

Stepping Forward Staying Informed

6th Annual
Consumer Research Conference

*Spinal Cord Injury Health,
Wellness, and Research*

Hosted by

New England Regional
Spinal Cord Injury Center
Boston Medical Center

Saturday October 23, 2010

10:00 AM-5:00 PM

Boston Convention and
Exhibition Center





The New England Regional Spinal Cord Injury Center (NERSCIC) is a 12-bed acute rehabilitation unit located within The Center for Rehabilitation at Boston Medical Center. Founded in 1955, NERSCIC became the first civilian spinal cord injury rehabilitation center in the United States.

NERSCIC is one of 14 federally funded Model Spinal Cord Injury Systems, receiving a grant from the National Institute of Disability and Rehabilitation Research and the Department of Education. NERSCIC is the only Model Systems Center in the New England region, proudly holding this designation since 1973.

Sharing the mission of Boston Medical Center, we at NERSCIC *provide exceptional care to all in need regardless of their status or ability to pay.* Focusing on patient care, education, and research, NERSCIC provides specialized rehabilitation to individuals who have sustained a new spinal cord injury. Our patients come to us not only from New England, but from around the World. Every program and service is designed to accommodate the specific needs of each patient we serve.

We are proud to act as an informational resource for hospitals and rehabilitation facilities throughout New England; however, it is our commitment to providing lifelong services, support, and information to individuals living with spinal cord injuries that is most rewarding.

MISSION STATEMENT:

We are committed to delivering exceptional, state-of-the-art, multidisciplinary rehabilitation services to enable individuals to reach their maximum level of independence following injury or illness.

We embrace the mission of Boston Medical Center by providing consistently excellent and accessible health services to all in need of care, regardless of status or ability to pay.

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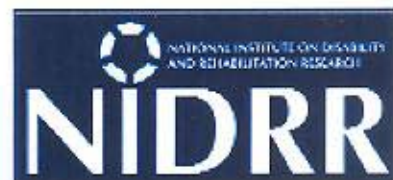
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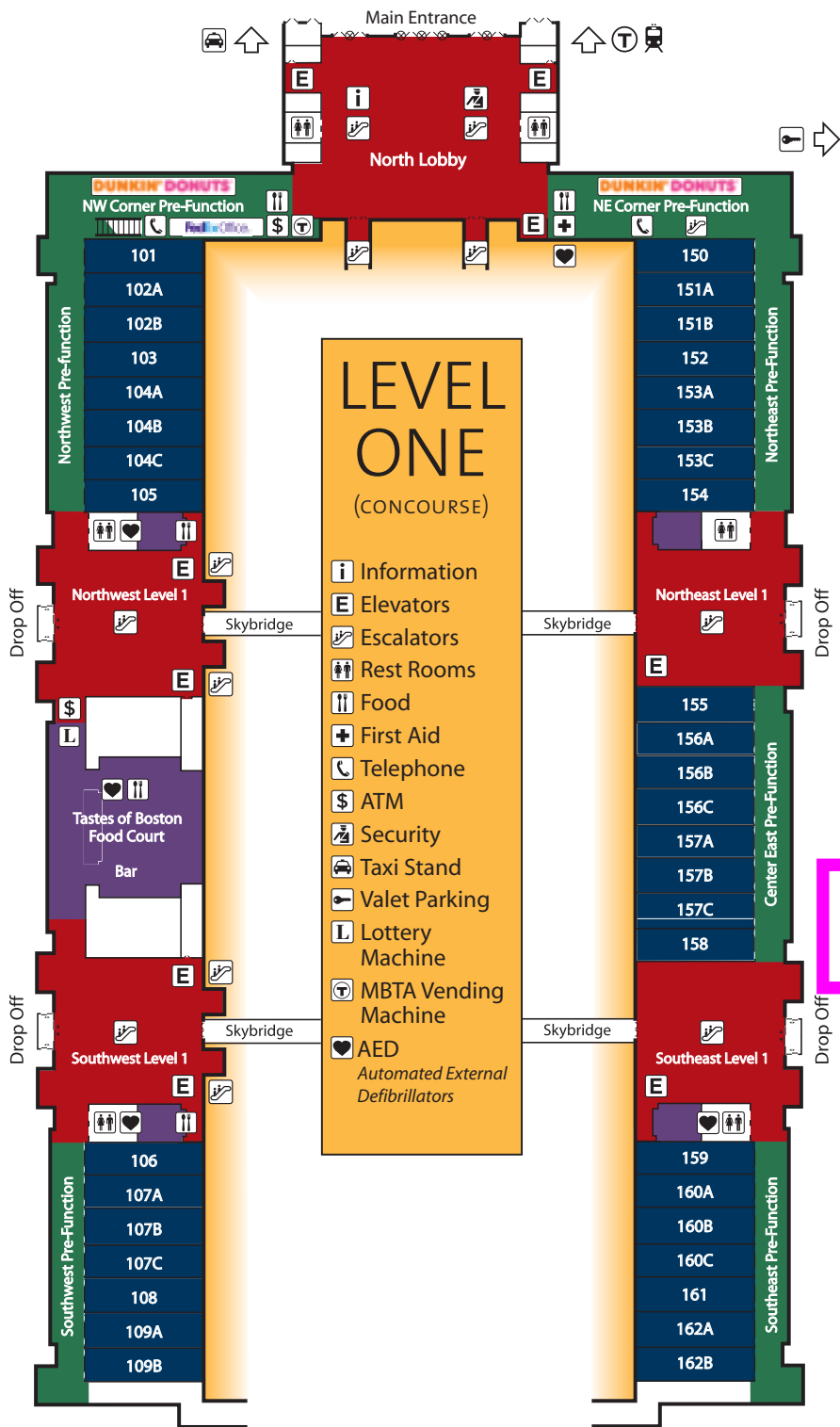


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Stepping Forward-Staying Informed

6th Annual Spinal Cord Injury Consumer Research Conference

Conference Schedule

October 23, 2010

9:00-9:45^{AM}

Registration & Continental Breakfast
Visit Exhibitors

10:00^{AM}

Welcome

Lisa Hemmerle, Mistress of Ceremonies

10:15-11:00^{AM}

From Then to Now to the Future

Susan P. Howley

11:00-11:15^{AM}

Q & A with Susan P. Howley

11:15^{AM}-12:00^{PM}

Cardiometabolic Disorders After Spinal
Cord Injury: Causes, Consequences, and
Effective Interventions

Mark Nash, Ph.D., FACSM

12:00-12:15^{PM}

Q & A with Mark Nash, Ph.D., FACSM

12:15-1:00PM

Lunch Provided in Lobby
Visit Exhibitors

1:00-1:30PM

Support Services for Individuals with
Spinal Cord Injuries and Their Informal
Caregivers
Sherri LeVela, Ph.D., MPH, MBA

1:30-1:45PM

Q & A with Sherri LeVela, Ph.D., MPH, MBA

1:45-2:15PM

Break-Refreshments Available in the Lobby

2:15-3:00PM

Aging with Spinal Cord Injury:
Implications for the Future
Suzanne Groah, MD, MSPH

3:00-3:15PM

Q & A with Suzanne Groah, MD, MSPH

3:15-3:30PM

Wrap-Up
Steve Williams, M.D.

Stepping Forward – Staying Informed
6th Annual Consumer Research Conference

Spinal Cord Injury Health, Wellness, and Research

October 23, 2010

Sponsored by:
Department of Rehabilitation Medicine
Boston Medical Center

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The Course Director and Program Coordinators have nothing to disclose with regards to commercial support.

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Educational Objectives

At the conclusion of this activity, participants will be able to:

1. Understand the field of spinal cord injury research past, present, and future.
2. Understand the programs offered and supported through the Christopher and Dana Reeve Foundation.
3. Understand the Christopher and Dana Reeve Foundation Paralysis Survey, One Degree of Separation, and its impact.
4. Understand causes and consequences of cardiometabolic disorders after spinal cord injury.
5. Understand the interventions that reduce health hazards from cardiac and endocrine-related disease after spinal cord injury.
6. Describe health and quality of life outcomes of informal caregivers.
7. Describe changes in outcomes for individuals with spinal cord injuries and their caregivers who participate in support service programs.
8. Describe how a spinal cord injury affects the aging process.
9. List 3 conditions commonly associated with aging in people with spinal cord injury.

Disclaimer

These materials and all other materials provided in conjunction with educational activities are intended solely for purposes of supplementing education programs for qualified health care professionals. Anyone using the materials assumes full responsibility and all risk for their appropriate use. Boston Medical Center makes no warranties or representations whatsoever regarding the accuracy, completeness, currentness, noninfringement, merchantability or fitness for a particular purpose of the materials. In no event will Boston Medical Center be liable to anyone for any decision made or action taken in reliance on the materials. In no event should the information in the materials be used as a substitute for professional care.

Lisa Hemmerle
Deputy Director of Economic Initiatives
Boston Redevelopment Authority
Boston, MA

Emcee

Lisa Hemmerle is the Deputy Director of Economic Initiatives at the Boston Redevelopment Authority. The mission of Economic Initiatives is the development of a vibrant business community through attraction and retention of Boston businesses. In 2007, Lisa graduated with honors from the Harvard Kennedy School with a Masters in Public Administration. From 2000 to 2008, Lisa ran a New Hampshire nonprofit she founded that is dedicated to individuals who have suffered a spinal cord injury. After eight years, the organization was merged with Granite State Independent Living, the state's largest cross-disability services nonprofit. Prior to that, Lisa worked as a CPA with KPMG, LLP as an auditor and consultant for domestic and international banks. Besides the U.S., she has lived in Germany, the Netherlands and China and traveled extensively.

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Faculty Disclosure

Lisa Hemmerle has no vested interests, and there are no conflicts of interest to disclose.

Faculty disclosure of off-label use

Lisa Hemmerle does not plan on discussing unlabeled/investigational uses of a commercial product.

Susan P. Howley
Executive Vice President, Research
Christopher and Dana Reeve Foundation
Short Hills, NJ

Susan Howley entered the spinal cord field in 1982 as Director of Administration for the Stifel Paralysis Research Foundation (SPRF), a family foundation in Short Hills, New Jersey. Several years later, SPRF merged with the American Paralysis Association (APA) where she was Executive Director from 1985 to 1992 and then became Director of Research. Today she serves as Executive Vice President and Director of Research for the Christopher & Dana Reeve Foundation (CDRF), where she was charged with implementing a strategic expansion of the Foundation's research program, which included development of the Translational Research Fund (TRF), the North American Clinical Trials Network (NACTN) and the NeuroRecovery Network (NRN).

Learning Objectives

From Then to Now to the Future

1. Participants will have an understanding of the field of spinal cord injury research past, present and future.
2. Participants have an understanding of the programs offered and supported through the Christopher and Dana Reeve Foundation.
3. Participants will have an understanding of the CDRF's Paralysis Survey, One Degree of Separation, and its impact.

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GERON INITIATES CLINICAL TRIAL OF HUMAN EMBRYONIC STEM CELL-BASED THERAPY IN PATIENTS WITH SPINAL CORD INJURY

First Patient Treated at Shepherd Center in Atlanta

MENLO PARK, Calif., October 11, 2010 – Geron Corporation (Nasdaq: GERN) today announced the enrollment of the first patient in the company’s clinical trial of human embryonic stem cell (hESC)-derived oligodendrocyte progenitor cells, GRNOPC1. The primary objective of this Phase I study is to assess the safety and tolerability of GRNOPC1 in patients with “complete” American Spinal Injury Association (ASIA) Impairment Scale grade A thoracic spinal cord injuries. Participants in the study must be newly injured and receive GRNOPC1 within 14 days of the injury.



geron corporation
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The patient was enrolled at Shepherd Center, a 132-bed spinal cord and brain injury rehabilitation hospital and clinical research center in Atlanta, GA. Shepherd Center is one of seven potential sites in the United States that may enroll patients in the clinical trial.

“Initiating the GRNOPC1 clinical trial is a milestone for the field of human embryonic stem cell-based therapies,” said Thomas B. Okarma, Ph.D., M.D., Geron’s president and CEO. “When we started working with hESCs in 1999, many predicted that it would be a number of decades before a cell therapy would be approved for human clinical trials. This accomplishment results from extensive research and development and a succession of inventive steps to enable production of cGMP master cell banks, scalable manufacture of differentiated cell product, and preclinical studies *in vitro* and in animal models of spinal cord injury, leading to concurrence by the FDA to initiate the clinical trial.”

“We are pleased to have our patients participating in this exciting research,” said Donald Peck Leslie, M.D., medical director, Shepherd Center. “Our medical staff will evaluate the patients’ progress as part of this study. We look forward to participating in clinical trials that may help people with spinal cord injury.”

David Apple, M.D., Shepherd Center’s medical director emeritus and principal investigator of the trial at Shepherd Center, said, “This clinical trial represents another step forward in Shepherd Center’s involvement in an attempt to find a cure for paralysis in people with spinal cord injury. Shepherd Center is an ideal place to conduct this study because of our clinical expertise and the volume of patients referred here for rehabilitation care.”

In addition to Shepherd Center, Northwestern Medicine in Chicago, IL is also open for patient enrollment. As additional trial sites come online and are ready to enroll patients, they will be listed on the Patient Information pages of Geron’s website at www.geron.com/patients/clinicaltrials/hESC.aspx and on the NIH clinical trials registry, ClinicalTrials.gov, at clinicaltrials.gov/ct2/show/NCT01217008?term=GRNOPC1&rank=1.

Further information on the criteria for patient eligibility for the study is also available on ClinicalTrials.gov.

(more)

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About Spinal Cord Injury

Spinal Cord Injury (SCI) is caused by trauma to the spinal cord that results in a loss of such functions as locomotion, sensation or bowel/bladder control. A traumatic blow to the spine can fracture or dislocate vertebrae that may cause bone fragments or disc material to injure the nerve fibers and damage the glial cells that insulate the nerve fibers in the spinal cord. Most human SCIs are contusions (bruises) to the cord, rather than a severance of the nerve fibers. Every year approximately 12,000 people in the U.S. sustain spinal cord injuries. The most common causes are automobile accidents, falls, gunshot wounds and sports injuries.



About GRNOPC1

GRNOPC1 contains hESC-derived oligodendrocyte progenitor cells that have demonstrated remyelinating and nerve growth stimulating properties leading to restoration of function in animal models of acute spinal cord injury. Preclinical studies showed that administration of GRNOPC1 significantly improved locomotor activity and kinematic scores of animals with spinal cord injuries when injected seven days after the injury. Histological examination of the injured spinal cords treated with GRNOPC1 showed improved axon survival and extensive remyelination surrounding the rat axons. For more information about GRNOPC1, visit www.geron.com/GRNOPC1Trial/.

About Shepherd Center

Shepherd Center is a private, not-for-profit rehabilitation hospital specializing in medical treatment, research and rehabilitation for people with spinal cord injury and disease, brain injury, multiple sclerosis, chronic pain and other neuromuscular conditions. Each year Shepherd Center admits more than 940 inpatients and more than 530 day program patients. Its staff also treats about 6,000 people on an outpatient basis annually. For more information, visit Shepherd Center online at shepherd.org.

