have clients evaluated for its use.

GAIT TRAINING
Gait training is a specific, more dynamic, activity measured on a consistent basis. Our clients all have the opportunity to participate in weight and load-bearing activities to achieve the goal of household or community ambulation. Our unique training program calls for each client to work with two members of the training team for most of each 3-hour-long session. This allows the client to perform more challenging activities in a safe and controlled manner.

With the addition of the sEMG, we are able to determine which gait training styles are more effective for each of our clients. The ability to switch between various ambulation styles within a session is helpful for a few reasons:

1. The spinal cord is highly plastic and has the potential to relearn and improve functional tasks with task-specific training practice. (Edgerton, et al., 1992) (Petruska, Hübscher, Rabchesvsky, 2013)

2. Task-oriented training improves joint awareness and postural control. (Zemková, 2010)

3. There are significant differences in sEMG amplitude/muscle activation with specific gait training. (Gorassini, Norton, Nevet-Duchcherer, Roy, Yang, 2009)

Although the last study speaks to treadmill training, we have seen similar changes in activation with our load-bearing styles of ambulation. For example, a client gait training with the use of bilateral forearm/Lofstrand crutches may want to work towards walking over even surfaces with decreasing upper extremity support to return to or get as close to his prior level of function.

INSTRUMENTATION
We use the sEMG on 6 bilateral muscle groups to analyze agonist/antagonist muscle activity. We place electrodes over specific muscles at the beginning of each training session.

After the electrodes have been placed on the selected muscles and the task has been performed, a raw sEMG signal is produced and appears as an unprocessed, peak-to-peak display of the muscle activity (Figure 1). From this data, the clinician processes the raw sEMG signal to make it easier to understand and interpret. The first step is to rectify the signal by taking the absolute value of each data point to make all points positive (Figure 2). This allows for easier reading and also to perform standard measurements such as mean and peak values.

![Figure 1. Raw sEMG signal from neurologically intact female on right bicep. X-axis: time (seconds) Y-axis: activation (microvolts)](image1)

![Figure 2. Rectified sEMG signal from neurologically intact female on right bicep. X-axis: time (seconds) Y-axis: activation (microvolts)](image2)
Once the signal has been rectified, the clinician can look at activation, amplitude of activation, and muscle firing patterns (Konrad, 2006). These types of simple analyses provide objective measures needed to choose the best treatment methods.

**sEMG IN ACTION**

With the client, Mr. K, pictured in the following figures, we placed electrodes on muscles in both the lower and upper extremities. We initially observed and measured activity in the muscle groups when Mr. K walked over 100’ with bilateral Lofstrand crutches and supervision as needed from two trainers (Fig. 3). He then walked the same distance, this time without crutches and with one trainer providing posterior trunk support and another trainer assisting with hip alignment and extension throughout the gait cycle (Fig. 4).

As one would expect, his sEMG signals look different. The most obvious difference is the amount of activation in his arms: when he has upper extremity support with crutches he presents with increased muscle activation through the triceps. With his arms positioned without support he shows significantly less upper extremity muscle activity.

The signal shown in Fig. 5 displays the reciprocal nature of a neurologically intact male’s right gastrocnemius during gait training. There are distinct bursts showing when the muscle is active and not active. While it is not perfectly symmetrical, it does demonstrate coordination during walking.

Recorded sEMG taken of our client ambulating with no upper extremity support (Fig. 6) versus with Lofstrand crutches (Fig. 7) showed both an increase in activity with the right gastroc-
Figure 7. Rectified EMG signal from right gastrocnemius with bilateral Lofstrand crutch ambulation. Note the amplitude of activation and the muscle on/off coordination.

We originally thought that Mr. K would show less neuromuscular activity in his legs when provided with upper extremity support, as he might try to off-weight himself throughout the gait cycle. However, using sEMG, we found that he actually has increased lower extremity muscle activity and shows improved coordination when using his upper extremities. This could possibly be due to the client feeling more balanced and in control of his posture, encouraging a more typical sEMG pattern.

Another common pattern may show reciprocal muscle activation, meaning that one group turns on while the other group is off. It may also show a more efficient recruitment pattern that could indicate more coordination with a functional task, and appropriate timing of muscle firing or activation.

Although this is just one example of muscle activity from Mr. K’s gait training session, it is an important one. The gastrocnemius plays a major role in balance and efficiency with both swing and stance phases of gait. It is important to know that Mr. K does not yet have the appropriate muscle activation effective walking without upper extremity support. As he becomes stronger and more coordinated with Lofstrand crutch walking and has improved postural control, he may benefit from a more challenging gait training session to reach his recovery goals.

sEMG FOR TRAINING FEEDBACK
Another way our clinic utilizes the sEMG system is with auditory and visual biofeedback. While one may expect that we would always want to encourage more activation in a muscle group, sometimes we need to decrease or inhibit activation.

For example, Ms. M wants to strengthen her triceps (Figure 8) to help with balance and activities of daily living (ADLs). However, she might not be able to fully activate them due to the opposing muscle group (biceps in this case) constantly firing. A muscle may constantly be firing due to tightness, tone, lack of sensorimotor awareness, or weakness. By using the sEMG we can help her to “look” into her muscles and see what is going on. The system provides auditory feedback as well to further assist with exciting or inhibiting muscle activity.

Figures 9 and 10 show the changes over a month with the use of visual biofeedback combined with auditory and verbal cuing to inhibit the right bicep to allow for right tricep activity. Ms. M was placed in the same comfortable position to limit any other variables. While the biceps still remained active in Fig. 10 she was better able to relax them to allow for

Figure 8. Muscles of the arm
SUMMARY
The sEMG system gives both our clinicians and clients a chance to glimpse into the body and start to answer our main question: “What are the muscles doing?” The sEMG system both assists and validates individualized treatment protocols. It is also helpful in making clinical decisions for treatment progression, and helps us recognize when we have progressed an activity too quickly. Most importantly, it helps the clients identify and train their muscles in the absence of full sensation and normal movement patterns.

Using sEMG is just one example of how combining a known tool with a new approach can propel the recovery process further by providing new information, increased awareness of sensation and functional improvements. As we continue to challenge ourselves and our clients to meet and exceed their recovery goals, identifying and experimenting with both known and new tools will play a critical role in the advancement of neuro recovery science.

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THE FUTURE PROMISE OF LOWER LIMB ROBOTIC EXOSKELETONS

BY CLARE HARTIGAN, PT, MPT & RYAN FARRIS, PHD

INTRODUCTION
A robotic exoskeleton (RE) is a powered lower limb orthosis that allows persons with muscle weakness due to neurological injury or disease to stand up and walk. These high tech devices are worn on the outside of the body and are currently being used for four main reasons: therapeutic intervention, exercise, research, and personal mobility. This new era of RE technology has given patients and their families great hope. REs can be used along the continuum of care, with appropriate medical clearance for weight bearing and walking activities, beginning in inpatient rehabilitation with continued use after discharge. Hundreds, if not thousands of people across the United States and Europe use REs. Amidst all the hype, though, limited research is available on how these devices may affect people in the long term. Will these high-cost devices stand the test of time as patients and researchers gain more experience with them? Will those who have invested in them really use them every day, or will they be placed in a corner after the novelty wears off? Answers to all of these questions remain to be seen. The keys to the success of REs will be safety, effectiveness, reliability, ease of use, and affordability.