About Geron

Geron is developing first-in-class biopharmaceuticals for the treatment of cancer and chronic degenerative diseases, including spinal cord injury, heart failure and diabetes. The company is advancing an anti-cancer drug and a cancer vaccine that target the enzyme telomerase through multiple clinical trials. For more information, visit www.geron.com.

This news release may contain forward-looking statements made pursuant to the "safe harbor" provisions of the Private Securities Litigation Reform Act of 1995. Investors are cautioned that statements in this press release regarding potential applications of Geron's human embryonic stem cell technology constitute forward-looking statements that involve risks and uncertainties, including, without limitation, risks inherent in the development and commercialization of

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potential products, uncertainty of clinical trial results or regulatory approvals or clearances, need for future capital, dependence upon collaborators and protection of our intellectual property rights. Actual results may differ materially from the results anticipated in these forward-looking statements. Additional information on potential factors that could affect our results and other risks and uncertainties are detailed from time to time in Geron's periodic reports, including the quarterly report on Form 10-Q for the quarter ended June 30, 2010.



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Mark S. Nash, PhD., FACSM is a tenured Professor of Neurological Surgery and Rehabilitation Medicine at the Miller School of Medicine of the University of Miami. He is also Founding Principal Investigator and Director of Applied Physiology Research for the Miami Project to Cure Paralysis and Director of Research for the Department of Rehabilitation Medicine. Dr. Nash is a Fellow of the American College of Sports Medicine, and has expertise in application of exercise interventions for persons with SCI. He has also studied causes of, and treatments for their cardiovascular dysregulation and lipid-related disease risks. He has published over 90 manuscripts, scholarly monographs, and book chapters on these and related topics and has served as a consultant and grant reviewer on disability topics for the U.S. national Institutes of Health.

Learning Objectives

Cardiometabolic Disorders after Spinal Cord Injury: Causes, Consequences, and Effective Interventions

1. Participants will be able to understand causes and consequences of cardiometabolic disorders after SCI.
2. Participants will understand the interventions that reduce health hazards from cardiac and endocrine-related disease after SCI.

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REHABILITATION AND PRACTICE

Cardiovascular disease, SCI and exercise: unique risks
and focused countermeasuresRACHEL COWAN¹ & MARK S. NASH²¹University of Miami, The Miami Project to Cure Paralysis, Lois Pope Life Center (R-48), Miami 33128, FL, USA and ²Department of Neurosurgery, University of Miami, Miami, FL, USA

Accepted May 2010

Abstract

Purpose. To summarise the spinal cord injury (SCI) specific profile of three cardiovascular disease risk factors (CVD): fasting dyslipidaemia, postprandial lipidaemia and vascular inflammation and to summarise exercise prescriptions that may attenuate each.

Method. NA.

Results. NA.

Conclusions. At least three CVD risk factors have unique profiles in the SCI population. Fasting dyslipidaemia is characterised in the SCI population by depressed HDL cholesterol and normal or low total cholesterol. In the post-prandial state, persons with SCI exhibit an exaggerated triglyceride rise and delayed clearance compared to non-disabled persons. Finally, vascular inflammation, as indexed by C-reactive protein, is markedly elevated in SCI. Exercise may improve each, although the specific prescriptions differs. Fasting dyslipidaemia responds to 8 weeks of moderate intensity aerobic exercise performed 5 days weekly for 30 min daily. Post-prandial lipaemia treatment requires daily moderate or vigorous aerobic exercise, as the effect dissipates day by day. The daily exercise duration is proportional to fitness level, with total caloric expenditure emphasised rather than time. Finally, attenuating vascular inflammation in non-disabled persons requires moderate or vigorous exercise performed for ≥ 12 months, 5 days weekly for ≥ 45 min; with aerobic exercise plus resistance training more effective than aerobic exercise alone.

Keywords: Cardiovascular disease, lipids, inflammation, diet, exercise, risks

Introduction

Extensive research attention has focussed on risks for all-cause cardiovascular diseases (CVD) and endocrine disorders after spinal cord injury (SCI). [1–3] The coalescing of these diseases into a so-called *cardiometabolic syndrome* (CMS) encompasses component disorders of central obesity, hypertriglyceridaemia, low levels of high-density lipoprotein cholesterol (HDL-C), hypertension and fasting dysglycaemia [4]. Unless effectively treated, these disorders instigate atherosclerotic plaque formation and premature CVD. These risks are considered so predictive of future disease that a clinical finding of three or more CMS components, or a diagnosis of diabetes by itself, confers the same CVD hazard as existing coronary artery disease [4].

Various component risks of the CMS are consistently reported after SCI. These include central obesity, diabetes and fasting dyslipidaemia [1–3]. Although other known CVD risks as physical deconditioning [5] and inflammatory vascular stress [5] are also observed in concert with, or independent of these components. The risks have a disconcerting tendency to cluster [6], which escalates the global CVD vulnerability experienced by persons with SCI. Unfortunately, evidence suggests an accelerated course for the diseases in which they occur earlier in life yet still advance without overt clinical symptoms. Such symptoms may also be dissimilar from those experienced by persons without SCI, and thus impose critical delays in treatment needed to prevent impending organ system damage. Otherwise, health professionals may simply be

115 unfamiliar with evidenced-based methods used to
 120 diagnose the disorders, or fail to intervene when
 indications confirm the need. The latter is a
 disconcerting reality, but remains widely reported
 in people with primary heart disease who either
 125 escape effective intervention or fail to reach targets
 for body weight, lipid levels, blood pressure and
 fitness levels conferring lower risk for secondary
 insult [6].

130 In most cases, therapeutic lifestyle intervention
 represents the first-line treatment for CMS [4].
 Countermeasures for isolated and clustered risks
 are typically undertaken by a combination strategy
 focusing on decreased caloric intake (i.e. diet) and
 135 increased daily caloric expenditure (i.e. exercise).
 Although these approaches are fairly straightforward
 for persons without disability, their effectiveness
 after SCI may be compromised by a number of
 factors. These factors may include the need for
 imprudent caloric restriction to lose body fat, and
 140 diminished exercise-induced caloric expenditures in
 those having a lessened active muscle mass and/or
 adrenergic dysfunction accompanying injury above
 the level of sympathetic nervous system outflow.
 Despite these special challenges, persons with SCI
 have effective exercise options. This monograph will
 address three component risks with SCI unique
 profiles and how each is may be best managed
 through targeted exercise prescriptions. Emphasis is
 145 placed on exercise as a favoured, yet not necessarily
 exclusive countermeasure to CVD, a conviction
 supported by literature, guidelines and logic. To
 address the targeted attributes of exercise, we will
 first define CVD risks factors with a SCI unique
 profile, and thereafter address how exercise can be
 150 beneficial.

Overview of cardiovascular risks factors

155 A comprehensive review of each CVD risk factor,
 each CMS symptom and the SCI specific profile for
 each is beyond the scope of this manuscript. Instead,
 we focus on three individual components spanning
 the evidence spectrum from well established through
 160 recently identified. We are specifically summarising
 evidence on fasting dyslipidaemia in the form of
 depressed HDL levels; elevated postprandial lipae-
 mia characterised by elevated triglycerides; vascular
 inflammation, represented by heightened C-reactive
 protein. Furthermore, we briefly review best evi-
 165 dence identifying the most effective exercise pre-
 scriptions to attenuate each of these factors. When
 possible, we draw on SCI-focussed research. When
 such research is absent, we draw upon studies
 170 utilising non-disabled populations who exhibit simi-
 lar risk factor profiles.

Terminology

To ensure clarity and enhance understanding, we are
 first defining terms that may be new to a subset of
 175 this readership. Dyslipidaemia is an authoritatively
 defined abnormal concentration of blood lipids that
 confers elevated risk for developing CVD [4]. Lipid
 level assessments to identify dyslipidaemia require an
 180 8 h fast prior to blood draw, making ‘fasting
 dyslipidaemia’ and ‘dyslipidaemia’ one in the same.
 However, lipids are also measured after an individual
 ingests food, i.e. in the non-fasting or ‘post-prandial’
 state. Post-prandial lipaemia is the natural blood
 185 lipid response to food ingestion lasting up to 8 h after
 intake. Unlike fasting dyslipidaemias, those occur-
 ring within the post-prandial period are not defined
 by authoritative standards, but rather post-prandial
 lipaemias are evaluated by comparing two popula-
 190 tions or multiple testing conditions and declaring
 one elevated. These testing conditions are typically
 represented by intercedence of factors such as
 exercise or drugs that blunt the rise of food intake
 on post-prandial lipids or inflammatory mediators.

Fasting dyslipidaemia as a CVD risk after SCI

The most widely-reported cause for accelerated
 CVD after SCI is dyslipidaemia, whose most
 200 consistent feature is a lowered blood concentration
 of the high-density lipoprotein cholesterol (HDL-C)
 [6–9]. While elevated concentrations of low-density
 lipoprotein cholesterol (LDL-C) has dominated
 coronary risk assessment for more than half a
 205 century, more recent evidence has observed a key
 role played by the HDL-C in cardioprotection.
 Authoritative guidelines and longitudinal population
 studies find HDL-C an independent, inverse cor-
 onary risk factor [10] with strong predictive power
 210 for future coronary risk. The strength of HDL-C in
 disease prevention has been reported in trial data
 from the Framingham Heart Study [11,12], and the
 Prospective Cardiovascular Münster (PROCAM)
 study [13]. Interventional trials including the Lipid
 215 Research Clinics Primary Prevention Trial [14] and
 the Helsinki Heart Study [15] reported that treat-
 ment resulting in HDL-C elevation subsequently
 lowered coronary events, a finding independent of
 LDL-C lowering. Outcomes of the recent Veterans
 Affairs HDL Intervention Trial (VA-HIT) [16]
 220 further supported the need to raise HDL-C levels
 independent of LDL-C lowering, as HDL-C eleva-
 tion accompanied by reduction of TG – but not
 LDL-C lowering – significantly decreased the
 225 incidence of CVD-related events and stroke. This
 observation is consistent with the conclusion of the
 AFCAPS/TexCAPS Primary Prevention Trial [17]

that HDL-C should be included in the risk assessments of subjects having even average cholesterol or LDL-C concentrations.

Post-prandial lipaemia as a CVD risk after SCI

Clinical- and trial-based evidence strongly support the relationship between *fasting* dyslipidaemias and all-cause CVD, although the fact remains that humans spend most of their lives in the *post-prandial*, not the unfed, state. This makes events involving uptake, transport and metabolism of nutrient-derived lipids important contributors to the atherogenic cascade.

Post-prandial CVD risks are set in motion by transport of ingested triglycerides (TGs) from the small intestines via blood-borne chylomicrons. These TGs undergo lipolysis and are further catalysed within tissues into atherogenic TG-rich remnant lipoproteins (TRLs). Elevated postprandial TG concentrations, which can reveal either a higher peak level achieved after food intake or a delay in their clearance, permit blood-borne accumulation of these atherogenic particles [16,18]. The time need for TG ingestion to end-metabolism of TRLs spans about 4 h, after which their concentrations decay. The same interval separates most daily meals, making the accumulation and metabolism of TRLs a routinely cyclical process.

An exaggerated post-prandial lipaemia (PPL) first described by Zilversmit [19] is an important stimulus for atherogenic disease progression, as delayed removal of blood-borne TRLs encourages their direct deposition on the arterial wall and increases the likelihood that LDL will undergo disease-accelerating oxidative modification. Post-prandial TGs are also thought to play an important role in the pathogenesis of CVD, as the TRLs they generate typically penetrate the endothelial cell layer and populate the sub-endothelial space. Once so localised, they accelerate formation of foam cells that represent a nascent feature of atherosclerosis.

To date, two studies have reported persistent elevation of postprandial TGs in the blood of persons with SCI when compared to non-disabled persons who ingested an identical oral fat load. The first of these studies reported an exaggerated PPL in a case series population of persons with chronic paraplegia having unremarkable levels of fasting TG, making the risk undetectable by routine testing of fasting blood samples [20]. The observation also occurred in persons with paraplegia who were relatively young, predominantly non-users of tobacco and recreationally active. With respect to their SCI, they had injuries at spinal levels fully sparing both sympathetic adrenergic function and movement in the arms and upper

trunk. By contrast, nearly half of individuals living with SCI will have higher levels of injury and adrenergic dysfunction than did participants in this study. The second study was performed using older military veterans with SCI, although the high fat intake stimulus and results of testing were the same [18].

Although the mechanisms underlying an exaggerated PPL after SCI are incompletely understood, they are consistent with various effects of physical deconditioning and accepted alterations of muscle physiology accompanying injury. Physical deconditioning commonly reported after SCI is known to lower skeletal muscle lipoprotein lipase activity, whose biological down-regulation slows post-prandial TG extraction from blood. Persons with SCI also lose sub-lesional muscle mass that might otherwise more substantially metabolise post-prandial TG as a fuel source. Sub-lesional muscle after SCI also transforms to faster myosin heavy chain isoforms that metabolise carbohydrates, not TG, as a preferred energy source for muscle. All of these post-injury morphological and biological changes disfavour efficient post-prandial TG uptake and metabolism.

Inflammation as a CVD risk after SCI

Although diagnosis and treatment of CVD risks are typically rooted in assessments of fasting atherogenic lipids, recent attention has also focussed on blood levels of pro-inflammatory cytokines as triggers for CVD. Atherosclerosis is a chronic disease that recruits inflammatory cells to instigate inflammatory responses from endothelial cells [21]. Interrelationships among atherosclerosis, inflammation, obesity and coronary risk are sufficiently well-established to permit modeling (Figure 1) [22]. Trial data have demonstrated a strong association between the prototypic inflammatory marker C-reactive protein (CRP) and future mortality from heart disease. Indeed, recent evidence finds that inclusion of CRP levels in forecasting models of CVD adds prognostic rigor to cholesterol and lipoprotein cholesterol assessments. The same is true for diagnosis of the cardiometabolic syndrome, where inclusion of CRP in prediction models enhances accuracy of disease forecasting [23,24]. In addition, many people with normal blood lipids still sustain cardiovascular events, suggesting the existence of non-lipid disease pathway. The actions of pro-atherogenic inflammatory cytokines satisfy such a pathway [25,26]. Last, use of anti-inflammatory drugs often reduces cardiovascular events, even without lowering lipid levels, suggesting that inflammation plays an important role as a disease endpoint [24,27,28]. This finding is well illustrated by outcomes of the recent JUPITER Trial, where persons with normal lipid levels yet elevated

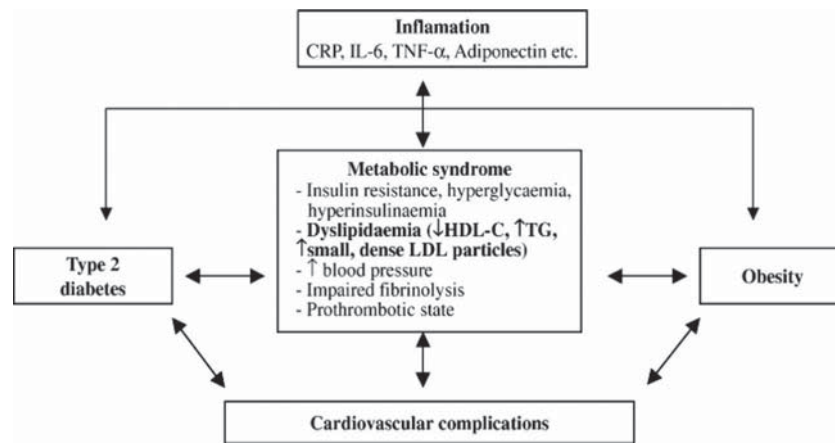


Figure 1. Inter-related risks of body somatotype, diabetes, lipids, coagulation disorders and pro-inflammatory.

inflammatory cytokines experienced reduction of cardiac events by statin-induced lowering of CRP [28,29].

CRP was the first acute phase protein associated with CVD, and remains the most investigated marker of human inflammation [30]. Numerous reports (reviewed in [30]) have established that baseline CRP values predict future risk for CVD in apparently healthy subjects independent of established risk factors, including LDL, HDL and the Framingham Risk Score [31–33]. In the Women’s Health Study, CRP strengthened the power of LDL in forecasting future CVD [32]. CRP levels are also increased in conditions associated with elevated risk for CVD, including obesity [34–36], insulin resistance [35,36], CMS [34,37,38], type 2 diabetes [34,35,39], hypertension [40,41], hypertriglyceridemia [42–44] and decreased HDL cholesterol [35], most of which are disturbingly prevalent in persons with SCI [42,43]. Recent studies also observed CRP within human atherosclerotic lesions, providing evidence that CRP may directly influence disease processes (reviewed in [45,46]). Mechanisms supporting this posit include the ability of CRP to inducing expression of endothelial cell adhesion molecules [47–49], induce expression of tissue factor on macrophages [49], increase the release of the pro-inflammatory cytokines TNF- α , IL-6 and IL-1 from macrophages [50], facilitate recruitment of monocytes into the arterial wall [51] and enhance uptake of LDL by macrophages [52].

Inflammatory cytokines in persons with SCI

Blood-borne concentrations of inflammatory cytokines, including CRP, are commonly increased after SCI [53], with elevation typically attributed to clinical infection, background bacteriuria and skin breakdown [54]. Elevated levels can also result from

activity-induced musculoskeletal injury [55] and heterotypic ossification [56,57], which are common sequelae of SCI. These CRP elevations have implications for CVD risk irrespective of their origin(s).

Various investigators have reported elevated serological inflammatory products in persons with SCI. In several studies these levels exceeded the described ‘cut-scores’ for elevated CVD risk, even when studying persons without overt evidence of illness or inflammatory disease [53,58–60]. In most cases testing revealed elevated CRP levels, although in one study elevated Interleukin(IL)-6, soluble vascular adhesion molecule (sVCAM)-1 and endothelin-1 were also observed [60]. In a small study ($n=10$), elevated CRP, but not IL-6, was associated with small pressure ulcers and use of indwelling catheters. Other studies have observed significant relationships between CVD risks and pro-inflammatory cytokines. In one investigation [60], 129 men with SCI who were judged free of infection and abstained from use of anti-inflammatory medicines were more likely to have CRP ≥ 3 mg/dl (risk ratio [RR] = 2.29) and HDL < 40 mg/dl (RR = 1.81) than age and gender-matched controls, although the significant difference for low HDL was abolished when controlling for elevated CRP. In a second study [61], a cross-sectional analysis of 93 persons with SCI reported a 22.6% prevalence for metabolic syndrome and a significant association between higher CRP level and insulin resistance, severe dyslipidaemia and elevated Framingham risk scores. Insulin resistance observed in the study participants was moderately correlated ($r=0.33$) with hs-CRP concentrations [62]. In a third study involving persons with SCI [58], abdominal sagittal diameter was significantly related to CRP levels, as well as higher fasting glucose, elevated fasting and post-load insulin, lower HDL and elevated TG [58]. CRP was similarly associated with body mass index (BMI) in a cross-sectional study of 64 men with SCI and primarily elevated in study

participants using a motorised wheelchair. Surprisingly, univariate predictors of CRP excluded age, injury duration and completeness, tobacco use, urinary tract infection, or the common cold in the preceding week, while finding significant predictive power for locomotive mode, BMI, heart disease, hypertension, and pressure ulcer within the past year [63]. While still in early stages of investigation, these studies provide persuasive evidence that the well-accepted relationship between inflammatory disease and CVD in persons without disability extends to those with SCI.

We (Nash et al.) have recently assessed CVD risk of elevated hs-CRP in persons with SCI [64]. Participants were 76 apparently healthy individuals (56 males, 20 females) aged 39.1 ± 11.5 years with chronic paraplegia and tetraplegia (ASIA A/B). The study population average for CRP was 7.51 ± 11.9 mg/dl, 50% higher than the reference range for non-specific inflammation. Even when excluding persons with non-cardiac causes for CRP elevation (i.e. CRP > 10 mg/dl) and when applying recommended risk stratification recommendations [65], 45.8% of the SCI population had greater than double the acceptable risk for future heart disease. When adopting other risk assessment authorities [66,67] 78%, 56% and 46% of the population, respectively, had double, triple and quadruple normal CHD risk.

Exercise as a CVD risk countermeasure

Pharmacotherapy effectively improves fasting dyslipidaemia, post-prandial lipaemia and vascular inflammation, but it is not the only available treatment paradigm. For persons with SCI, many accompanying conditions are already pharmacologically managed; pain, elevated muscle tone, spasticity, bladder spasms and recurrent urinary tract infections to name a few, thus non-pharmacologic treatment approaches are an attractive alternative. Exercise holds promise as an effective alternative and should be viewed as a first course of action. However, optimal modification of fasting dyslipidaemia, elevated post-prandial lipaemia and inflammation will occur via comprehensive lifestyle interventions addressing smoking cessation, dietary modifications and increasing physical activity/exercise.

Exercise to attenuate fasting dyslipidaemia

Physical activity and/or structured exercise are promising approaches to favourably modify fasting dyslipidaemia in persons with SCI. Although the specific dose-response relationship is undefined, 20 min of moderate intensity exercise performed

three times weekly for 8 weeks improves fasting lipid profiles in persons with SCI [68]. We suggest the observed changes extrapolate to a 20% reduction in CVD risk. During the two decades since this study, additional research has improved fasting lipids via exercise based interventions in persons with SCI [69–71]. Each intervention involved a minimum of moderate intensity exercise conducted three times weekly, for at least 30 continuous minutes. Each also utilised a different activity mode, suggesting any activity of moderate intensity sustained for 30+ min could be an effective intervention. The effectiveness of exercise as a therapy to improve fasting lipid profiles is further supported by cross-sectional data suggesting persons with paraplegia and tetraplegia who are habitually highly active, or fit relative to their peers, have less atherogenic lipid profiles [58,72–74]. Interestingly, most of the aforementioned interventions fall short of the 2007 American College of Sports Medicine/American Heart Association (ACMS/AHA) guidelines that recommend a minimum of 30 min of moderate-intensity aerobic (endurance) physical activity on 5 days each week, or 20 min of vigorous-intensity physical activity performed on 3 days per week [75]. Thus, it appears reasonable to suggest that attainment of the ACSM/AHA physical activity targets would favourably alter fasting lipid profiles in persons with SCI. Given the ACSM/AHA acknowledged dose-response relationship between fitness and health [75], attaining or exceeding these targets may induce even greater improvements in fasting lipid profiles than previously observed. Additional research precisely defining the minimal dose required to favourably modify fasting lipids is warranted.

Exercise to attenuate post-prandial lipaemia

Although data from the non-disabled population supports acute exercise as an effective therapy to attenuate postprandial lipaemia, no studies have examined this effect in persons with SCI. In a 2006 review, Katsanos suggests exercise occurring up-to 16 h before and 90 min after a meal favourably modifies the post-prandial lipidaemic response [76]. Katsanos reports moderate or vigorous intensity exercise is required to modify PPL, with low-intensity exercise generally ineffective [76]. However, a 2008 study conducted in sedentary non-disabled men with CMS reported that continuous low- and moderate-intensity exercise sessions achieving the same caloric expenditure both effectively altered PPL [77]. The specific exercise duration required to attenuate PPL is tied to total caloric expenditure, with as little as 350 kilocalories demonstrated to have an effect. Although even that amount

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is a challenging threshold for many persons for SCI to reach, the amount required for an effect appears proportional to an individual's fitness level. Thus, even the most deconditioned persons with SCI may be able to reach a minimum energy expenditure threshold by which their PPL response is modified.

It is currently unknown how long beyond 16 h post-exercise the PPL is attenuated, but the effect is thought to dissipate by 24 h. Although benefits of chronic exercise on the PPL are less well understood than acute exercise, it is likely that daily bouts of exercise will be needed to lessen the risk of PPL. Thus, a comprehensive plan for hazard reduction would include 30 min of moderate-intensity exercise on a daily basis. This amount exceeds ACSM/AHA minimum guidelines, is consistent with exercise needed to improved HDL-C levels in approximately 8 weeks and would potentially attenuate the PPL response.

Exercise to attenuate vascular inflammation

Exercise interventions traditionally target vascular inflammation by supporting weight loss, as a reduction in adipose tissue reduces inflammation [78]. However, recent evidence also suggests long term exercise participation attenuates inflammation independent of weight loss [79]. The potential for exercise to reduce all-cause inflammation after SCI without weight or fat loss has important implications. First, achieving weight loss via exercise alone is difficult for all persons, regardless of ability or disability. Body fat reduction requires an exercise energy expenditure of >2000 kcal per week [80]. In non-disabled adults, this is equivalent to 200–300 min of weekly exercise, or 40–60 min undertaken 5 days a week. However, more exercise time is required for most persons with SCI to exceed >2000 kcal weekly. In highly trained men with paraplegia, 46 min of daily handcycling (322 min weekly) would be needed to expend 2100 kcal in 1 week [81]. For the typical person with paraplegia, and more so for those with tetraplegia, expending >2000 kcal per week in moderate intensity exercise could easily require a minimum of 60 min of activity every day of the week. Thus, weight loss via exercise interventions absent dietary modifications may be difficult, if not impractical for most persons with SCI. Second, an exercise effect on inflammation independent of weight or fat loss could help both lean persons with SCI having non-cardiac elevation of CRP [53–57], but an otherwise idealised CVD risk profile and persons who are not accurately identified as possessing excessive adipose tissue. Although weight loss is indicated in the non-disabled adult population when body mass index (BMI) exceeds 25 kg/m² [80], the point at which disease risk markedly increases, this

cut point fails to correctly classify a substantial portion of persons with SCI as having supra optimal fat levels. In fact, a BMI > 22 kg/m² was recently demonstrated to be a more accurate cut-point identifying a person with SCI as overweight [82]. These data signify that chronic exercise induced weight loss independent of inflammation attenuation is especially relevant for persons with SCI.

The potential of exercise to directly attenuate low grade inflammation is rooted in cross-sectional studies demonstrating inverse correlations between self-reported activity [83–85], cardiovascular fitness [86–89] and CRP. Recent intervention studies confirm longitudinal exercise conditioning decreases blood borne CRP concentrations independent of weight loss [90,91]. Establishing the direct exercise effect on inflammation attenuation is an important advancement, as previous mechanisms explaining CRP lowering depended on reducing adipose tissue secretion of this pro-inflammatory cytokine.

Two recent intervention studies in non-disabled cohorts support weight loss independent exercise based inflammation attenuation. Campbell et al. [90] reduced CRP levels by 10% in an obese, sedentary, post-menopausal cohort without inducing weight loss via a 12-month moderate-intensity programme performed 5 days weekly for ≥45 min daily. Interestingly, the greatest reductions in CRP were observed in the most obese of women. Campbell et al. [90] suggested exercise-based CRP reduction would be most effective for individuals with the highest baseline CRP levels. If true, persons with SCI may be an ideal population in which to test this concept, as CRP levels are commonly elevated [53]. Most recently, Balducci et al. [91] demonstrated that a 12-month exercise programme decreased CRP levels in older, obese, type 2 diabetic adults with CMS, a reduction observed to be independent of weight loss. In this randomised controlled trial, two exercise interventions were evaluated, each occurring twice a week for 60 min. One required vigorous intensity aerobic activity for 60 min, while the second required 40 min of vigorous aerobic activity plus 20 min of resistance training. While both reduced CRP, the aerobic + resistance training intervention reduced CRP levels by 54% versus 28% for aerobic activity only. Although lowering of CRP by exercise has yet to be reported in persons with SCI, current research suggests that effective programs will require extended compliance (12 months) will exceed the minimum targets set by ACSM/AHA and may require vigorous intensity exercise.

Practical application

Given evidence that the exercise dosing required improve each cardiovascular risk factor is unique, a

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valid concern is what dosing should be targeted? We suggest clinicians first consult their national authorities to identify recommendations and implementation guidelines developed specifically for their nation. Absent such recommendations, we suggest the minimum recommendations jointly endorsed by the American College of Sports Medicine and the American Heart Association as an ideal target to promote and maintain health; ≥ 30 min of moderate-intensity aerobic (endurance) physical activity on ≥ 5 days each week, or ≥ 20 min of vigorous-intensity physical activity performed on ≥ 3 days per week, plus resistance training ≥ 2 times a week [75]. Support for clinical implementation of these guidelines is available via the Exercise is Medicine™ initiative (<http://www.exerciseismedicine.org/>). Although not SCI specific, these recommendations are based on the best available evidence in the non-disabled population. There are no indications that the minimum dosing for persons with SCI are less than the minimum dosing for non-disabled individuals.

Summary recommendations

Persons with SCI experience elevated and accelerated component risks of CVD, including fasting dyslipidaemia, post-prandial lipaemia and vascular inflammation. Exercise offers benefits for treating all three risks, although by different mechanisms. In addition, effective exercise prescriptions may differ from those applied to non-disabled persons. Achieving the minimum ACSM/AHA physical activity/exercise targets for 8 weeks should improve fasting dyslipidaemia in persons with SCI. These targets include: 30 min of moderate exercise 5 days a week; 20 min of vigorous intensity exercise 3 days a week; or a combination of these approaches. However, daily, moderate-intensity exercise may be needed to attenuate elevated post-prandial lipaemia, even for highly fit individuals. Finally, attenuation of inflammatory stress may require long-term compliance using a vigorous exercise intervention, which might exceed minimum authoritative recommendations used to guide exercise programming in persons without disability.

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References

1. Nash MS. Cardiovascular disease after spinal cord injuries. *Top Spinal Cord Inj Rehabil* 2009;14:1–109.
2. Bauman WA, Spungen AM. Coronary heart disease in individuals with spinal cord injury: assessment of risk factors. *Spinal Cord* 2008;46:466–476.