CRITERIA FOR USE
The four most notable REs in use in the United States are Ekso™, Indego®, ReWalk™, and Rex™ (See figure 1). Each has its own unique features and different applications (See table 1). However, they all have very similar requirements for use:

- User height from 5’1” to 6’3”
- Body weight under 250 lbs.
- Healthy bones (osteopenia is often acceptable, certain levels of osteoporosis are not)
- Range of motion at hips/knees and ankles within functional limits
- Spasticity moderate or less
- Stable cardiovascular system
- Can tolerate supported upright standing (standing frame, tilt table or other) without a drop in blood pressure
- Healthy intact skin where it would interface with the device
- Cleared by a physician for gait training

Time since injury can vary from only a few weeks to over 20 years, as long as the person meets the general inclusion criteria above. ReWalk™ is currently the only Class II RE device approved by the FDA for personal use, but Ekso™, Indego®, and Rex™ are expected to follow.

HISTORICAL OPTIONS
Options for return to walking after severe injury have always been limited. An estimated 276,000 persons are living with spinal cord injury (SCI) in the United States. The average age at injury is 42 years; 79% are males. The most common type of SCI is incomplete tetraplegia (45%) followed by incomplete paraplegia (21%), complete paraplegia (20%) and complete tetraplegia (14%). (National SCI Statistics Center 2014) Persons with SCI who are paraplegic or incomplete tetraplegic have long been able to walk using conventional long leg braces, reciprocal gait orthoses, ankle foot orthoses (AFOs), and other combinations of conventional leg/knee/ankle bracing. Persons with complete or incomplete paraplegia or incomplete tetraplegia who respond to functional electrical stimulation (FES) have also been able to walk with neuroprosthetics such as Bioness®, WalkAide® and Parastep®. After a severe injury requiring a wheelchair for mobility, almost every patient's main goal is "to walk again, no matter what it takes.” What people with complete paraplegia quickly learn is that walking with conventional long leg bracing and/or an available neuroprosthetic is often very cumbersome, slow, tiring, and painful on their shoulders, wrists and hands. Depending on the level of injury, the effort required often limits them to household or very limited community distances. Despite the limitations imposed by conventional bracing and neuroprosthetics, many people with incomplete injuries or lower levels of complete paraplegia remain quite functional walking inside, outside, on uneven surfaces, and on stairs. There is no evidence in the literature that conventional bracing or neuroprosthetics have allowed persons with C5-6 motor complete tetraplegia to stand and walk. However, persons with motor complete C5-6 injury have been successful with standing and walking with assistance of 2 persons for exercise distances using Ekso™, Indego® and Rex™.

HEALTH BENEFITS OF SUPPORTED STANDING
In addition to mobility losses, other several major body systems can be affected by neurological paralysis, including:

- Skin
- Cardiovascular
- Bowel and bladder
- Muscle mass
- Fat mass
- Bone-mineral density
- Respiratory capacity

The collective effect of primary and secondary impairments following SCI has...
potential to lead to a decrease in quality of life, depression, and a substantial increase in the cost of health care. (Phillips et al., 1987; Noreau et al., 2000; Ragnarsson K, 2007) No long-term (greater than one year) comprehensive study on the health effects of RE walking has been published to date.

Several studies do however indicate a number of health benefits associated with supported standing for non-ambulatory individuals with SCI, including improvements in well-being, blood circulation, bowel and bladder function, skin integrity, sleep, and reduced spasticity and pain (Eng et al., 2001; Glickman et al., 2010; Nordstrom et al., 2013). If these benefits can be derived from a static standing frame, more dramatic health benefits may result from walking with RE. An exoskeleton provides upright weight-bearing posture like a standing frame, but also provides lower limb movement, coordinated upper body movement, and cyclic weight bearing shifts from one leg to the other. Because the exoskeleton also provides mobility, it has the potential for a greater frequency and duration of use compared to a standing frame. More frequent or intensive use of REs could further enhance some of the benefits of upright weight bearing.

### Table 1. Summary of the 4 robotic exoskeletons in the US

<table>
<thead>
<tr>
<th>Device Name</th>
<th>Eksobionics.com</th>
<th>Indego.com</th>
<th>ReWalk.com</th>
<th>Rexbionics.com</th>
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<td>Website</td>
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<td>ReWalk.com</td>
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<td>Videos</td>
<td>Refer to website</td>
<td>Refer to website</td>
<td>Refer to website</td>
<td>Refer to website</td>
</tr>
<tr>
<td>Cost; Ranges from $70,000 to $150,000</td>
<td>Pending; Has approval as Class I Rehab device to date</td>
<td>Pending; Goal for late 2015</td>
<td>Yes; Rehab use T4 and below; Home use with support person T7 and below</td>
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<td>FDA approval as Class II Medical Device for use in rehab and home</td>
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<td>~26 lbs.</td>
<td>~50 lbs.</td>
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<tr>
<td>Requires support person with the user for safety?</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
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<tr>
<td>Ability for user to self to transport?</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>Ability to wear in a standard wheelchair?</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>Use for persons with paraplegia (motor complete or incomplete)</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Use for persons with complete tetraplegia C5 – C6</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>Use for persons with stroke as seen in the literature?</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>Requires stability aid?</td>
<td>Yes: Options Platform Rolling walkers, Rolling Walkers, Forearm Crutches, Canes</td>
<td>Yes: Options Platform Rolling walkers, Rolling Walkers, Forearm Crutches, Canes</td>
<td>Yes: Option Forearm Crutches only</td>
<td>No: Controlled via joy stick and is self-balancing</td>
</tr>
<tr>
<td>Can use and perform ADLs?</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Can walk over level inside and outside surfaces?</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>General speed; 0.4 m/s is an appropriate walking speed for persons with SCI seen in the literature for outside of the home.</td>
<td>Regularly achieves 0.4 m/s</td>
<td>Regularly achieves 0.4 m/s</td>
<td>Regularly achieves 0.4 m/s</td>
<td>Does not typically achieve 0.4 m/s</td>
</tr>
</tbody>
</table>
Few studies have been published on the potential health benefits of using exoskeletons for non-ambulatory individuals for less than one year. A pilot study of the ReWalk™ exoskeleton was conducted with 12 individuals with motor-complete thoracic-level SCI. Although the primary objective was establishing safety and efficacy, the study indicated improvements in pain, bowel and bladder function, spasticity, and emotional well-being (Esquenazi et al., 2012). Another study of six subjects with motor-complete paraplegia using the ReWalk™ exoskeleton found that all sustained a significant loss of fat tissue mass after 20-60 hours of use (Spungen et al., 2013). A reduction in fat tissue may decrease predisposition to diabetes or cardiovascular disease. (Gutierrez et al., 2009). Finally, anecdotal evidence suggests that regular use of RE may enhance sensory or motor function in individuals with incomplete SCI, stroke, brain injury, or other conditions with only partial paralysis.