3. Myers J, Lee M, Kiratli J. Cardiovascular disease in spinal cord injury: an overview of prevalence, risk, evaluation, and management. *Am J Phys Med Rehabil* 2007;86:142–152.
4. Third Report of the National Cholesterol Education Program (NCEP). Expert panel on detection, evaluation, and treatment of high blood cholesterol in adults (Adult Treatment Panel III) final report. *Circulation* 2002;106:3143–3421.
5. Cowan RE, Malone LA, Nash MS. EXERCISE is Medicine®: exercise prescription after SCI to manage CVD risk factors. *Top SCI Rehabil* 2009;14:69–83.
6. Nash MS, Mendez AJ. A guideline-driven assessment of need for cardiovascular disease risk intervention in persons with chronic paraplegia. *Arch Phys Med Rehabil* 2007;88:751–757.
7. Bauman WA, Spungen AM, Zhong YG, Rothstein JL, Petry C, Gordon SK. Depressed serum high density lipoprotein cholesterol levels in veterans with spinal cord injury. *Paraplegia* 1992;30:697–703.
8. Bauman WA, Spungen AM, Raza M, Rothstein J, Zhang RL, Zhong YG, Tsuruta M, Shahidi R, Pierson RN, Wang J, et al. Coronary artery disease: metabolic risk factors and latent disease in individuals with paraplegia. *Mt Sinai J Med* 1992;59:163–168.
9. Brenes G, Dearwater S, Shapera R, LaPorte RE, Collins E. High density lipoprotein cholesterol concentrations in physically active and sedentary spinal cord injured patients. *Arch Phys Med Rehabil* 1986;67:445–450.
10. Pietrobelli A, Lee RC, Capristo E, Deckelbaum RJ, Heymsfield SB. An independent, inverse association of high-density-lipoprotein-cholesterol concentration with nonadipose body mass. *Am J Clin Nutr* 1999;69:614–620.
11. Vrentzos GE, Papadakis JA, Ganotakis ES, Paraskevas KI, Gazi IF, Tzanakis N, Nair DR, Mikhailidis DP. Predicting coronary heart disease risk using the Framingham and PROCAM equations in dyslipidaemic patients without overt vascular disease. *Int J Clin Pract* 2007;61:1643–1653.
12. D'Agostino RB, Vasani RS, Pencina MJ, Wolf PA, Cobain M, Massaro JM, Kannel WB. General cardiovascular risk profile for use in primary care: the Framingham Heart Study. *Circulation* 2008;117:743–753.
13. Assmann G, Cullen P, Schulte H. Simple scoring scheme for calculating the risk of acute coronary events based on the 10-year follow-up of the prospective cardiovascular Munster (PROCAM) study. *Circulation* 2002;105:310–315.
14. The Lipid Research Clinics Coronary Primary Prevention Trial results. I. Reduction in incidence of coronary heart disease. *JAMA* 1984;251:351–364.
15. Frick MH, Elo O, Haapa K, Heinonen OP, Heinsalmi P, Helo P, Huttunen JK, Kaitaniemi P, Koskinen P, Manninen V. Helsinki Heart Study: primary-prevention trial with gemfibrozil in middle-aged men with dyslipidemia. Safety of treatment, changes in risk factors, and incidence of coronary heart disease. *N Engl J Med* 1987;317:1237–1245.
16. Rubins HB, Robins SJ. Conclusions from the VA-HIT study. *Am J Cardiol* 2000;86:543–544.
17. Brown AS. Primary prevention of coronary heart disease: implications of the Air Force/Texas coronary atherosclerosis prevention study (AFCAPS/TexCAPS). *Curr Cardiol Rep* 2000;2:439–444.
18. Emmons RR, Cirmigliaro CM, Moyer JM, Garber CE, Kirshblum SC, Spugen AM, Bauman WA. Exaggerated postprandial triglyceride response identified in individuals with spinal cord injury with cardiac risk factors. In American College of Sports Medicine Annual Meeting, 2009. pp 404–405.
19. Zilvervmit DB. Atherogenesis: a postprandial phenomenon. *Circulation* 1979;60:473–485.
20. Nash MS, DeGroot J, Martinez-Arizala A, Mendez AJ. Evidence for an exaggerated postprandial lipemia in chronic paraplegia. *J Spinal Cord Med* 2005;28:320–325.

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21. Ross R. Atherosclerosis – an inflammatory disease. *N Engl J Med* 1999;340:115–126.
22. Libby P, Ridker PM, Maseri A. Inflammation and atherosclerosis. *Circulation* 2002;105:1135–43.
23. Ridker PM. High-sensitivity C-reactive protein and cardiovascular risk: rationale for screening and primary prevention. *Am J Cardiol* 2003;92:17K–22K.
24. Jialal I, Devaraj S, Venugopal SK. C-reactive protein: risk marker or mediator in atherothrombosis? *Hypertension* 2004;44:6–11.
25. Granger JP. Inflammatory cytokines, vascular function, and hypertension. *Am J Physiol Regul Integr Comp Physiol* 2004;286:989–990.
26. Ito T, Ikeda U. Inflammatory cytokines and cardiovascular disease. *Curr Drug Targets Inflamm Allergy* 2003;2:257–265.
27. Sun H, Koike T, Ichikawa T, Hatakeyama K, Shiomi M, Zhang B, Kitajima S, Morimoto M, Watanabe T, Asada Y, Chen YE, Fan J. C-reactive protein in atherosclerotic lesions: its origin and pathophysiological significance. *Am J Pathol* 2005;167:1139–1148.
28. Rao M, Jaber BL, Balakrishnan VS. Inflammatory biomarkers and cardiovascular risk: association or cause and effect? *Semin Dial* 2006;19:129–135.
29. Ridker PM, Danielson E, Fonseca FA, Genest J, Gotto AM, Kastelein JJ, Koenig W, Libby P, Lorenzatti AJ, Macfadyen JG, Nordestgaard BG, Shepherd J, Willerson JT, Glynn RJ. Rosuvastatin to prevent vascular events in men and women with elevated C-reactive protein. *N Engl J Med* 2008.
30. Pepys MB, Baltz ML. Acute phase proteins with special reference to C-reactive protein and related proteins (pentaxins) and serum amyloid A protein. *Adv Immunol* 1983;34:141–212.
31. Albert MA, Glynn RJ, Ridker PM. Plasma concentration of C-reactive protein and the calculated Framingham Coronary Heart Disease Risk Score. *Circulation* 2003;108:161–165.
32. Ridker PM, Rifai N, Rose L, Buring JE, Cook NR. Comparison of C-reactive protein and low-density lipoprotein cholesterol levels in the prediction of first cardiovascular events. *N Engl J Med* 2002;347:1557–1565.
33. Koenig W, Lowel H, Baumert J, Meisinger C. C-reactive protein modulates risk prediction based on the Framingham Score: implications for future risk assessment: results from a large cohort study in southern Germany. *Circulation* 2004;109:1349–1353.
34. Guerrero-Romero F, Rodriguez-Moran M. Relation of C-reactive protein to features of the metabolic syndrome in normal glucose tolerant, impaired glucose tolerant, and newly diagnosed type 2 diabetic subjects. *Diabetes Metab* 2003;29:65–71.
35. Leinonen E, Hurt-Camejo E, Wiklund O, Hulten LM, Hiukka A, Taskinen MR. Insulin resistance and adiposity correlate with acute-phase reaction and soluble cell adhesion molecules in type 2 diabetes. *Atherosclerosis* 2003;166:387–394.
36. McLaughlin T, Abbasi F, Lamendola C, Liang L, Reaven G, Schaaf P, Reaven P. Differentiation between obesity and insulin resistance in the association with C-reactive protein. *Circulation* 2002;106:2908–2912.
37. Festa A, D'Agostino R, Howard G, Mykkanen L, Tracy RP, Haffner SM. Chronic subclinical inflammation as part of the insulin resistance syndrome: the Insulin Resistance Atherosclerosis Study (IRAS). *Circulation* 2000;102:42–47.
38. Aronson D, Sella R, Sheikh-Ahmad M, Kerner A, Avizohar O, Rispler S, Bartha P, Markiewicz W, Levy Y, Brook GJ. The association between cardiorespiratory fitness and C-reactive protein in subjects with the metabolic syndrome. *J Am Coll Cardiol* 2004;44:2003–2007.
39. Mojiminiyi OA, Abdella N, Moussa MA, Akanji AO, Al Mohammedi H, Zaki M. Association of C-reactive protein with coronary heart disease risk factors in patients with type 2 diabetes mellitus. *Diabetes Res Clin Pract* 2002;58:37–44.
40. Niskanen L, Laaksonen DE, Nyyssonen K, Punnonen K, Valkonen VP, Fuentes R, Tuomainen TP, Salonen R, Salonen JT. Inflammation, abdominal obesity, and smoking as predictors of hypertension. *Hypertension* 2004;44:859–865.
41. Bautista LE, Vera LM, Arenas IA, Gamarra G. Independent association between inflammatory markers (C-reactive protein, interleukin-6, and TNF-alpha) and essential hypertension. *J Hum Hypertens* 2005;19:149–154.
42. Tamakoshi K, Yatsuya H, Kondo T, Hori Y, Ishikawa M, Zhang H, Murata C, Otsuka R, Zhu S, Toyoshima H. The metabolic syndrome is associated with elevated circulating C-reactive protein in healthy reference range, a systemic low-grade inflammatory state. *Int J Obes Relat Metab Disord* 2003;27:443–449.
43. Fredrikson GN, Hedblad B, Nilsson JA, Alm R, Berglund G, Nilsson J. Association between diet, lifestyle, metabolic cardiovascular risk factors, and plasma C-reactive protein levels. *Metabolism* 2004;53:1436–1442.
44. Grau AJ, Buggle F, Becher H, Werle E, Hacke W. The association of leukocyte count, fibrinogen and C-reactive protein with vascular risk factors and ischemic vascular diseases. *Thromb Res* 1996;82:245–255.
45. Jialal I, Devaraj S, Venugopal SK. C-reactive protein: risk marker or mediator in atherothrombosis? *Hypertension* 2004;44:6–11.
46. Li JJ, Fang CH. Atheroscleritis is a more rational term for the pathological entity currently known as atherosclerosis. *Med Hypotheses* 2004;63:100–102.
47. Pasceri V, Willerson JT, Yeh ET. Direct proinflammatory effect of C-reactive protein on human endothelial cells. *Circulation* 2000;102:2165–2168.
48. Pasceri V, Cheng JS, Willerson JT, Yeh ET. Modulation of C-reactive protein-mediated monocyte chemoattractant protein-1 induction in human endothelial cells by anti-atherosclerosis drugs. *Circulation* 2001;103:2531–2534.
49. Verma S. Endothelin antagonism and insulin's vascular effects. *Hypertension* 2002;40:12–13.
50. Ballou SP, Lozanski G. Induction of inflammatory cytokine release from cultured human monocytes by C-reactive protein. *Cytokine* 1992;4:361–368.
51. Woollard KJ, Phillips DC, Griffiths HR. Direct modulatory effect of C-reactive protein on primary human monocyte adhesion to human endothelial cells. *Clin Exp Immunol* 2002;130:256–262.
52. Chang MK, Binder CJ, Torzewski M, Witztum JL. C-reactive protein binds to both oxidized LDL and apoptotic cells through recognition of a common ligand: Phosphorylcholine of oxidized phospholipids. *Proc Natl Acad Sci USA* 2002;99:13043–13048.
53. Frost F, Roach MJ, Kushner I, Schreiber P. Inflammatory C-reactive protein and cytokine levels in asymptomatic people with chronic spinal cord injury. *Arch Phys Med Rehabil* 2005;86:312–317.
54. Lang CH, Frost RA. Role of growth hormone, insulin-like growth factor-I, and insulin-like growth factor binding proteins in the catabolic response to injury and infection. *Curr Opin Clin Nutr Metab Care* 2002;5:271–279.
55. Miliás GA, Nomikos T, Fragopoulou E, Athanasopoulos S, Antonopoulou S. Effects of eccentric exercise-induced muscle injury on blood levels of platelet activating factor (PAF) and other inflammatory markers. *Eur J Appl Physiol* 2005;95:504–513.
56. Banovac K, Sherman AL, Estores IM, Banovac F. Prevention and treatment of heterotopic ossification after spinal cord injury. *J Spinal Cord Med* 2004;27:376–382.

57. Estrores IM, Harrington A, Banovac K. C-reactive protein and erythrocyte sedimentation rate in patients with heterotopic ossification after spinal cord injury. *J Spinal Cord Med* 2004;27:434–437. 915
58. Manns PJ, McCubbin JA, Williams DP. Fitness, inflammation, and the metabolic syndrome in men with paraplegia. *Arch Phys Med Rehabil* 2005;86:1176–1181.
59. Wang TD, Wang YH, Huang TS, Su TC, Pan SL, Chen SY. Circulating levels of markers of inflammation and endothelial activation are increased in men with chronic spinal cord injury. *J Formos Med Assoc* 2007;106:919–928. 920
60. Liang H, Mojtahedi MC, Chen D, Braunschweig CL. Elevated C-reactive protein associated with decreased high-density lipoprotein cholesterol in men with spinal cord injury. *Arch Phys Med Rehabil* 2008;89:36–41. 925
61. Lee MY, Myers J, Hayes A, Madan S, Froelicher VF, Perkasch I, Kiratli BJ. C-reactive protein, metabolic syndrome, and insulin resistance in individuals with spinal cord injury. *J Spinal Cord Med* 2005;28:20–25.
62. Matthews DR, Hosker JP, Rudenski AS, Naylor BA, Treacher DF, Turner RC. Homeostasis model assessment: insulin resistance and beta-cell function from fasting plasma glucose and insulin concentrations in man. *Diabetologia* 1985;28:412–419. 930
63. Morse LR, Stolzmann K, Nguyen HP, Jain NB, Zayac C, Gagnon DR, Tun CG, Garshick E. Association between mobility mode and C-reactive protein levels in men with chronic spinal cord injury. *Arch Phys Med Rehabil* 2008;89:726–731. 935
64. Nash MS, SL Gintel, AJ Mendez, LF Hamm, JE Lewis, SL Groah. Elevated CRP and vascular disease after SCI: inflammatory epiphenomenon or pathologic agent? *J Spinal Cord Med* 2006;29:252.
65. Biasucci LM. CDC/AHA Workshop on Markers of Inflammation and Cardiovascular Disease: Application to Clinical and Public Health Practice: clinical use of inflammatory markers in patients with cardiovascular diseases: a background paper. *Circulation* 2004;110:560–567. 940
66. Ridker PM, Cushman M, Stampfer MJ, Tracy RP, Hennekens CH. Inflammation, aspirin, and the risk of cardiovascular disease in apparently healthy men. *N Engl J Med* 1997;336:973–979. 945
67. Feng D, Tracy RP, Lipinska I, Murillo J, McKenna C, Tofler GH. Effect of short-term aspirin use on C-reactive protein. *J Thromb Thrombolysis* 2000;9:37–41.
68. Hooker SP, Wells CL. Effects of low- and moderate-intensity training in spinal cord-injured persons. *Med Sci Sports Exerc* 1989;21:18–22. 950
69. de Groot PC, Hjeltnes N, Heijboer AC, Stal W, Birkeland K. Effect of training intensity on physical capacity, lipid profile and insulin sensitivity in early rehabilitation of spinal cord injured individuals. *Spinal Cord* 2003;41:673–679. 955
70. El-Sayed MS, Younesian A. Lipid profiles are influenced by arm cranking exercise and training in individuals with spinal cord injury. *Spinal Cord* 2005;43:299–305.
71. Nash MS, Jacobs PL, Mendez AJ, Goldberg RB. Circuit resistance training improves the atherogenic lipid profiles of persons with chronic paraplegia. *J Spinal Cord Med* 2001;24:2–9. 960
72. Dallmeijer AJ, Hopman MT, van der Woude LH. Lipid, lipoprotein, and apolipoprotein profiles in active and sedentary men with tetraplegia. *Arch Phys Med Rehabil* 1997;78:1173–1176.
73. Dallmeijer AJ, van der Woude LH, Hollander AP, van As HH. Physical performance during rehabilitation in persons with spinal cord injuries. *Med Sci Sports Exerc* 1999;31:1330–1335. 965
74. Janssen TW, van Oers CA, van Kamp GJ, TenVoerde BJ, van der Woude LH, Hollander AP. Coronary heart disease risk indicators, aerobic power, and physical activity in men with spinal cord injuries. *Arch Phys Med Rehabil* 1997;78:697–705.
75. Haskell WL, Lee IM, Pate RR, Powell KE, Blair SN, Franklin BA, Macera CA, Heath GW, Thompson PD, Bauman A. Physical Activity and Public Health: updated Recommendation for Adults from the American College of Sports Medicine and the American Heart Association. *Med Sci Sports Exerc* 2007;39:1423–1434. 970
76. Katsanos CS. Prescribing aerobic exercise for the regulation of postprandial lipid metabolism : current research and recommendations. *Sports Med* 2006;36:547–560. 975
77. Mestek ML, Plaisance EP, Ratcliff LA, Taylor JK, Wee SO, Grandjean PW. Aerobic exercise and postprandial lipemia in men with the metabolic syndrome. *Med Sci Sports Exerc* 2008;40:2105–2111. 980
78. Selvin E, Paynter NP, Erlinger TP. The effect of weight loss on C-reactive protein: a systematic review. *Arch Intern Med* 2007;167:31–39.
79. Plaisance EP, Grandjean PW. Physical activity and high-sensitivity C-reactive protein. *Sports Med* 2006;36:443–458.
80. Donnelly JE, Blair SN, Jakicic JM, Manore MM, Rankin JW, Smith BK. American College of Sports Medicine Position Stand. Appropriate physical activity intervention strategies for weight loss and prevention of weight regain for adults. *Med Sci Sports Exerc* 2009;41:459–471. 985
81. Abel T, Kroner M, Rojas VS, Peters C, Klose C, Platen P. Energy expenditure in wheelchair racing and handbiking – a basis for prevention of cardiovascular diseases in those with disabilities. *Eur J Cardiovasc Prev Rehabil* 2003;10:371–376. 990
82. Laughton GE, Buchholz AC, Martin Ginis KA, Goy RE. Lowering body mass index cutoffs better identifies obese persons with spinal cord injury. *Spinal Cord* 2009;47:757–762.
83. Dufaux B, Order U, Geyer H, Hollmann W. C-reactive protein serum concentrations in well-trained athletes. *Int J Sports Med* 1984;5:102–106. 995
84. Ford ES. Does exercise reduce inflammation? Physical activity and C-reactive protein among U.S. adults. *Epidemiology* 2002;13:561–568.
85. Pitsavos C, Chrysohoou C, Panagiotakos DB, Skoumas J, Zeimbekis A, Kokkinos P, Stefanadis C, Toutouzas PK. Association of leisure-time physical activity on inflammation markers (C-reactive protein, white cell blood count, serum amyloid A, and fibrinogen) in healthy subjects (from the ATTICA study). *Am J Cardiol* 2003;91:368–370. 1000
86. Aronson D, Sheikh-Ahmad M, Avizohar O, Kerner A, Sella R, Bartha P, Markiewicz W, Levy Y, Brook GJ. C-Reactive protein is inversely related to physical fitness in middle-aged subjects. *Atherosclerosis* 2004;176:173–179. 1005
87. Church TS, Barlow CE, Earnest CP, Kampert JB, Priest EL, Blair SN. Associations between cardiorespiratory fitness and C-reactive protein in men. *Arterioscler Thromb Vasc Biol* 2002;22:1869–1876. 1010
88. LaMonte MJ, Durstine JL, Yanowitz FG, Lim T, DuBose KD, Davis P, Ainsworth BE. Cardiorespiratory fitness and C-reactive protein among a tri-ethnic sample of women. *Circulation* 2002;106:403–406.
89. Isasi CR, Deckelbaum RJ, Tracy RP, Starc TJ, Berglund L, Shea S. Physical fitness and C-reactive protein level in children and young adults: the Columbia University BioMarkers Study. *Pediatrics* 2003;111:332–338. 1015
90. Campbell PT, Campbell KL, Wener MH, Wood BL, Potter JD, McTiernan A, Ulrich CM. A yearlong exercise intervention decreases CRP among obese postmenopausal women. *Med Sci Sports Exerc* 2009;41:1533–1539. 1020
91. Balducci S, Zanuso S, Nicolucci A, Fernando F, Cavallo S, Cardelli P, Falluca S, Alessi E, Letizia C, Jimenez A, Falluca F, Pugliese G. Anti-inflammatory effect of exercise training in subjects with type 2 diabetes and the metabolic syndrome is dependent on exercise modalities and independent of weight loss. *Nutr Metab Cardiovasc Dis* 2009. 1025

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Learning Objectives

Support Services for Individuals with Spinal Cord Injuries and their Informal Caregivers

1. Participants will be able to describe health and quality of life outcomes of informal caregivers.
2. Participants will be able to describe changes in outcomes for individuals with SCI and their caregivers who participate in support service programs.

Disclosure Policy

In order to ensure balance, independence, objectivity and scientific rigor at all programs, the planners and faculty must make full disclosure indicating whether the planner, faculty or content specialist and/or his/her spouse family has any relationships with pharmaceutical companies, biomedical device manufacturers and/or corporations whose products or services are related to pertinent therapeutic areas. All planners, faculty, content specialists and feedback specialists participating in educational activities must disclose to the audience information listed below.

Faculty Disclosure

Sherril LaVela, PhD, MPH, MBA. has no vested interests, and there are no conflicts of interest to disclose.

Faculty disclosure of off-label use

Sherril LaVela, Ph.D., MPH, MBA, **does not** plan on discussing unlabeled/investigational uses of a commercial product.

Support Services for Individuals with SCI and their Informal Caregivers

Select findings from support services program users:

- *Caregivers experienced **significantly reduced burden** after the respite program than at baseline.
- *There were no significant changes in *physical health* after receipt of respite services; however, the **emotional health scores significantly improved** from before to after support services were received.
- *Use of support services did not change reported *positive aspects of caregiving*.
- *Care-recipients had **fewer inpatient admissions** and **shorter average lengths of stay** after use of the support services program (comparisons were made 3 months before and 3 months after the date of initial respite use).
- *Although there were trends for fewer *emergency room visits*, no statistically significant differences were found.

Quotes from support letters received from program participants:

Caregivers

- *“This program was an answer to many prayers for rest, sleep, and to rejuvenate my body and mind.”*
- *“My husband's care was consistent and caring. He was able to have everything that is familiar to him right where it always would be.”*

Care-recipients

- *“I must say this is one of the better programs that I have had the pleasure of being involved in...”*
- *“We hope this is but the start of a ripple that will be of great help and relief to many veterans and their caregivers.”*

Please feel free to contact me with questions.

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INTRODUCTION

Between 40 and 45 percent of individuals with spinal cord injuries (SCI) need personal assistance with some daily activities. The majority have tetraplegia and often need assistance with getting in or out of bed, managing bowel and bladder issues, bathing, and dressing. The lower the level of injury, the less assistance is needed.

PCA VS CAREGIVER

Most often, a parent, spouse or other close family member is the first to provide personal care following injury. Although this initial care and attention is normal, it is not generally recommended for the long-term. If at all possible, it is best to have a paid Personal Care Attendant (PCA) provide the majority of long-term care while a loved one provides occasional care.

Unfortunately, many individuals with SCI have no option other than to rely on a family member for daily assistance. Whereas a PCA is an employee, a *caregiver* is the term used for an unpaid family member who is primarily responsible for the care of a loved one.

There is no "typical" family following SCI. Each situation is unique, and each caregiver and the person they care for will eventually create a system of care that works best for them.

ADJUSTMENT TO SCI

As a caregiver, you will likely face many unique challenges. First, there is often the initial worry and concern for the condition and recovery of your loved one. There is often stress over juggling work and finances while getting your home accessible for your loved one.

At the same time, you are learning about the many issues of SCI and how to be a caregiver. You may need to learn about bowel, bladder, and respiratory care. You need to learn how to do daily skin checks

and recognize signs of a pressure sore. Likewise, you may need to learn the symptoms of Autonomic Dysreflexia or ventilator care and what to do in case of an emergency. There are a number of educational materials available from reliable Internet sources, and it is to your advantage to familiarize yourself with such resources.

Long-Term caregiving for a loved one can put a strain on any relationship. There are often many lifestyle adjustments that need to be made in providing long-term care. The basis for a healthy relationship centers on open communication, learning the facts about life after injury, a willingness to adjust one's views in many areas, and paying attention to the health of both the individual with SCI as well as the caregiver.

MANAGING SELF-HEALTH

While it is important to learn how to take care of your loved one, it is even more important for you to learn how to take care of yourself. Maintaining self-health is essential for your wellness and your ability to adequately care for your loved one. After all, you cannot expect to effectively care for your loved one when you are in distress.

Recognizing Stress

Stress is a physical, chemical, or emotional factor that causes tension in your body or mind. Most everyone has some type of stress in their life. Stress is common because it is almost impossible to escape.

Stress can quickly become a problem for people who have learned to ignore signs and symptoms of stress until it gets out of control. Continued stress puts people at higher risk for serious health problems including illness, addiction, and depression.

There are several signs and symptoms of stress that you can learn to recognize when stress might be getting out of control. When you are under a lot of stress, you may experience one or more of the following:

Mood (Emotional) Symptoms of Stress

Anxious
Scared
Irritable
Moody

Thought Symptoms of Stress

Low self-esteem
Fear of failure
Inability to concentrate
Embarrassing easily
Worrying about the future
Preoccupation with thoughts/tasks
Forgetfulness

Behavioral Symptoms of Stress

Stuttering and other speech difficulties
Crying for no apparent reason
Acting impulsively
Startling easily
Laughing in a high pitch and nervous tone of voice
Grinding your teeth
Increasing smoking
Increasing use of drugs and/or alcohol
Being accident prone
Losing your appetite or overeating

Bodily Symptoms of Stress

Perspiration/sweaty hands
Increased heart beat
Trembling
Nervous ticks
Dryness of throat and mouth
Tiring easily
Sleeping problems
Diarrhea/indigestion/vomiting
Butterflies in stomach
Headaches
Premenstrual tension
Pain in the neck and or lower back
Weight loss or gain

Source: <http://ub-counseling.buffalo.edu/stressmanagement.shtml>

Adopting a Healthy Lifestyle

A healthy lifestyle includes a balance of things you can do to feel better emotionally and physically. Healthy behaviors reduce stress and increase our ability to cope with problem issues. A few simple acts can be a great foundation for self-health. For example:

- ◆ Get enough sleep.
- ◆ Eat regular, healthy meals and snacks.
- ◆ Participate in regular physical activities because your body can fight stress better when it is fit.
- ◆ Take quiet time for yourself to listen to soothing music, soak in a warm bath or shower, read an interesting book or magazine or go to the park or some other place quiet.
- ◆ Cut down or cut out use of caffeine and tobacco.
- ◆ Do not rely on food, alcohol or drugs to reduce stress.
- ◆ Balance your life with work and play.
- ◆ Spend quality time with friends and family.
- ◆ Enjoy hobbies or crafts.
- ◆ Hug somebody!
- ◆ Be assertive instead of aggressive. "Assert" your feelings, opinions, or beliefs instead of becoming angry, defensive, or passive.
- ◆ Do not volunteer for something if you do not have the time or energy to do.
- ◆ Keep things organized.
- ◆ Seek out social support to share ideas, resources and coping skills.

Getting Help

Getting help is essential to finding time for yourself. Help can come in various forms such as other family members helping with household chores. It may be an understanding boss that allows you to work from home or adjust your work schedule to be able to maintain your job while still providing care.

Asking for help is a sign of strength - not weakness. It may not be easy at times to ask for and receive assistance. This difficulty usually stems from two notions of thought.

First, some people may not ask for help because they do not want to "burden" others, especially family members. If you feel this way, ask yourself if it would be a burden on you to help a loved one in need. We are part of a family; we are part of a society; and we all need each other. We all need help at times, and we rely on each other in many ways, and most people gladly help family and friends if needed.

A person's impression of "independence" is the second problem notion of thought. Some people may not seek

assistance or refuse it if offered because they believe that being independent means doing things without the help from others. The reality is that there is no shame in asking for and receiving help when you need it. And you will probably make your everyday life more of a burden on you if you do not get assistance when you need it.

Caregiving is not a one-person job. You need time away for a healthy lifestyle, and there are going to be times when you are sick or need to get away for other reasons. The best thing that you can do is have a list of people that you can call when you need someone. You might also have one or two people on your list who can be a backup care provider on short notice in case of sickness or crisis.

Learning to Solve Problems

Although avoiding problems might ease stress in the short-run, most problems do not simply fade away. In fact, you can usually expect stress to continue until you resolve your problem issue

Research suggests that having effective problem solving skills is also essential for the health of both the caregiver and care recipient. You can use problem solving skills in almost all aspects of your life. As you set out to resolve problems, it is important to set your priorities. What needs to be done first? What can be left until later? Work on what needs to be done first. There are 5 basic steps for effective problem solving.

STEP 1 - Identify the problem: you must know the problem in order to solve it. You might make a list of your problems and rank them in order of importance. You need to make sure that you break large problems into smaller parts, and select the most troublesome problem to resolve first. Remember to work on one issue at a time and get all of the facts before moving onto step 2.

STEP 2 - Brainstorm for possible solutions: thinking about the problem you most need to resolve, make a list of as many possible solutions to your problem as you can. Be free thinking, and do not judge your ideas at this time. If you have problems thinking of possible solutions, ask your family and/or friends for their thoughts on how they might solve the problem. If you

need more information, you might search on the Internet or at your local library.

STEP 3 - Select the best solution: from your list of possible solutions, choose the solution that you think will best solve your problem. Again, you can ask for opinions on which solution might work best. Once you make your choice, put your list in a safe place to keep for a later date if needed.

STEP 4 - Try your solution: the only way to know if the solution works is to try it out. Take notes on your progress and any problems that you experience.

STEP 5 - Evaluate your tried solution: if your solution works, give yourself a big pat on the back for a job well done. If you are not satisfied with the results of your solution, review your notes. It may be that there were unforeseen obstacles that need to be corrected. Make adjustments if needed. Try another possible solution from your list, or you can do more brainstorming for other ideas and edit your solution list based on new information.

Learning to Relax

Relaxation techniques are additional self-care skills you can learn. You first need to prepare yourself before you can relax. You can dim the lights and quiet all distractions by turning off the television, radio and phones. You can sit back in a comfortable chair.

Self-Guided Imagery:

- ◆ Close your eyes. Focus on your breathing and take slow, deep breaths.
- ◆ Imagine that you are in a peaceful setting such as relaxing on a beach, meadow, or mountain top.
- ◆ Focus on the peaceful setting that you are imagining and pay close attention to all the details. Notice the sounds (any birds, wind rustling the leaves, waves crashing on the shore?). Pay attention to what you feel (warm sun on your skin, hot sand on your feet, cool grass beneath you). Attend to any smells and tastes you may imagine having. Spend some time focusing on all the sensations you are experiencing while imagining your peaceful place.
- ◆ After a few minutes return your attention on your breathing. Notice how you are breathing deeply in and out and focus on what is going on around you

(the pressure of the seat against your legs, the ticking of a clock, etc.).