During the spring of 2014, our research team at Shepherd Center investigated the use of Indego® for persons with C5-L1 SCI. The objective of this study was to evaluate mobility outcomes for individuals with SCI after five gait-training sessions with a powered exoskeleton, with the

Table 2. Subject demographics of Indego 5-session study

<table>
<thead>
<tr>
<th>Subject #</th>
<th>Sex</th>
<th>Age</th>
<th>Height (cm)</th>
<th>Weight (kg)</th>
<th>Neurological Level of Injury</th>
</tr>
</thead>
<tbody>
<tr>
<td>G2 04</td>
<td>Male</td>
<td>24</td>
<td>163</td>
<td>61</td>
<td>C5B</td>
</tr>
<tr>
<td>G2 06</td>
<td>Male</td>
<td>19</td>
<td>191</td>
<td>91</td>
<td>C6B</td>
</tr>
<tr>
<td>G2 14</td>
<td>Male</td>
<td>19</td>
<td>193</td>
<td>102</td>
<td>C6A</td>
</tr>
<tr>
<td>G2 02</td>
<td>Male</td>
<td>41</td>
<td>175</td>
<td>79</td>
<td>T5A</td>
</tr>
<tr>
<td>G2 09</td>
<td>Male</td>
<td>28</td>
<td>180</td>
<td>66</td>
<td>T7A</td>
</tr>
<tr>
<td>G2 16</td>
<td>Male</td>
<td>40</td>
<td>173</td>
<td>82</td>
<td>T5A</td>
</tr>
<tr>
<td>G2 17</td>
<td>Male</td>
<td>51</td>
<td>185</td>
<td>84</td>
<td>T6A</td>
</tr>
<tr>
<td>G2 18</td>
<td>Female</td>
<td>28</td>
<td>173</td>
<td>65</td>
<td>T7C</td>
</tr>
<tr>
<td>G2 01</td>
<td>Male</td>
<td>43</td>
<td>180</td>
<td>86</td>
<td>T12A</td>
</tr>
<tr>
<td>G2 03</td>
<td>Male</td>
<td>43</td>
<td>188</td>
<td>80</td>
<td>T10A</td>
</tr>
<tr>
<td>G2 05</td>
<td>Female</td>
<td>18</td>
<td>157</td>
<td>54</td>
<td>T10A</td>
</tr>
<tr>
<td>G2 07</td>
<td>Male</td>
<td>22</td>
<td>173</td>
<td>61</td>
<td>T11B</td>
</tr>
<tr>
<td>G2 10</td>
<td>Female</td>
<td>39</td>
<td>173</td>
<td>59</td>
<td>T9A</td>
</tr>
<tr>
<td>G2 11</td>
<td>Male</td>
<td>44</td>
<td>183</td>
<td>88</td>
<td>T12A</td>
</tr>
<tr>
<td>G2 13</td>
<td>Male</td>
<td>50</td>
<td>170</td>
<td>64</td>
<td>L1 C</td>
</tr>
<tr>
<td>G2 15</td>
<td>Male</td>
<td>48</td>
<td>178</td>
<td>82</td>
<td>T12A</td>
</tr>
</tbody>
</table>

STUDIES
Few studies have been published on the potential health benefits of using exoskeletons for non-ambulatory individuals for less than one year. A pilot study of the ReWalk™ exoskeleton was conducted with 12 individuals with motor-complete thoracic-level SCI. Although the primary objective was establishing safety and efficacy, the study indicated improvements in pain, bowel and bladder function, spasticity, and emotional well-being (Esquenazi et al., 2012). Another study of six subjects with motor-complete paraplegia using the ReWalk™ exoskeleton found that all sustained a significant loss of fat tissue mass after 20-60 hours of use (Spungen et al., 2013). A reduction in fat tissue may decrease predisposition to diabetes or cardiovascular disease. (Gutierrez et al., 2009). Finally, anecdotal evidence suggests that regular use of RE may enhance sensory or motor function in individuals with incomplete SCI, stroke, brain injury, or other conditions with only partial paralysis.

During the spring of 2014, our research team at Shepherd Center investigated the use of Indego® for persons with C5-L1 SCI. The objective of this study was to evaluate mobility outcomes for individuals with SCI after five gait-training sessions with a powered exoskeleton, with the
### Table 3. Subject performance data from Indego pilot study

<table>
<thead>
<tr>
<th>Subject #</th>
<th>PRW or FCs</th>
<th>10MWT Time (s)</th>
<th>10MWT Speed (m/s)</th>
<th>6MWT Distance (m)</th>
<th>Assist to Walk</th>
<th>Surfaces</th>
<th>Don Time (m:s)</th>
<th>Doff Time (m:s)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tetra (C5-C7)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>G2 04</td>
<td>PRW</td>
<td>42</td>
<td>0.24</td>
<td>74.2</td>
<td>Min A of 1</td>
<td>I,O,R</td>
<td>D 8:00</td>
<td>D 5:00</td>
</tr>
<tr>
<td>G2 06</td>
<td>PRW</td>
<td>53</td>
<td>0.19</td>
<td>46.9</td>
<td>Mod A of 1</td>
<td>I,O,R</td>
<td>D 15:00</td>
<td>D 5:00</td>
</tr>
<tr>
<td>G2 14</td>
<td>PRW</td>
<td>46</td>
<td>0.22</td>
<td>71.2</td>
<td>Mod A of 1</td>
<td>I,O,R,G</td>
<td>D 10:00</td>
<td>D 2:00</td>
</tr>
<tr>
<td>G2 02</td>
<td>RW</td>
<td>40</td>
<td>0.25</td>
<td>62.1</td>
<td>Supervision</td>
<td>I,O,R</td>
<td>C 10:00</td>
<td>S 4:00</td>
</tr>
<tr>
<td>G2 09</td>
<td>RW</td>
<td>31.5</td>
<td>0.32</td>
<td>92.8</td>
<td>Supervision</td>
<td>I,O,R</td>
<td>S 2:15</td>
<td>S 2:00</td>
</tr>
<tr>
<td>G2 16</td>
<td>RW</td>
<td>46</td>
<td>0.22</td>
<td>74.8</td>
<td>Min A of 1</td>
<td>I,O,R</td>
<td>C 8:00</td>
<td>C 2:00</td>
</tr>
<tr>
<td>G2 17</td>
<td>RW</td>
<td>39.6</td>
<td>0.25</td>
<td>81.03</td>
<td>Min A of 1</td>
<td>I,O,R</td>
<td>C 10:00</td>
<td>C 3:00</td>
</tr>
<tr>
<td>G2 18</td>
<td>RW</td>
<td>42</td>
<td>0.24</td>
<td>69</td>
<td>Min A of 1</td>
<td>I,O</td>
<td>C 10:00</td>
<td>C 5:00</td>
</tr>
</tbody>
</table>