- ◆ Ask yourself how relaxed you are at the moment using a scale from 0 - 10 with zero indicating not relaxed at all and 10 reflecting the most relaxed you have ever been.

Abdominal Breathing:

- ◆ Slow your breathing down by taking slow, deep breaths.
- ◆ You know you are breathing abdominally by placing your hand on your abdomen and seeing that your hand moves up and down.
- ◆ This is the type of slow, deep breathing that we do while we are sleeping. Slowing the rate of your breathing can slow your heart rate and give you a peaceful sense of relaxation.
- ◆ This takes practice, so keep trying if you are unable to do it the first few times.

Progressive Muscle Relaxation:

- ◆ Beginning with your toes, slowly work your way up through the muscles in your body by tensing and then relaxing your muscles. After your toes, slowly tense and relax your feet, then your calves, thighs, abdomen, arms, hands, fingers, neck, and finally, your face.
- ◆ Take as long as you need to tense and then relax all the muscles in your body.

PARTNER OR SPOUSE CAREGIVING_____

For couples, it is very important to keep the partner/spouse role separate from the caregiver role. One way to do this is to have a routine that keeps the caregiving activities separate from those of a partner. Another way is to have a specific area or room devoted to intimacy - where no caregiving tasks are performed. Keeping the two roles as distinct and separate as possible will help you to avoid confusing and blurring the roles in your mind. When you and your partner are feeling romantic, you will be better able to see yourself as a romantic partner and not as a caregiver.

Couples need to also work to maintain equality within their relationship. Both partners need to make significant and meaningful contributions with every day issues such as parenting, various household chores or money management. This equality will help caregivers not to

become resentful of being "overwhelmed" with daily responsibilities or duties.

Problem Issues

Most couples face obstacles early after injury. For most adults, pre-injury life is routine, familiar, and comfortable. People usually have established views of what they consider "normal," and they generally have defined notions of their relationship.

In most cases, pre- and post-injury routines are very different for caregivers and their spouses or partners. Like many other aspects of life post-injury, changes in views and established routines are usually necessary in adapting to life after injury.

Again, each family is different, so every family will not necessarily experience the same problem issues. As a caregiver, however, you will likely experience many of the same issues as others. Research has shown that caregivers generally report problem issues with:

1. the negative attitude of the person with SCI;
2. personal feelings of guilt;
3. lack of appreciation for being a caregiver;
4. not enough time for personal activities;
5. having to say "no" to the person with SCI; and
6. feeling overwhelmed.

Individuals with SCI expressed problem issues with:

1. wanting to walk;
2. sexual function;
3. pain;
4. bowel and bladder function;
5. lack of money;
6. not being able to do simple tasks; and
7. being anxious.

Although the two groups are affected by the same injury, those reported problem issues tend to be self-oriented. Therefore, the key to a healthy relationship centers on open communication, learning the facts about life after injury, and a willingness to adjust one's views in many areas.

It is essential to talk about problem issues and openly discuss how these issues are affecting your relationship.

In time, hopefully, the two of you can reach a mutual understanding of how, together, you can overcome the situation, resolve problem issues if possible and strengthen the relationship.

Resolving Conflict

You cannot avoid conflict because it is a necessary and healthy element in all relationships. People are simply different. Disagreements are going to occur because everyone has a unique point of view that often results in differing opinions.

If a problem is important to one member of the family, it is important to all. But conflicts with loved ones can be especially stressful for everyone involved. This is why it helps to learn how to resolve conflict to reduce or relieve stress.

STEP 1 - Ground Rules: when two people disagree about an issue, the first emotional reaction is often anger. It is nearly impossible for people to resolve issues when they are angry. Therefore, it is important for everyone to let emotions calm before making an effort to resolve conflicts.

The purpose of conflict resolution is not to have one winner. It is to reach a solution in which all sides agree. When you think of resolving issues this way, people are likely to respond with a willingness to succeed. If the conflict is a question of fact, it is everyone's responsibility to know the facts.

Basic Conflict Resolution Guidelines:

- ◆ Keep things in perspective.
- ◆ Focus on resolving one issue at a time.
- ◆ Be clear and direct when discussing issues.
- ◆ One person talks at a time.
- ◆ Allow each person to respond.
- ◆ Don't use physical contact, intimidation, or threats to get your way.
- ◆ Don't use the "Silent Treatment" and expect others to know what you think or feel.
- ◆ Don't dig up old issues that are not important to the issue at hand.
- ◆ Don't use emotional blackmail by saying "if you really love me, you would..."
- ◆ Don't over exaggerate or use words like "always" and "never."

STEP 2 - State the Problem: you cannot resolve issues unless everyone knows exactly what the issue is. You are more likely to have success in resolving the problem if you are respectful when stating the issue. For example, state the problem in the form of a self-expression, not a personal attack.

Examples of Request:

- ◆ "I feel like my work is not appreciated."
- ◆ "I feel overwhelmed because I am getting no time for myself."
- ◆ "I feel guilty when I take time for myself."

Example of Attacking Statement:

- ◆ "You make me mad when you do not give me a break."

If the problem is about behavior, make it a positive request about behavior, not a demand.

Examples of Request:

- ◆ "I would like you to take a more active role in helping with the children."
- ◆ "I prefer that we do (something) this way."

Examples of Demand Statement:

- ◆ "You have to start acting like a father."
- ◆ "You are going to do (something) my way."

STEP 3 - Listen and Understand: listening is the hardest yet most important part of conflict resolution. Listening requires an open mind to hear what is said. When two people are in an emotional argument, who is really listening? Sometimes people talk over each other hoping the loudest voice wins. Many people who are not talking are thinking about what they are going to say instead of listening. Resolving issues requires a willingness to listen to what is said.

It is tough being a good listener. If you find it difficult, you might try to "repeat" in your head what is being said as another person talks. That way, you stay focused on hearing what is said. There may be times when you hear what is said but do not really understand the other person's meaning. When someone talks to you, it is natural to imply your own reasoning to what is being said. However, people often mean to express themselves differently than you might think. If you are not clear about another person's meaning, you can easily repeat

what they said and ask for more information. If you are open minded, listen and understand; it is easier to suggest possible solutions that both parties can agree.

STEP 4 - Problem Solve for Resolutions: Following the 5 problem solving steps on page 3, conflict resolution is often similar to solving other problems. You want to work together because your goal is to resolve the issue in a manner that is acceptable to all those involved. Work together to pick one or more solutions from your list that everyone agrees offers a realistic chance for success. If you try a solution that does not work for everyone, work together to modify your solution or choose other possible solutions from your list.

STEP 5 - Resolution: the issue is finally resolved when the solution works for everyone.

However, there may be issues that cannot be resolved. If the conflict is a matter of opinion, recognize that it is impossible to control the thoughts of anyone else. You may not change another person's mind even with your best efforts and intentions. Likewise, you cannot change other people's behaviors.

When there is no mutual resolution, you have to resolve the issue for yourself. You might agree to disagree on

matters of opinion, or "let go" of a matter that you simply have no control over. These concepts may be hard to do at times, but they can be the best thing that you can do for your overall health.

CONCLUSION _____

As a caregiver, you can expect to experience ups and downs. You may feel overwhelmed or stressed at times with all of the added responsibilities you have. You might feel under appreciated for all your hard work and devotion.

Caregiving takes hard work and devotion, and providing care for a loved one is an expression of affection and commitment. After all, you are choosing to be primarily responsible for the care of someone you love. Therefore, it is important to take care of your health to best be able to give your loved one the care he or she needs.

However, it is equally important that you make a commitment to take care of yourself because it is best for you, too. You need care and attention as much as anyone else. Although it takes hard work and devotion, you can find balance in your life if you make that commitment. Do not forget that!

REFERENCES & RESOURCES _____

Accepting New Help

A brochure from Craig Hospital
303-789-8202

www.craighospital.org/SCI/METS/acceptingNewHelp.asp

Caregiver's Guide to Self-Health: Solving Problems and Reducing Stress

University of Alabama at Birmingham
www.spinalcord.uab.edu/show.asp?durki=117376

Caregiving

A brochure from Craig Hospital
303-789-8202

<http://www.craighospital.org/SCI/METS/>

[caregiving.asp](http://www.spinalcord.uab.edu/show.asp?durki=36069)

Healthy Living: Relationships

An article from the Pushin' On, Vol 19[1], 2001.
University of Alabama at Birmingham
www.spinalcord.uab.edu/show.asp?durki=36069

Long-term Care Givers

A brochure from Craig Hospital
303-789-8202
<http://www.craighospital.org/SCI/METS/longtermCareGivers.asp>

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Personal Care Attendant

Spinal Cord Injury
InfoSheet



Level - All Audiences

INTRODUCTION

Between 40 and 45 percent of individuals with spinal cord injuries (SCI) need personal assistance with some daily activities [1]. It is understandable that the majority of persons needing assistance have higher levels of injury. They may need personal care assistance with getting in or out of bed, managing bowel and bladder issues, bathing, and dressing. Some individuals may need someone to drive, shop, and clean for them too. However, there is also a growing percentage of persons with lower levels of injury needing assistance as they get older. They may need assistance with household activities as they grow older and experience increased pain or fatigue.

ASKING AND RECEIVING

It may not be easy at times to ask for and receive assistance. This difficulty usually stems from two notions of thought.

First, some people may not ask for help because they do not want to “burden” others, especially family members. If you feel this way following SCI, ask yourself if it would be a burden on you to help a loved one in need. Probably not. However, many people with SCI still do not ask for the help they need.

We are part of a family; we are part of a society; and we all need each other. We all need help at times, and we rely on each other in many ways, and most people gladly help family and friends if needed. Children are dependent on their parents and rely on them for care, and children commonly assist their parents as they age and become increasingly dependent. It is a natural state. Likewise, we function as a society helping each other throughout life. Health care professionals help us when we are sick; teachers help educate us; and police officers and fire fighters help protect us from danger. In fact, most jobs provide some type of service for people. The reality is that there is no shame in

asking for and receiving help when you need it. And you will probably make your everyday life more of a burden on you if you do not get assistance when you need it.

A person's impression of "independence" is the second problem notion of thought. Some people may refuse assistance if offered because they believe that being independent means doing things without the help from others. However, the reality is that people who refuse help are less independent than people who ask for and receive help. Independence has little to do with what you can do. Independence is having the freedom to choose what you want to do. For example, people who do not have the ability to drive can still choose to go somewhere if they have assistance. When you get assistance, you have the opportunity for independence. It is that simple.

FINDING A PCA

There really is no “best” way to find a Personal Care Attendant (PCA). You may need to use a number of ways to find people who might be interested in the job. If you qualify for services, you might start your search by checking with your State Department of Rehabilitation Services to see if there's a local program to help you find a PCA. Another option is to advertise in your local newspaper describing your need for PCA services. A classified ad will cost money to purchase, but you can reach a lot of potential candidates who are searching for employment. If you place an ad, it is a good idea to advertise on weekends because that will reach the most people. Another option is posting flyers in community areas likely to catch the eye of persons in the field of providing personal care. For example, you might put a flyer on a hospital or nursing home bulletin board. You can also post a flyer at a local college in the schools of nursing, occupational therapy and physical therapy. Finally, people often learn of jobs through word of mouth, so let people know you are searching for a PCA.

INTERVIEWING FOR A PCA _____

When you get calls from people interested in the job, you should schedule an interview with each person. This is your chance to get to know the person, and it gives the person a chance to find out more information about the job. You should clearly explain the types of tasks that your PCA will need do, and you should invite questions from the candidate to make sure he/she understands your needs. Many duties are of a very personal nature, so you want to be sure candidates are comfortable doing these tasks. Describe all the duties involved such as lifting, bathing, bowel and bladder programs, housecleaning, or grocery shopping. Discuss pay. Also, tell them what education and training you will provide.

You can save time by preparing a list of questions to ask each candidate. A few examples might be:

- ◆ Do you have previous experience?
- ◆ Do you have physical problems that prevent you from lifting or pulling?
- ◆ Will you cook and do housework?
- ◆ Do you have a driver's license, and are you willing to drive?
- ◆ Do you have dependable transportation to and from work?
- ◆ How much money do you need to make?
- ◆ Do you feel comfortable assisting with more "sensitive" personal care such as bathing, bowel and bladder care?

If you are having problems deciding on a candidate, you might make a checklist of your needs and the personal qualities that you want in a PCA.

- ◆ Is the person dependable and on time?
- ◆ Is the person trustworthy and honest?
- ◆ Is the person able to follow instructions?
- ◆ Is the person someone who is friendly?
- ◆ Is the person someone you can be friends with?

Based on your interviews, you can select the best candidate for you. Once you select someone, *always ask for references*. If a candidate does not provide references after you ask, you may want to choose another person who will provide references because *you should always check all references before hiring* someone who is going to come into your home. Talk with previous

employers to learn about the qualities that you want in an employee. You might get the candidate's driver's license number to ask the local police to run a security check on the person. You are ready to hire the person who checks out and best fits the qualities that you desire. Initially, you might hire the person on a temporary basis. This will give both you and the PCA time to get to know each other and find out if there is a good working relationship.

EDUCATION AND TRAINING _____

Most PCAs need education and training on general issues associated with SCI. You can find and print information sheets from reliable sources on the Internet. Gives these sheets to your PCA to read.

Even if you find a PCA with a lot of experience, you also have unique needs. Although all issues are important, your bowel, bladder, skin, and respiratory care must be understood by your PCA. Communicate your bowel and bladder needs clearly. Make sure you stress the importance of daily skin care, and your PCA should know how to conduct daily skin checks and spot problems. PCAs need to know about respiratory sickness too. Flu and pneumonia can be life-threatening for most people with SCI. This fact makes it important to have PCAs understand these dangers and work to prevent spreading these conditions. Washing hands should always be done often to help prevent the spread of germs. PCAs who are sick with a cold or flu should avoid contact when possible. If contact is unavoidable, PCAs should wear a mask and wash hands more often.

For individuals on a ventilator, PCA training on all the mechanical works of a ventilator can mean life or death. There should also be an emergency plan for ventilator problems and failures.

PARTNER OR SPOUSE VS. PCA _____

A spouse or partner is often the first to provide personal care following injury. Although this arrangement is initially common for couples, the partner/caregiver role can be unhealthy if it continues long following injury. They may feel it is their "duty". Some family members do not want an outsider caring

TOP 10 REASONS PCAs QUIT THEIR JOBS

- 1 Their initial job description was incomplete or keeps changing.
- 2 The method and order in which they must perform their duties are illogical, inefficient and waste time.
- 3 Their working environment is messy, unpleasant, disorganized, etc.
- 4 They're not paid enough, don't get appropriate raises or don't feel their work is appreciated.
- 5 They feel another PCA is favored over them.
- 6 The employer (YOU) is either too passive or too aggressive in his/her style of interaction.
- 7 The employer is dishonest about the hours worked, the salary owed, or has inappropriate expectations such as monetary loans or sexual favors.
- 8 There are unreasonable duties—those the employer is able to perform alone, those which cannot be performed in the allotted time or those which are too tightly supervised.
- 9 The employer is intolerant of honest mistakes, the need for sick time, etc.
- 10 The employer doesn't respect PCA's personal life and expects that his or her needs should take priority over all else in the PCA's life.

Source: Home Health Aides: How to Manage the People Who Help You, by Al DeGraff, 1988, Saratoga Access Publications, P.O. Box 1427, Fort Collins, CO 80522-1427.

for their loved one. However, it is the individual with SCI who needs to decide what help he/she needs and who will provide it.

Although a spouse or partner might provide care at times, it is generally recommended that the primary care provider be someone other than a family member. This separation of roles allows individuals with SCI to be independent of family members and avoid unnecessary conflict with loved ones. Additionally, this separation ensures that family members do not become resentful of the added responsibilities or duties in the relationship.

Unfortunately, some couples have no option other than for a partner or spouse to be the primary caregiver. In this instance, it is very important to keep the partner/spouse role separate from the caregiver role. One way to do this is to have a routine that keeps the caregiving activities separate from those of a partner. Couples also need to have occasional time apart. Keeping the partner/caregiver roles as distinct and separate as possible will help you to avoid confusing and blurring of the partner role with the caregiver role, which is healthier for a couple's personal relationship [2].

FUNDING

The US Department of Labor's Wage and Hour Division administers and enforces the federal minimum wage law. The federal minimum wage for employees is currently \$5.85 per hour, and the minimum wage

will increase over time to \$6.55 per hour effective July 24, 2008 and to \$7.25 per hour effective July 24, 2009 [3]. Many states also have minimum wage laws. In cases where an employee is subject to both the state and federal minimum wage laws, the employee is entitled to the higher of the two minimum wages.

Many people cannot afford a PCA without financial assistance. You may qualify for local or state programs that can help in paying a PCA. You might contact your local Independent Living Center, State Department of Rehabilitation Services or, for veterans, the Department of Veteran's Affairs. In some cases, private insurance may pay for "skilled nursing care," which may provide some aspects of personal care. If you are getting a financial settlement for your injury, it is important to include the projected lifetime costs for a PCA.

Like most things in life, you get what you pay for when it comes to a PCA. A reliable, dependable and skilled PCA is going to cost you. You want to make the job as appealing as possible to hire and keep the best possible PCA. Utilize all of the outside services that you qualify for to pay for a PCA, and you can also pay what you can afford out of pocket. Give occasional bonuses if you can, too.

Finally, you should probably talk with an accountant about any possible issues related to the Internal Revenue Service [4]. Before you can know how to treat payments you make for services, you must first know the business relationship that exists between you and

the person performing the services. If you have an employee, you may be responsible for Federal Income Tax Withholding, Social Security and other taxes as an employer. You may also need an accountant to help you with what you can and cannot claim on your personal income tax returns.

WORKING WITH AN PCA _____

A PCA is often your friend and employee. It is up to you to balance the two roles. The first step is to make clear that a PCA's role is helping you with daily activities that you cannot do for yourself, and it is you who decides what assistance is needed.

There are times when you need to be assertive, and you need to also be flexible sometimes. If there is a specific way that your care needs to be done, give the PCA clear directions on what needs to be done and the proper techniques involved. However, a PCA is a person, too. Although you are in charge of your care, your PCA may have a different approach to providing the same quality care. So you need to be reasonable in listening and accepting different ideas and opinions. It

REFERENCES _____

- 1 Accepting New Help
A brochure from Craig Hospital
303-789-8202
www.craighospital.org/SCI/METS/acceptingNewHelp.asp
- 2 Healthy Living: Relationships
An article from the Pushin' On, Vol 19[1], 2001.
University of Alabama at Birmingham
www.spinalcord.uab.edu/show.asp?durki=36069
- 3 U.S. Department of Labor
1-866-4-USWAGE
www.dol.gov/esa/whd/flsa/

is also nice to express your appreciation to your PCA for the help he/she is providing for you. Finally, it is important that you are understanding if your PCA has a "bad" day or makes a mistake. Hopefully, you will find that you can be flexible but still keep a professional relationship.

Finally, you cannot rely on one PCA all the time. If your spouse or partner is your primary caregiver, it is very important that you find a way to give him/her personal time for rest and enjoyment. Your PCA also needs days off, and there are unexpected circumstances that require absences from work. Therefore, you need to plan ahead. Make sure you have options and the ability to call on multiple sources if needed.

CONCLUSION _____

Many individuals with SCI need assistance with daily activities. Although the process of finding, hiring, training, and supervising a PCA is a necessity, asking for and receiving help may be difficult for some people. But a PCA can enhance your independence and quality of life.

4 The Internal Revenue Service
800-829-1040
www.irs.gov/

OTHER RESOURCES _____

Center for Personal Assistance Services
1-866-PAS-9577 (free call)
www.pascenter.org

State Rehabilitation Providers
1-800-772-1213 (free call)
www.ssa.gov/work/ServiceProviders/rehabproviders.html

Published by: Office of Research Services
619 19th Street South - SRC 529
Birmingham, AL 35249-7330
(205) 934-3283 or (205) 934-4642 (TTD only)
www.spinalcord.uab.edu
Email: sciweb@uab.edu

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National Rehabilitation Hospital
Washington, DC

Dr. Groah is currently the Director of Spinal Cord Injury Consultation Liaison Service and of Spinal Cord Injury Research at the National Rehabilitation Hospital (NRH) and Associate Professor of Rehabilitation Medicine at Georgetown University. Dr. Groah has been the Project Director of the federally-funded Rehabilitation Research and Training Center on Secondary Conditions after SCI since 2003 and is the current Project Director of the National Capital Spinal Cord Injury Model System. She has a subspecialty certification in SCI from the American Board of Physical Medicine and Rehabilitation (ABPMR), and has been a writer for the ABPMR SCI Subspecialty Examination for the past 3 years. She reviews regularly for the Archives of Physical Medicine and Rehabilitation, Spinal Cord, American Journal of Physical Medicine & Rehabilitation, Journal of Spinal Cord Medicine, and Journal of NeuroTrauma. She has been an expert panel member for the PVA Consortium Guideline on Bladder Management and is currently an expert panel member for the upcoming PVA Consortium Guideline on Carbohydrate and Lipid Disorders After SCI. Dr. Groah was recently identified in the 2009-2010 “Best Doctors in America” for the District of Columbia and in 2008 was nominated for the NSCIA SCI “Hall of Fame”.

Learning Objectives

Aging with SCI: Implications for the Future

1. Participants will be able to describe how a spinal cord injury effects the aging process.
2. Participants will be able to list 3 conditions commonly associated with aging in people with spinal cord injury.

Disclosure Policy

In order to ensure balance, independence, objectivity and scientific rigor at all programs, the planners and faculty must make full disclosure indicating whether the planner, faculty or content specialist and/or his/her spouse family has any relationships with pharmaceutical companies, biomedical device manufacturers and/or corporations whose products or services are related to pertinent therapeutic areas. All planners, faculty, content specialists and feedback specialists participating in educational activities must disclose to the audience information listed below.

Faculty Disclosure

Suzanne L. Groah, MD, MSPH has no vested interests, and there are no conflicts of interest to disclose.

Faculty disclosure of off-label use

Suzanne L. Groah, MD, MSPH does not plan on discussing unlabeled/investigational uses of a commercial product.

Aging with a Spinal Cord Injury: Mythbusters

Suzanne L. Groah, MD
National Rehabilitation Hospital
October 23, 2010

*Supported by NIDRR Grants
H133B090002 and H133N060028*

Objectives

- Determine if the following are *myth* or *fact* (*can we by mythbusters?*)
 - Disease and aging are synonymous
 - Older are less physically active
 - Older are less mentally active
 - Aging is associated with diminished quality of life
- And, let's all have fun today!

WHAT IS NORMAL AGING?

Theories of Aging

- Biologic clock
- DNA damage
- Immune theory
- Cumulative injury theory (“wear & tear”)
- Failure of maintenance
- Evolutionary (natural selection)

AND, WHEN DOES AGING START?

Aging and SCI

- Texas Life Status Study
- Oliver and Zarb
 - social & environmental support issues
- Whiteneck
 - hospitalization expenses, attendant care & equipment
- Trieschmann
 - personal experiences
- US Collaborative Aging Study
- Craig 20+ Study
- Craig Collaborative Aging Study

SYSTEM BY SYSTEM AGING

Systemic Conditions that Occur in an Older Population

- Aging Fact
 - Alzheimer's disease and other dementias
 - Arthritis
 - Cancer
 - Cardiovascular disease
 - Diabetes
 - Hypertension and stroke
 - Osteoporosis

Skin Changes with Age

- Aging Fact
 - Skin becomes less flexible and epidermis thins
 - Delayed wound healing
- SCI Fact
 - Pressure sores
 - most common cause of morbidity
 - incidence increases with increasing age

Musculoskeletal Changes with Age

- Aging Fact
 - Flexibility & ROM ↓
 - Pain
 - Bone mass ↓
 - Fracture risk ↑
- SCI Fact
 - Joint pain & stiffness
 - Paras > Tetras > All D's
 - Increases with increasing duration of injury

Immune System Changes with Age

- Aging Facts
 - ↓ ability to fight infection
 - ↓ responsiveness to vaccinations
 - ↑ incidence of autoimmune disease
- SCI Facts
 - ↑ risk of infection

Respiratory

- Aging Fact
 - Natural reduction in lung function with age
- SCI Fact
 - Lung and breathing function are reduced in people with tetraplegia and high paraplegia

Kidney and Bladder Function

- Aging Fact
 - Kidney (renal) function declines with age
- SCI Fact
 - Urinary tract infections are THE most common cause of morbidity
 - Tetraplegics affected more than paras

Bowel Function

- Aging Fact
 - Reduction in natural bowel contractions
 - Diminished tolerance for certain foods
 - ↓ vitamin & mineral absorption
- SCI Fact
 - Hemorrhoids in SCI
 - Older age
 - Longer duration of injury
 - Gallbladder disease
 - ↑ colonic transit time
 - Constipation

Nervous System

- Aging Fact
 - ↓ brain volume
 - ↑ in entrapment neuropathies
 - ↓ reaction time
- SCI Fact
 - ↑ in entrapment neuropathies
 - ↑ risk of syringomyelia

Endocrine

- Aging Fact
 - ↓ ovarian function
 - ↓ testicular function
 - ↑ diabetes
 - ↓ thyroid function
- SCI Fact
 - ↑ insulin resistance and diabetes
 - ? ↓ testicular function

Cardiovascular Aging

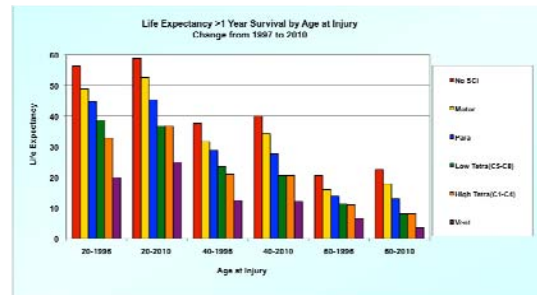
- Aging Fact
 - ↑ incidence of heart disease
 - ↑ blood pressure
 - ↑ cholesterol levels
 - ↑ glucose intolerance
- SCI Fact
 - ↓ hypertension
 - ↓ HDL cholesterol
 - ↑ obesity
 - ↑ inflammation

Psychosocial Function

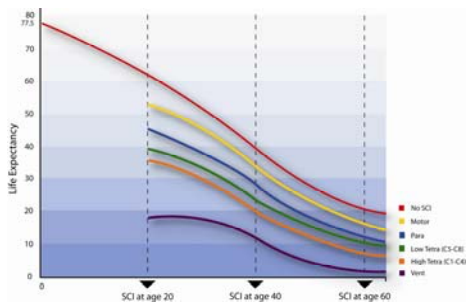
- Aging Fact
 - ↑ depression with age
 - ↑ subjective well-being
- SCI Fact
 - Depression may be higher in people with SCI
 - Quality of life may be similar
 - May have ↓ perceived health

IS AGING ACCELERATED IN SCI?

Life Expectancy Over Time



Life Expectancy After SCI



Is Aging Accelerated in SCI?

- *“The percentage of elderly persons in the prevalent population will not increase meaningfully until significant progress is made in reducing the high annual mortality rates currently observed among older persons with SCI. Those who reach older ages will typically have incomplete and/or lower level injuries and will have relatively high degrees of physical independence and overall good health and community participation.”*

What is Successful Aging?

- *“Successful aging is multidimensional, encompassing the avoidance of disease and disability, the maintenance of high physical and cognitive function, and sustained engagement in social and productive activities”*

(Rowe JW, Kahn RL. Successful aging. Gerontologist 1997;37(4):433-41)

Myth or Fact?

- Disease and aging are synonymous?
- Older are less physically active?
- Older are less mentally active?
- Aging is associated with diminished quality of life?

Thank you!

Suzanne Groah, MD, MSPH
National Rehabilitation Hospital
www.sci-health.org



Stepping Forward-Staying Informed Consumer Education Program

This unique program is designed to educate individuals living with spinal cord injury, their families, and healthcare professionals about current research, emerging treatments, and new programs that can have a direct impact on people's quality of life.

Scientists and clinicians from around the country present cutting edge topics such as current progress in stem cell initiatives, activity-based locomotor training, and the benefits of exercise for people living with paralysis. Consumers have the opportunity to interact directly with researchers, who present scientific information using language that is easily understood by those without a medical or scientific background.

The Stepping Forward– Staying Informed Consumer Education Program consists of a 1-day Annual Consumer Research Conference and a bi-monthly Evening Lecture Series.

Annual Consumer Research Conference

The conference takes place in the fall of each year and is held at the Boston Convention and Exhibition Center. This all day event brings 4-5 nationally and internationally recognized researchers and clinicians to Boston to discuss their innovative research and treatment techniques in the field of spinal cord injury. Consumers are also able to visit the exhibitor area to learn about various products and services provided by organizations and vendors serving people with SCI. Breakfast, lunch, and refreshments are provided.

Bi-Monthly Evening Lecture Series

The Evening Lecture Series takes place every other month (typically January, March, May, July, and November each year). Lectures are held in the Hiebert Lounge of the Boston University School of Medicine located on the Boston Medical Center Campus. Lectures are also available to those beyond Massachusetts via webcast. Each 90-minute session begins with the guest speaker presenting his or her work, followed by a 45-minute open discussion with consumers. Audience members are able to speak at length with or submit questions through the live chat to the speaker. This format gives attendees the opportunity to hear how the work presented may or may not specifically affect them or their family members.



For more information:

www.bmc.org/sciedu

Judi.Zazula@BMC.org

617-638-7314

Past lectures can be viewed at

www.bmc.org/SCIconference



SCI Guide

The Best Sites — Chosen by You for You



www.SCIguide.org

What's So Special About The SCI Guide?

If you type “Spinal Cord Injury” into a search engine, you will get over 2 million web pages about spinal cord injury! How do you search through all of this and find valid web pages that give you the information you need quickly and easily?