| G2 01 | FC | 19 | 0.53 | 143.9 | Supervision | I,O,R,G | S 2:30 | S 2:00 |
| G2 03 | FC | 24.2 | 0.41 | 129.4 | Supervision | I,O,R,G | S 12:00 | S 6:00 |
| G2 05 | RW | 28 | 0.36 | 92.4 | Min A of 1 | I,O,R,G | S 13:00 | S 3:00 |
| G2 07 | RW | 21.5 | 0.47 | 140 | Supervision | I,O | S 5:00 | S 3:00 |
| G2 10 | RW | 32.7 | 0.31 | 91.5 | Min A of 1 | I,O,R,G | C 3:30 | S 4:00 |
| G2 11 | RW | 18.8 | 0.53 | 140.8 | Supervision | I,O,R | S 13:00 | S 12:00 |
| G2 13 | FC | 18.5 | 0.54 | 136.9 | Supervision | I,O,R,G | S 11:00 | S 3:00 |
| G2 15 | FC | 24.3 | 0.41 | 91.5 | Supervision | I,O,R,G | S 3:30 | S 2:30 |

**Results:** At the end of 5 sessions (1.5 hours per session), average walking speed was 0.22 m/s for persons with C5-6 motor complete tetraplegia, 0.26 m/s for thoracic levels one through 8 (T1-8) motor complete paraplegia, and 0.45 m/s for thoracic level 9 through lumbar level one (T9-L1) paraplegia. Distance covered in 6 minutes averaged 64 m for those with C5-6, 74 m for T1-8, and 121 m for T9-L1. Additionally, every participant was able to walk on both indoor and outdoor surfaces.

Our Indego® trial results after only five sessions suggest that persons with tetraplegia and paraplegia learn to use the Indego® exoskeleton quickly and can manage a variety of surfaces. Walking speeds and distances achieved also indicate that some individuals with paraplegia can quickly become limited community walkers using this system. The subjects’ resulting proficiency after five sessions suggests that the Indego is capable of providing individuals with SCI the ability to ambulate outside of a clinical setting in both indoor and outdoor environments, particularly in the case of lower paraplegia. With additional training sessions, we expect to see further improvement in user proficiency. A longer study is required to evaluate how many gait training sessions would be required for a person with paraplegia to achieve modified independence for all aspects of Indego use. Regardless of the number of training sessions provided, persons with motor complete tetraplegia would continue to need assistance of one to two persons for all aspects of Indego donning, doffing, set up, and safe walking, since they do not have use of major upper extremity muscle groups.

For individuals with higher-level SCI (tetraplegia), the use of Indego® may be most...
appropriate for exercise purposes and rehabilitative training in a clinical setting. The results also indicate that some users will be capable of independent donning, doffing, and walking, and will ambulate at speeds appropriate for use outside of the clinic, particularly in the case of lower paraplegia.

**Figure 3:** Average 10 Meter Walk Test gait speeds with standard deviations shown for the three test groups: Tetraplegia, Upper Paraplegia, and Lower Paraplegia.

**Figure 4:** Average 6 Minute Walk Test distances with standard deviations shown for the three test groups: Tetraplegia, Upper Paraplegia, and Lower Paraplegia.
SUMMARY

Based on limited clinical trials, REs appear to be safe and effective at providing persons with severely limited mobility the potential to stand and walk on a variety of surfaces. Due to the great expense and varied functionality of the devices, we strongly recommend that rehabilitation centers who want to incorporate them into their programs and users who want to purchase them should trial several different devices before making any decisions. Before any trials, persons who want to test these devices should be fully evaluated by physical therapists and have permission for weight bearing and walking from their physicians. Additional long term studies are needed to evaluate the extent of training required for persons with paraplegia to become self-sufficient with these systems and to track any resulting secondary health changes for all users.

REFERENCES


AN INTERVIEW WITH NECATI HACIKADIROĞLU, CEO OF MATIA ROBOTICS, ISTANBUL, TURKEY AND LONDON, ENGLAND.

BY WENDIE A. HOWLAND MN RN-BC CRRN CCM CNLCP LNCC

Tell us a bit about your company and the device you offer.
Matia Robotics is a team of expert inventors and engineers, dedicated to the creation of innovative robotic mobility devices. Our goal is to improve the health, wellness, and sense of independence for as many people as we can reach.

After years of development, planning, and testing, the Tek RMD is our first product to hit the market. We designed the Tek RMD to add more freedom to the lives of individuals with paralysis, allowing them to live in places not designed for them, and to move more independently in the world.

Matia Robotics is the developer of an unusual standing mobility device for paraplegics, the Tek RMD. We interviewed Mr. Hacikadiroğlu remotely.

How did you get interested in spinal cord injury mobility?
Necati Hacikadiroğlu studying at a University in Istanbul started working on two-legged walking robots. As he developed the two-legged walking robot, he saw how well these robots could be used as exoskeletons for people with walking
disabilities. He met with spinal cord injured people and started working with them. Through their feedback, he came to the realization that the priority for disabled people is to be independent and mobile and to have use of their hands like able-bodied people. He realized an exoskeleton was not the solution as hands were needed for balance. Additionally, these devices were expensive, require extended periods of training, and only permit slow movement.

With the support of Enes Canidemir, he developed Tek RMD, a simple device to enable users to perform their daily activities independent of outside help and at eye-level with others in their surroundings. Video of the device in use is up on the company website at www.matiarobotics.com and at http://tinyurl.com/bwpds2e. You can also see four people using the device for the first time at http://tinyurl.com/owx8b7, http://tinyurl.com/mcs9ow, and http://tinyurl.com/kmwrwed.

What are the big advantages to upright mobility in SCI?

**Economic Benefits**

- Increases physical exercise while people complete their daily tasks. This helps prevent unwanted health problems and reduces medical costs.
- Gives users ability to minimize need for caregiving in daily life, reduces related costs.
- Correct standing position gives the ability to live and work in regular environments by decreasing the need to modify homes and offices to accommodate wheelchairs.

**Medical benefits**

- People forced to spend their lives in a wheelchair face unwanted health issues, especially cardiovascular disease, blood pressure irregularity, pressure injuries, loss of bowel and/or bladder functions, and fractures from osteoporosis. Such complications directly lead to additional medical costs, furthermore decreases quality of life. Upright posture can mitigate these risks.

**Psychological benefits**

- Enables users to perform their daily activities independently and at eye level with others in their surroundings, which positively affects users’ psychology and also increases their overall morale.
- Interpersonal dynamics for a person with disability living with other able-bodied people change as the person with disability is able to participate more naturally.