The purpose of The SCI Guide (copyright, 2006), a National Institute of Disability and Rehabilitation Research (NIDRR) funded project, was to create a guide that would bring together a listing of the best websites on SCI from the consumer's perspective. In order to accomplish this, The New England Regional Spinal Cord Injury Center (NERSCIC) at Boston Medical Center assembled a diverse team of individuals with spinal cord injury to review websites and evaluate them based on several factors, including validity and quality of information and user-friendliness. In order to meet the range of needs of the SCI community, reviewers varied in background, experience, and injury level. Members of the team gave special consideration to the needs of the newly injured and first-time Internet users when selecting sites for this guide.

The SCI Guide includes:

- 1) A concise listing of websites in all areas of living with SCI: Introduction to SCI, Medical Information, Sexuality and Relationships, Employment, Education, Assistive Technology, Community Living, and many more!
- 2) Directions for how to navigate each site and its best features, for new Internet users or anyone who doesn't have time to get “lost”.
- 3) Icons for quick reference: rating out of 5 stars, good for newly injured, good for all levels of injury.
- 4) Websites with high quality information and resources that can be accessed directly online for free by anyone in the country.
- 5) Reviews directly quoted from our team of reviewers with SCI.
- 6) Top Sites for Newly Injured (copyright, 2006).
- 7) Best of the Best SCI Websites (copyright, 2006).
- 8) Interactive feature for users to post ratings and suggest new sites.

The development of this product was supported by the National Institute on Disability and Rehabilitation Research (Grant Number: H133N000024)

Locating Information about Spinal Cord Injury



This information sheet was developed by The University of Alabama at Birmingham Model Spinal Cord Injury System. Other SCI related materials can be found at:

WWW.SPINALCORD.UAB.EDU

AGRABILITY PROJECT

800-825-4264 or 765-494-5088

email: bng@ecn.purdue.edu

www.agrability.org

Purdue University, 1146 ABE Building
West Lafayette, IN 47907-1146

An international source for information and resources on rehab technology for persons with disabilities working in agriculture.

AMERICAN ASSOC OF PEOPLE WITH DISABILITIES

800-840-8844 or 202-457-0046

email: aapd@aol.com

www.aapd.com

1629 K Street NW, Suite 503, Washington, DC 20006

Provides economic clout and power in numbers, unity, leadership and impact in the disability rights movement.

CENTER FOR ASSISTIVE TECHNOLOGY & ENVIRONMENTAL ACCESS

404-894-4960

email: catea@coa.gatech.edu

www.sedbtac.org

490 10th Street, Atlanta, GA 30318

Provides ADA information, technical assistance and training to businesses and people with disabilities. They also provide referrals to the other ten regional centers around the country.

CENTER FOR RESEARCH ON WOMEN WITH DISABILITIES

800-443-7693 or 713-798-5782

email: crowd@bcm.tmc.edu

www.bcm.edu/crowd

Baylor College of Medicine, Dept of PM&R
1475 West Gray, Suite 165, Houston, TX 77019

Focuses on issues related to health, aging, civil rights, abuse and independent living of women with disabilities. Develop and disseminate information to expand the life choices of women with disabilities.

CENTER FOR UNIVERSAL DESIGN

800-647-6777 or 919-515-3082

email: cud@ncsu.edu

www.design.ncsu.edu/cud

College of Design, North Carolina State University
Campus Box 8613, Raleigh, NC 27695-8613

Collects, updates, publishes, and distributes resource information about construction and home modifications for accessibility. Provides information and technical assistance on universal design and accessible housing.

CHRISTOPHER & DANA REEVE PARALYSIS RESOURCE CENTER

800-539-7309

email: info@paralysis.org

www.paralysis.org

Provides a comprehensive, national source of information for people living with paralysis. You may email questions or call the toll-free number to speak with an Information Specialist.

DISABLED SPORTS USA

301-217-0960

email: information@dsusa.org

www.dsusa.org

451 Hungerford Dr, Suite 100, Rockville, MD 20850

Provides children & adults with disabilities access to sports, recreation, and physical education programs. They sponsor "learn to" programs in a variety sports; competitive programs for serious athletes; family services; training and certification of professionals; and educational videotapes and manuals.

FES INFORMATION CENTER

216-231-3257

email: info@fesc.org

<http://fescenter.cwru.edu/>

11000 Cedar Ave, Cleveland, OH 44106-3052

Provides a literature (brochures, information packets, and bibliographies) and referral service on FES (Functional Electrical Stimulation) technology.

JOB ACCOMMODATION NETWORK (JAN)

800-526-7234 (or 800-232-9675 for ADA Info)

email: jan@jan.wvu.eduwww.jan.wvu.edu

PO Box 6080, Morgantown, WV 26506-6080

Provides methods, devices, and strategies for solving job accommodation problems for workers with disabilities.

MIAMI PROJECT TO CURE PARALYSIS

800-782-6387 or 305-243-7147

www.miamiproject.miami.edu

PO Box 016960 (R-48), Miami, FL 33101

A comprehensive research center dedicated to finding more effective treatments and ultimately a cure for paralysis.

NAT COUNCIL ON INDEPENDENT LIVING (NCIL)

877-525-3400 or 202-207-0334

email: ncil@ncil.orgwww.ncil.org

1710 Rhode Island Ave NW, 5th Floor, Washington, D.C. 20036

Coordinates efforts of Independent Living Centers, that advocate for rights of people with disabilities.

NAT FAMILY CAREGIVERS ASSOCIATION (NFCA)

800-896-3650

email: info@thefamilycaregiver.orgwww.nfcacares.org

10400 Connecticut Ave, Ste 500, Kensington, MD 20895

Works to improve the quality of life of family caregivers. Provides information, education, support, public awareness and advocacy.

NAT REHABILITATION INFORMATION CTR (NARIC)

800-346-2742 or 301-459-5900

email: naricinfo@heitechservices.comwww.naric.com

4200 Forbes Boulevard, Suite 202, Lanham, MD 20706

A library and information center on disability providing brochures, resources guides, fact sheets and collecting and distributing results of federally funded research projects.

NATIONAL SPINAL CORD INJURY ASSOC (NSCIA)

800-962-9629 or 301-214-4006

email: info@spinalcord.orgwww.spinalcord.org

6701 Democracy Blvd, Ste 300-9, Bethesda, MD 20817

Works to develop programs and serve as advocates for people with SCI, families and health care providers.

PARALYZED VETERANS OF AMERICA (PVA)

800-424-8200

email: info@pva.orgwww.pva.org

801 18th Street NW, Washington, DC 20006

(PVA continued)

A veterans service organization devoted to maximizing the quality of life for people with spinal cord injury or spinal disease through research, education, advocacy, and recreation programs.

(see [Paraplegia News](#) on page 3)

SPINALCORD INJURY INFORMATION NETWORK

205-934-3283

email: sciweb@uab.eduwww.spinalcord.uab.edu

619 19th Street S., SRC-529, Birmingham, AL 35249

Website with SCI materials and links to resources for people with disabilities. Managed by the University of Alabama at Birmingham Model Spinal Cord Injury System.

SPINALCORD INJURY NETWORK INTERNATIONAL

800-548-2673 or 707-577-8796

email: spinal@sonic.netwww.spinalcordinjury.org

3911 Princeton Dr, Santa Rosa, CA 95405-7013

Provides an information and referral service for persons with SCI. They loan SCI related videotapes through the mail to individuals with spinal cord injury and their families.

THROUGH THE LOOKING GLASS (TLG)

800-644-2666 or 510-848-1112

email: tlg@lookingglass.orgwww.lookingglass.org

2198 Sixth St, Suite 100, Berkeley, CA 94710

A research and training center that offers clinical and supportive services, training, and research to families in which one or more members has a disability or medical issue.

UNITED SPINAL ASSOCIATION

800-404-2898

www.unitedspinal.org

75-20 Astoria Boulevard, Jackson Heights, NY 11370

An organization is dedicated to enhancing the lives of individuals with spinal cord injury or disease by ensuring quality health care, promoting research, advocating for civil rights, educating the public about these issues, and enlisting its help to achieve these fundamental goals.

WHEELCHAIR SPORTS, USA

732-422-4546

email: wsusa@aol.comwww.wsusa.org

P.O. Box 5266, Kendall Park, NJ 08824

Developes wheelchair sporting opportunities. Sporting events for adults and youth include Paralympics, archery, shooting, swimming, table tennis and more.

Visit the UAB Traumatic Brain Injury Model System website at www.uab.edu/tbi

Magazines & Newsletters

INTER@CT

408-793-6433

www.tbi-sci.org/interact.html

This bi-annual newsletter of the Santa Clara Valley Medical Center's Rehabilitation Research Center on traumatic brain injury and spinal cord injury, reports news in both areas from this Center. Also available via email.

NEW MOBILITY MAGAZINE

215-675-9133

www.newmobility.com

Subscription: \$27.95 (US) 1 year

PO Box 220, Horsham, PA 19044

Publisher of magazine and books on disability issues, especially spinal cord injury.

PARAPLEGIA NEWS

888-888-2201

email: info@pnnews.com

www.pvamagazines.com/pnnews/

Subscription: \$23 (US) 1year

2111 E. Highland Ave, Ste 180, Phoenix, AZ
85016-4702

This magazine, published by the PVA, covers the latest on spinal-cord-injury research, new products, legislation, people with disabilities, accessible travel, computers, and more.

PVA also publishes **Sports 'n Spokes** magazine.

PUSHIN' ON

205-934-3283

email: sci@uab.edu

www.spinalcord.uab.edu/show.asp?durki=21396

Subscription: Free to individuals with SCI

UAB Model SCI System, 619 19th St S, SRC 529,
Birmingham, AL 35249-7330

Newsletter published twice a year covering health, research, and other issues related to SCI.

THE PROJECT

800-782-6387

www.miamiproject.miami.edu/x25.xml

PO Box 016960 (R-48), Miami, FL 33101-6960

Subscription: Free online

Newsletter published 3 times a year about work of the Miami Project to Cure Paralysis.

SCI ACCESS

734-936-7059

email: model_sci@umich.edu

www.med.umich.edu/pmr/modelsci/access.htm

Subscription: Free online

Newsletter of the Univ Michigan - Model SCI System, providing information on living effectively with SCI to persons with SCI, family members, and interested parties. Published 2 times/year.

SPINAL CORD INJURY UPDATE

206-543-3600

email: rehab@u.washington.edu

<http://depts.washington.edu/rehab/sci/update.html>

Issues: 4 issues per year

1959 NE Pacific Street, Box 356490, Seattle, WA 98195

Newsletter from the University of Washington, Department of Rehabilitation Medicine. Contains articles on SCI for health care providers and consumers. Also includes summaries of current literature on SCI.

NOTE

More information on newsletters
and magazines can be found at

www.spinalcord.uab.edu/show.asp?durki=21817

Online Communication Resources

Through the Internet and Communication Software you can "talk" to others via your computer. Connect to news groups, bulletin boards, discussion groups, message boards, and Chat Rooms for topics related to SCI and disabilities.

CANADIAN ABILITIES FOUNDATION

www.enablelink.org/chat.html?showchat=1

DISABLED INDIVIDUALS MOVEMENT FOR EQUALITY

NETWORK (DIMENET) www.dimenet.com

DISABOOM.COM

<http://www.disaboom.com/Forums/>

VIRTUAL CENTER FOR INDEPENDENT LIVING

www.virtualcil.com/chats/

NEW MOBILITY MAGAZINE CHAT ROOM

www.newmobility.com/chat.cfm

QUAD-LINK

www.2tim.net

QUAD-LIST

<http://come.to/quadlist>

VENT-USERS DISCUSSION GROUP

www.makoa.org/ventuser.htm

LOCAL AGENCIES

There are local or regional services that may be able to assist you with needs that occur due to spinal cord injury. A Social Worker at your rehabilitation center usually has the names of other agencies in your area.

INDEPENDENT LIVING CENTERS

Independent Living Centers (ILCs) offer a variety of programs and services for individuals with disabilities. ILC staff work to help the individuals achieve independence and become active in their community by providing independent living skills, peer support, and advocacy. ILC staff help determine needs and make referrals concerning issues such as accessible housing and personal care assistance. To locate an ILC in your area contact:

* **Independent Living Research Utilization (ILRU) Program**

Phone: 713-520-0232 www.ilru.org email: ilru@ilru.org

2323 S. Shepherd, Ste 1000, Houston, TX 77019

* **ILRU Directory of Centers** www.ilru.org/html/publications/directory/index.html

In **Alabama** contact:

* **Birmingham ILC** 205-251-2223 www.birminghamilc.org

* **Montgomery ILC** 334-281-8780

* **Mobile ILC** 251-460-0301

* **Jasper ILC** 205-387-0159

STATE VOCATIONAL REHABILITATION SERVICES

The goal of this agency is to help individuals with disability find gainful employment. They work to ensure that the individual is prepared and trained to work in the job best suited for his/her skills and abilities. Services may include: evaluation and assessment, counseling, skills or job training, purchase of assistive devices, job placement and follow-up. The name of each state's agency may vary. In **Alabama** it is called *Alabama Department of Rehabilitation Services*. Look in the Blue Pages of your telephone directory under State Government or in the White Pages under Government Agencies for an office in your area.

* **State Vocational Rehabilitation Services** (for phone numbers) www.spinalcord.uab.edu/show.asp?durki=30035

* **Alabama State Vocational Rehabilitation Services** www.rehab.state.al.us

* **Birmingham Vocational Rehabilitation Services** 800-441-7609

PROTECTION & ADVOCACY SYSTEMS (P&A)

The federal government supports P&A Systems in each state and territory. These systems work to protect the rights of individuals with disabilities by acting as legal advocates. They help with discrimination problems related to disability in the areas of housing, employment, education, transportation and public services. To locate the **P&A programs** in your state, contact:

* **National Disability Rights Network** 202-408-9514 www.napas.org email: info@ndrn.org

900 Second St NE, Ste 211, Washington, DC 20002

In **Alabama** contact:

* **Alabama Disabilities Advocacy Program (ADAP)** 800-826-1675 www.ADAP.net

email: adap@adap.ua.edu

Box 870395, Tuscaloosa, AL 35487

* **American's with Disabilities Act (ADA) Information Line** 800-205-9986

* **Statewide Technology Access & Response (STAR)** 334-281-8780 or 800-441-7607

www.rehab.state.al.us/star

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Certificate of Attendance

This certifies that

Attended the
**Stepping Forward-Staying Informed
Consumer Research Conference**
Spinal Cord Injury Health, Wellness, and Research

On October 23, 2010
10:00am-5:00pm

Hosted by
The New England Regional Spinal Cord Injury Center at Boston Medical Center

Learning Objectives

Attendees of this conference will

1. Understand the field of spinal cord injury research past, present, and future.
2. Understand the programs offered and supported through the Christopher and Dana Reeve Foundation.
3. Understand the Christopher and Dana Reeve Foundation Paralysis Survey, One Degree of Separation, and its impact.
4. Understand causes and consequences of cardiometabolic disorders after spinal cord injury.
5. Understand the interventions that reduce health hazards from cardiac and endocrine-related disease after spinal cord injury.
6. Describe health and quality of life outcomes of informal caregivers.
7. Describe changes in outcomes for individuals with spinal cord injuries and their caregivers who participate in support service programs.
8. Describe how a spinal cord injury effects the aging process.
9. List 3 conditions commonly associated with aging in people with spinal cord injury.