**Do you have literature references to support this?**

Research show that standing up on a regular basis significantly improves the health, and quality of life for these people.

**Have any of your clients noticed problems with pressure points at knees, feet, etc. while using this device?**

Some users got dizzy, or faced other minor issues when they stand up for the first time in a long time. However, we have not faced any problems with pressure points. We suggest the users to start using the device in short intervals until they are totally comfortable with it, check their bodies after every use, and see their physicians regularly.

**What is the optimal patient for this device? Who would not be appropriate? How many are in actual use today?**

The optimal user is from 4'7” to 6'3” and weights between 88 lbs and 265 lbs, have the full strength on their upper body, arms and full use of their hands. As a rule of thumb we say if a user can stand up with any other device, and have full use of their upper body, they can stand up with Tek RMD. We currently have devices in use in few EU countries, in Australia and Mexico. Currently we are going through the FDA 510 K process for US. We hope to get FDA clearance in the next few months.

**What are the anticipated costs for purchase? Where would maintenance be available in the US? What would be the replacement interval?**

The device is projected to sell for $18,000 USD. Currently, we are establishing our US distribution network. Our goal is once we have the FDA clearance we will have technical support available nationwide.

**What were the biggest challenges you faced in getting clinicians to accept it?**

We got support from Heidelberg University, Germany for the ergonomics of the device. It is taking a long time to enter many countries. However, because positive effects of standing up is widely known, the clinicians accepted it relatively easily.

---

**NECATI HACIKADIROĞLU**

Necati Hackakdiroğlu is the CEO of Matia Robotics and the inventor of the Tek RMD. Necati started his robotics research in the Koc University Robotics Community. Since then he has worked as an expert on a variety of robotic projects. He has over 10 years of experience in the robotics field and holds a number of patents.
INTRODUCTION
Life happens, disrupting our carefully crafted plans for a day, a month, or long-range plans for the future. Whether unexpected or gradual, disease or disability can be a minor speed bump or a major roadblock to our plans for simply participating in life’s daily activities. One of the most common, easily taken for granted, is driving. Driving can be a critical link to independence for school, work, recreation, and family life. For new drivers with a cognitive, visual, or physical disability, driving often seems like an unattainable goal. For experienced drivers with a serious injury like paraplegia or tetraplegia, getting back on the road can seem like a difficult and confusing task. For families with a parent or grandparent experiencing age-related
changes or memory loss or dementia, knowing when to confiscate the keys can be a difficult decision. There is help available to support your clients and families in the pursuit of safe, independent community mobility. A group of professionals who specialize in working with drivers (new, experienced, aging), who have medical conditions that may interfere with driving can be found in almost any community across the United States and Canada.

For drivers who need customized specialized care, consider referral to a certified driver rehabilitation specialist (CDRS™). Though other driver rehabilitation specialists may offer the same services, a CDRS has had additional training in the effects of disability, vision changes, and aging can have on the task of driving. Providers typically have a background in allied health, such as occupational therapy, while other specialists come from the fields of driver education and traffic safety. A CDRS offers specific assessment and instructional skills, experience, and understanding for people with visual, physical, or cognitive changes that may interfere with driving, and will conduct a thorough driver evaluation followed by driver's training and education as indicated. Look for the CDRS credential.

THE EVALUATION PROCESS
The evaluation process generally includes a clinical assessment and a behind-the-wheel road test. The clinical assessment can take 90-120 minutes and includes tests of vision, physical and motor function, perceptual skills, reaction time, and knowledge about driving rules and regulations. Typically following the clinical assessment, the CDRS/DRS will conduct a behind the wheel assessment. Depending on the client’s specific needs, the road test will focus on the driver’s performance and skills with operating a motor vehicle, managing traffic and road way conditions and hazards avoidance. This portion of the evaluation can last up to 120 minutes, is conducted on roadways that offer a variety of driving scenarios, and is typically performed in a vehicle specially outfitted with a variety of adaptive driving equipment. If the client needs special equipment to operate the vehicle or if modifications will be required, the CDRS/DRS may conduct the road test in multiple sessions as to best determine the type and style of equipment as well as to determine the client’s aptitude and proficiency in learning how to operate the newly introduced equipment. The complete evaluation, clinical and behind the wheel, can take between three and eight hours. Multiple sessions may be required depending on the client’s unique situation.

ADAPTATIONS
A thorough driver evaluation allows the CDRS/DRS to consider all options and assist drivers in determining the modifications most suited to their needs. Recommended vehicle adaptations can include:
- Ignition controls
- Steering devices
- Hand controls
- Foot pedal extensions
- Dashboard control modifications
- Other adaptive driving controls

Vehicle modifications may also be necessary to assist the driver with entering/exiting the vehicle, stowing a mobility device, or other significant modifications to the body of the vehicle, such as lifts, ramps, special mirrors, or custom seating.

TRAINING
The CDRS/DRS will also determine how much training the driver will need before obtaining a new driver’s license or before modifications are made to a personal vehicle. For most clients for whom vehicle adaptations or modifications are recommended, training is mandatory. The training can be performed by the DRS/CDRS who also is a state licensed driving school instructor or an independent driving school instructor who has experience working with drivers with disabilities. Finally, the DRS/CDRS will help the driver navigate licensing procedures and work with modified mobility equipment to ensure a positive outcome.

The CDRS/DRS will share all final recommendations with the client and referring physician. Depending on the situation and with the client’s permission, the report may also be shared with funding sources, such as vocational rehabilitation services, or other case management services as needed. Notification to the Division of Motor Vehicles may be mandatory in the case of a recommendation to stop driving, when license restrictions are required, or when the driver needs special adaptive driving equipment.

Referrals to a driver rehabilitation program can be made by physicians, other
RESOURCES FOR ADAPTIVE DRIVING

FOOT CONTROLS
Better Life Mobility
7239 Indiana Ave
Riverside, CA 92395
951-686-3152
Spoke with Lena
-Foot Controls: $550.00 total ($330.00 for the equipment and 2 hours of labor)

Ability Center
711 S Allen St,
San Bernardino, CA 92408
(800) 454-3862
Spoke with Jeff
He was hesitant about providing costs before seeing a driver evaluation, but did give range of $500-$600 for equipment and installation.

DRIVER TRAINING
Handicapped Driver Training (is the company name)
Lena, at Better Life Mobility, gave me the number to Handicapped Driver Training, Frank 951-515-5125.
Spoke with Frank- owner
Equipment Evaluation $200.00
Comprehensive Evaluation $500.00
Driver Training $175 per 1.5 hours.
There is not an average range for training. It depends on the person and how adaptable they are to the equipment and driving changes.

health care professionals, and eye care professionals, family members, rehabilitation agencies or even the DMV.
Costs for the evaluation vary from facility to facility and generally depend on the amount of time required. Some facilities bill medical insurance while others bill as an out-of-pocket or fee-for-service program.
Some questions to ask when making a referral:
- Can this program meet the specific needs of my client?
- What is required for a referral?
- What is the cost for the evaluation service and is medical insurance billed?
- If driver training is recommended, what is the cost for service? Is that
covered by insurance?

- How long is the evaluation and how many visits are typical given my client’s condition?
- Does the client have to go to the facility or is home-based assessment an option?
- Where does the final report go and is the DMV notified?

For those that require a comprehensive driver evaluation, referral to a driver rehabilitation program is recommended. Not all programs are alike. Driver rehabilitation services vary, from basic programs that work primarily with drivers with cognitive deficits or minimal physical issues, to more complex programs offering high-tech driving equipment evaluations. It is important to understand the type of program and discover whether it can meet your client’s needs. (See Spectrum of Driver Services)

It will also be helpful to understand the licensing laws in your state. Licensing requirements, renewal procedures, reporting procedures, and the role of the medical advisory board can vary from state to state. A helpful resource used as a quick guide with contact information is the Physician’s Guide to Assessing and Counseling Older Drivers, 2nd edition. This guide includes recommended screening assessment tools, patient counseling tips, and links to relevant state regulations. It was produced by the American Medical Association in collaboration with the National Highway Traffic Safety Administration and is available for free at http://www.nhtsa.gov/people/injury/olddrive/OlderDriversBook/pages/Contents.html.

DRIVER EDUCATION SERVICES

In a 2012 member survey, the Association for Driver Rehabilitation Specialists (ADED) collected data on driver rehabilitation program services. From that survey, ADED found that typical payer sources include (in order of frequency): private pay, Medicare, HMO, worker’s compensation insurance, and vocational rehabilitation services. For occupational therapy billing, typical CPT codes include (by frequency of use): 97004, 97770, 97110, 97112, and 97003. If the payer source is vocational rehabilitation services or independent living services, administrators call for bids for services and determine the proper providers for evaluation, training, or both. As with the DMVs, vocational rehabilitation regulations and procedures will vary by state.

Costs for services also vary, depending on the type of service offered, setting in which the service is provided, and time involved. Costs ranged from $250-$800 per evaluation. High-tech evaluations (e.g., vans with electronic driving controls) rates ranged as high as $1500 per evaluation. To find a CDRS/DRS, see ADED’s website at www.aded.net.

Community-based Driver Education For clients that are not in need of a comprehensive driving evaluation, community-based education is available that can enhance self-awareness, offer driving choices and improve the capacity to self-limit driving. AARP, AAA, or traditional driving schools typically offer these programs. For more in-depth screening, health care professionals such as physicians or occupational therapists can perform a clinical instrumental activity of daily living (IADL) assessment. These assessments are designed to evaluate and interpret risks associated with driving, but are not designed to determine fitness for driving.

CONCLUSION

Bringing a driver rehabilitation specialist into the care mix for your clients can breathe new life into their daily routines. Returning to safe, independent driving can be a lifesaver for many and allow them to rejoin the community, the workforce, and family and recreation functions. For drivers nearing the end of their driving career, a referral to a driver rehabilitation program can help determine fitness to drive, ease the transition, and provide valuable insight into your

ABOUT ADED: The Association for Driver Rehabilitation Specialists, or ADED, is a non-profit organization made up of members dedicated to promoting safe, independent community mobility for persons with disabilities and the aging. The group provides education, research, and support to professionals working in the fields of driver education, driver training, and transportation equipment modifications for those with disabilities. ADED is the only organization in North America to offer the Certified Driver Rehabilitation Specialist (CDRS) designation. The first CDRS exam was conducted in 1995. In 2014, ADED members numbered 900 worldwide, with 350 active CDRS professionals in the U.S. and Canada. ADED is registered as a 501 (c) (3) corporation.
Spectrum of Driver Services: Right Services for the Right People at the Right Time
A description consumers and health care providers can use to distinguish the type of services needed for an older adult.

<table>
<thead>
<tr>
<th>Program Type</th>
<th>COMMUNITY-BASED EDUCATION</th>
<th>MEDICALLY-BASED ASSESSMENT, EDUCATION AND REFERRAL</th>
<th>SPECIALIZED EVALUATION AND TRAINING</th>
</tr>
</thead>
<tbody>
<tr>
<td>Typical Providers and Credentials</td>
<td>Program specific credentials (e.g., AARP and AAA Driver Improvement Program).</td>
<td>Licensed Driving Instructor (LDI) certified by state licensing agency or Dept. of Education.</td>
<td>Health care professional (e.g., physician, social worker, neuropsychologist).</td>
</tr>
<tr>
<td>Required Provider’s Knowledge</td>
<td>Program specific knowledge.</td>
<td>Knowledge of relevant medical conditions, assessment, referral, and / or intervention processes.</td>
<td>Knowledge of medical conditions and the implication for community mobility including driving.</td>
</tr>
<tr>
<td>Typical Services Provided</td>
<td>1) Classroom or computer based refresher for licensed drivers: review of rules of the road, driving techniques, driving strategies, state laws, etc. 2) Enhanced self-awareness, choices, and capability to self-limit.</td>
<td>1) Counsel on risks associated with specific conditions (e.g., medications, fractures, post-surgery). 2) Investigate driving risk associated with changes in vision, cognition, and sensory-motor function. 3) Determine actions for the at-risk driver: • Refer to IADL evaluation, driver rehabilitation program, and / or other services. • Discuss driving cessation; providing access to counseling and education for alternative transportation options. 4) Follow reporting / referral structure for licensing recommendations.</td>
<td>Applies knowledge of medical conditions with implications to driving.</td>
</tr>
<tr>
<td>Outcome</td>
<td>Provides education and awareness. Enhances skills for healthy drivers.</td>
<td>Indicates risk or need for follow-up for medically at-risk drivers.</td>
<td>Determines fitness to drive and provides rehabilitative services.</td>
</tr>
</tbody>
</table>

*AOTA – Health professional degree with specialty training in driver evaluation and rehabilitation. *CDRS – Certified Driver Rehabilitation Specialist-Credentialed by ADED (Association for Driver Rehabilitation Specialists). *SCDMC – Specialty Certified in Driving and Community Mobility by AOTA (American Occupational Therapy Association). *Quality Approved Provider by NMDHA (National Mobility Equipment Dealers Association).
## Spectrum of Driver Rehabilitation Program Services

A description consumers and health care providers can use to distinguish the services provided by driver rehabilitation programs which best fits a client’s need.

<table>
<thead>
<tr>
<th>Program Type</th>
<th>DRIVER REHABILITATION PROGRAMS</th>
<th>LOW TECH</th>
<th>HIGH TECH</th>
</tr>
</thead>
</table>
| **Levels of Program and Typical Provider Credentials** | Determine fitness to drive and / or provide rehabilitative services. | Driver Rehabilitation Specialist*, Certified Driver Rehabilitation Specialist*, Occupational Therapist with Specialty Certification in Driving and Community Mobility+; or in combination with LDI. | Driver Rehabilitation Specialist*, Certified Driver Rehabilitation Specialist*, Occupational Therapist with Specialty Certification in Driving and Community Mobility+.
Certification in Driver Rehabilitation is recommended as the provider for comprehensive driving evaluation and training. |
| **Program Service** | Offers driver evaluation, training and education. May include use of adaptive driving aids that do not affect operation of primary or secondary controls (e.g., seat cushions or additional mirrors). May include transportation planning (transition and options), cessation planning, and recommendations for clients as passengers. | Offers comprehensive driving evaluation, training and education, with or without adaptive driving aids that affect the operation of primary or secondary controls, vehicle ingress / egress, and mobility device storage / securement. May include use of adaptive driving aids such as seat cushions or additional mirrors. At the Low Tech level, adaptive equipment for primary control is typically mechanical. Secondary controls may include wireless or remote access. May include transportation planning (transition and options), cessation planning, and recommendations for clients who plan to ride as passengers only. | Offers a wide variety of adaptive equipment and vehicle options for comprehensive driving evaluation, training and education, including all services available in Low Tech and Basic programs. At this level, providers have the ability to alter positioning of primary and secondary controls based on client’s need or ability level. High Tech adaptive equipment for primary and secondary controls includes devices that meet the following conditions: 1) capable of controlling vehicle functions or driving controls, and 2) consists of a programmable computerized system that interfaces / integrates with an electronic system in the vehicle. |
| **Access to Driver’s Position** | Requires independent transfer into OEM^ driver’s seat in vehicle. | Addresses transfers, seating and position into OEM^ driver’s seat. May make recommendations for assistive devices to access driver’s seat, improved positioning, wheelchair securement systems, and / or mechanical wheelchair loading devices. | Access to the vehicle typically requires ramp or lift and may require adaptation to OEM driver’s seat. Access to driver position may be dependent on use of a transfer seat base, or clients may drive from their wheelchair. Provider evaluates and recommends vehicle structural modifications to accommodate products such as ramps, lifts, wheelchair and scooter hoists, transfer seat bases, wheelchairs suitable to utilize as a driver seat, and / or wheelchair securement systems. |
| **Typical Vehicle Modification: Primary Controls: Gas, Brake, Steering** | Uses OEM^ controls. | Primary driving control examples: A) mechanical gas / brake hand control; B) left foot accelerator pedal; C) pedal extensions; D) park brake lever or electronic park brake; E) steering device (spinner knob, tri-pin, C-cuff). | Primary driving control examples (in addition to Low Tech options): A) powered gas / brake systems; B) power park brake integrated with a powered gas / brake system; C) variable effort steering systems; D) reduced diameter steering wheel, horizontal steering, steering wheel extension, joystick controls; E) reduced effort brake systems. |
| **Typical Vehicle Modification: Secondary Controls** | Uses OEM^ controls. | Secondary driving control examples: A) remote horn button; B) turn signal modification (remote, crossover lever); C) remote wiper modification; D) gear selector modification; E) key / ignition adaptions. | Electronic systems to access secondary and accessory controls. Secondary driving control examples (in addition to Low Tech options): A) remote panels, touch pads or switch arrays that interface with OEM^ electronics; B) wiring extension for OEM^ electronics; C) powered transmission shifter. |

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### Notes

- DRS – Health professional degree with specialty training in driver evaluation and rehabilitation.
- *CDRS – Certified Driver Rehabilitation Specialist – Credentialed by ADED (Association for Driver Rehabilitation Specialists).
- SDCCM – Specialty Certified in Driving and Community Mobility by AOTA (American Occupational Therapy Association).
- OEM – Original Equipment installed by Manufacturer.

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**Driver Rehabilitation Programs: Defining Program Models, Services, and Expertise.**

Elizabeth Green, OTR/L, CDRS, is the executive director for the Association for Driver Rehabilitation Specialists (ADED). She may be reached at ADED: 200 1st Ave NW #505 Hickory NC 28601. 866-672-9466. Elizabeth.green@driver-ed.org
MEETING TRAVEL CHALLENGES AFTER SCI

BY DEBRA MOREHEAD, LNCP-C, CLC

I collected this information from the travel sources as indicated for use by the nurse life care planner to share with clients to travel who are unable to drive or go by private vehicle. Contact the providers at the websites listed.

One day you are behind the wheel cruising through the countryside or city streets and you blink your eyes and discover that you are no longer behind the wheel but sitting in a wheelchair...unable to walk and possibly not even feel your legs. You find that you are totally dependent on others for almost every aspect of your life, including your mobility. You are no longer able to get in the car and go anywhere you want. You are no longer able to drive to that doctor’s appointment or the drug store or even to walk in once you get there. This is where many of our clients find themselves.

Realizing that the unexpected is always a step away and it’s part of this adventure called life, my motto has long been, “Those who are (mentally) flexible bend and don’t break.” Unfortunately, it is more difficult to anticipate and be prepared for every “unexpected” opportunity when dealing with physical limitations.

Enter the Nurse Life Care Planner...Each of us has an important role - to empower our patients! One way is by providing detailed information that will give them the power to overcome the obstacles that have come into their lives.

Losing the ability to be independently mobile is taken away even temporarily is very disturbing, even frightening, as some of us know from personal experience. Everyone needs to be mobile.

The life care planner’s assessment of the patient will provide historical and current information to guide our decisions and recommendations. Regardless of the client's stage of recovery, transportation is an important consideration...medical appointments, hospital/clinic visits, therapy, pharmacy, grocery store, church, social outings, vacations, and the list goes on. How will they get there?

My goal is to provide fellow nurse life care planners with a summary of optional services and tips that will assist you in educating and providing transportation guidelines. Whether they’re traveling in a rural area or a bustling city, let’s help our clients be mobile! Show them their options regardless of their location. After all we are everywhere and so are our clients!

GROUND TRANSPORTATION

Accessible Van Rentals:
http://www.wheelchairgetaways.com/
Advertise the availability of accessible van rentals from Phoenix to Detroit, San Francisco to Miami offering daily, weekly, monthly and long-term accessible van rentals. Service that moves people. 800-642-2042
http://www.accessiblevans.com
Accessible Vans of America also advertises its rentals with a long list of available locations on its website.

Regardless of what rental company, remember to request hand controls if indicated. They can put hand controls in pretty much any car.

For those who choose to be prepared ahead of time, hand controls are available for purchase through numerous vendors. One example is the PHC-3 PORTABLE HAND CONTROL. It folds to 18” long, weighs only 2.4 pounds and will fit in carry-on luggage or a briefcase. It is available for purchase for $379.00. It fits just about anything with an automatic transmission. Installs in minutes! No tools, no modifications to the car. The website offered free shipping within the USA and guarantee of satisfaction. http://wheelability.com Note that in some jurisdictions, these may not be permitted by state regulations. (see Green E, Adaptive Driving, page XX)

A SCI traveler on the http://sci.washington.edu/info/forums/reports/travel_2011.asp recommends bringing a transfer board for self-transfers, because of the potential of a gap between the car seat and wheelchair. One example of advertised transfer boards is a maple sliding transfer board with ergonomic hand slots enabling the patient to have a stronger grasp when transferring. Listed weight capacity: 300 lbs. weight: 3 lbs. An 8x24 and 8x30 size is available. Price listed is $30.46. Photos and transfer instructions may be viewed at http://www.activeforever.com/maple-sliding-transfer-board.

PUBLIC TRANSPORTATION AND THE ADA

The Spinal Cord Injury Association of Illinois recommends, “It is useful to spend some time becoming educated about how the Americans with Disabilities Act (ADA) and the Air Carriers Access Act (ACAA) affect the traveler with SCI.

“The ADA, passed in 1990, gave civil rights protections to individuals with disabilities. It guarantees equal opportunity in employment, transportation, public accommodations, telecommunications, and state and local government. For travelers with SCI, this means travel related services, such as lodging, dining, entertainment venues, bus and rail stations, cruise ship terminals, and airports are impacted and should be more accessible as the industry comes into compliance.

“The ACAA, passed in 1986, guarantees that people with disabilities receive consistent and non-discriminatory treatment
when traveling by air. An experienced travel agency will provide SCI travelers with a copy of the ACAA. It is recommended that travelers with SCI bring a copy of the ACAA whenever flying. Having a copy on hand can help both the passenger with a SCI and airline personnel clarify any misunderstanding about what is covered.

“These laws have dramatically improved how individuals with SCI travel. However, travel industry suppliers need to be constantly educated about their obligation under this law.”

A lengthy list of accessible transportation choices is available on their website. http://www.sci-illinois.org/transportation

When making travel plans every traveler should always confirm all arrangements directly. Do not depend on websites. Make a call, know who you are speaking with, ask if there are any variations in terrain such as curbs, ramps, and stairs. Is there an elevator? A trip can quickly turn into a disaster if the destination claims to be accessible and when you arrive to find that there are two stairs and no ramp. Be prepared ahead of time. Make your needs known before you go.

Purchasing travel insurance in case connections don’t connect or claims of accessibility are inaccurate should be a consideration for costly travel.

I have chosen companies that are readily available in my area for reference and each is for example only. Regardless of what company you use, check out your transportation companies before you make reservations.

**TRAIN TRAVEL:**
Amtrak offers accommodations and discounts for train travelers with disabilities. Call 800-872-7245 or go to http://www.amtrak.com and click “Special Needs & Accessibility” under the “Plan” tab.

Passengers with disabilities and up to one traveling companion are eligible for a rail fare discount. Consult the discount detail page for discount amounts and any restrictions that may apply.

This Amtrak website reviews the types of manual and powered wheeled mobility devices that can be accommodated onboard including the exact measurements, weight limits, etc.

If you are traveling in a collapsible wheelchair you have the option of transferring to a train seat. Traveling in a wheelchair that is not collapsible requires that you remain seated in your device. Detailed information about boarding and detraining procedures is outlined as well.

Service animals are the only animals allowed on the train and may remain with you during your journey. Reservations must be made by phone prior to travel. Call 1-800-USA-RAIL (1-800-872-7245) or TTY (1-800-523-6590). Agents are available 24 hours a day, 7 days a week.

Specific and detailed guidelines for the use of oxygen while onboard are listed as well.

Some routes in the Amtrak system include Thruway services. These include transportation provided by bus, train, ferry, van or taxi through a variety of operators. Amtrak dedicated Thruway bus services are accessible and lift-equipped. Thruway services provided by partners are also accessible but may require up to 48 hours advance notice.

**COMMERCIAL BUS SERVICE**
Assistance is available to customers with disabilities when they travel on Greyhound. They list four important steps prior to travel:

1. Contact the Greyhound Customers with Disabilities Travel Assistance Line at 1-800-752-4841 before travel with questions and concerns you may have regarding your travel.

2. When booking your trip in a terminal, notify the ticket agent if you need assistance and if you will be traveling in a wheeled mobility device. When booking your trip online, make sure to self-select as a passenger traveling in a wheeled mobility device if that is the case. If you purchase your ticket over the phone or through any other means, let us know that you are traveling with a wheeled mobility device.

3. Arrive on time for your selected schedule.

4. Inform Greyhound employees and contractors of your needs during your trip.”

The following are Greyhound’s listed guideline for Traveling in a Wheeled Mobility Device:

“The combined weight of the customer and wheeled mobility device cannot
DEBRA MOREHEAD RN LNCP-C, CLC
Debra Morehead RN LNCP-C, CLC is the president of the Morehead Group of SC, offering research and outlining of expected medical costs for persons with accident, illness, injury, or disability. She may be contacted at 864-324-1412, deb@rnlifeplan.com

Fig 4. Greyhound bus lift

Greyhound’s website details approved service animals, oxygen guidelines and recommends you have a travel companion if you require any personal assistance.


Their ADA Compliance Corporate Office may be reached at 1-800-755-2357.

CITY BUS:
Less than 10,000 people live in my small town of in South Carolina. City bus service was first established a few years ago. This year they upgraded to all electric buses. All buses are equipped to accommodate individuals with disabilities. Individuals with disabilities needing other than regular route service must be certified with present verification for disability. This is a free service to our community and makes stops at the medical facilities, pharmacies, grocery, local university and shopping areas.

Metropolitan areas generally offers bus routes that are equipped with wheelchair lifts. (Fig. 5, City bus lift) While there is a fare for everyone, discounts are offered to individuals with disabilities. Some cities also have a Dial-a-Ride service. Consult the individual city transit authority website for details.

COMMUTER TRAIN/MASS TRANSIT
In Atlanta, Georgia, MARTA operates Mobility Services for qualified riders. They also offer ADA Complementary Paratransit Service, an advanced reservation service. Service is restricted to the ADA-designated service area within two counties. They offer a mobility discount for one or multiple trip ticket options.

Consult the individual city transit authority website for details. Maps and stop information is usually available on line and/or brochures available at local government offices. Reservations for paratransit may be required so it is always recommended to call first.

Taxi or cab service is available almost anywhere, but the type of vehicles and the accessibility should be determined prior to requesting a pick-up. Not all taxi fleets have assessable vans with wheelchair lifts. Storage of your foldable wheelchair and transfer assistance are other consideration when traveling via taxi.

Fig 5. City bus lift

NURSING DIAGNOSES
- Impaired physical mobility, Domain 4, Activity/Rest; Class 2 Activity/Exercise
- Risk for compromised human dignity, Domain 6, Self-perception; Class 1, Self-concept
- Situational low self-esteem, Domain 6, Self-perception; Class 2, self-esteem
- Impaired social interaction, Domain 7, Role relationships; Class 3, Role performance
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