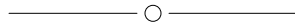


Staying Well After SCI



What You Can Do and How We
Can Help

Susan Biener Bergman, M.D.

- Commonwealth Community Care
(formerly Boston's Community Medical
Group)
- Boston Medical Center

- Framingham Solo Practice
- Framingham ACO
- New England Quality Care Alliance

Special Thanks

- Dr. Sungyul Kim- Mary Glover, ANP-BC
- My professor and Co-founder of BCMG
colleague who provided invaluable Executive Director, CCC
insights

Health Care Crisis

- Chinese word for "Crisis" combines characters for "Danger" and "Opportunity"
- We are in a unique situation which causes concern but also presents opportunities for innovation and significant improvement of health care for everyone.
- We need to emulate innovators of the past who created SCI care as we know it out of nothing.

Health Care Crisis

Danger- runaway costs threaten hard-won gains

- System in flux can reduce access to care
- Morbidity and mortality seems to be increasing
- Tendency to be “penny wise and pound foolish” .

Opportunity- many entities are scrambling to adapt and exploring creative solutions

- Dual Eligible population has potential for positive or negative change
- Past experience offers us possible solutions

Biggest Future Challenge

Acute Medical Problems in Chronic SCI Patients

- Unique medical problems: AD, Chronic Decubitus Ulcers with complications, Bladder & Bowel issues, etc.
- Most Primary Care Physicians are unfamiliar with those problems
- Patients with these problems may require longer term hospitalization while the pressure is on to get them discharged.



SCI Care - Past, Present and Future

Going back to some of the old, time honored techniques of the past will help prevent some of the most threatening and expensive SCI complications.

Investing in the right equipment and educating consumers and providers will pay off in the long run!

Past Experience

- A Brief History of SCI Care
- SCI initially “an ailment not to be treated”
- Long term survival after SCI dates back to the development of antibiotics at the end of World War II.
- Suddenly people were living longer after SCI. There was a large cohort of people who were entering the health care system, but no one really knew how to care for them.
- Parallel developments in the civilian and veteran populations. (We see this today with TBI)

SCI Care Pioneers

- Most of what we know now about best practices in SCI care comes from the work of Sir Ludwig Guttman at Stoke-Mandeville Hospital in England and Donald Munro at Boston City Hospital in the U.S.



Sir Ludwig
Guttman, MD
(1899 – 1980)



Donald
Munro, MD
(1898 – 1978)

Sir Ludwig Guttman

- German Jewish neurosurgeon who escaped Nazi Germany in 1935
- The British government recruited him to build a program to treat veterans and civilians with SCI injured in World War II. Sir Ludwig worked with returning British veterans during the war and developed management strategies for the most life threatening sequelae of SCI.

SCI Sequelae and Sir Ludwig's Solutions

- Frequent turning to prevent decubiti
- Chest PT and assisted cough
- Timed intermittent catheterization to decompress neurogenic bladder and keep down bacterial numbers in the urine
- Use of urinary acidifiers
- Timed bowel regime to maintain continence

Community Reentry- Wheelchair Sports

- Sir Ludwig believed in staying active to prevent negative SCI side effects. He developed the game of "Netball" in the mid 1940's.
- He and a group of 26 SCI patients also experimented with table tennis, archery, javelin, shot-put, and lawn bowling.
- These innovations formed the basis of the Paralympics (Harriet May Savitz in *Wheelchair Champions: A History of Wheelchair Sports*)

Boston Roots of SCI Care

- At around the same time, US Neurosurgeon Donald Munro was working on SCI care for the whole person.
- Called "Father of Paraplegia"
- Established the 1st SCI unit in US at the Boston City Hospital in 1936
- Greatest Contribution- Attitude of optimism and compassionate care for the whole person.

Other Pioneers

- Alain Rossier, MD (1930 - 2006)
 - Pioneered care for treating subsequent medical issues in chronic SCI patients.
 - Advocated for the care of SCI patients regardless of the stage of SCI
- Fred Fay, PhD
 - Former Director of RT-7 Assistive Technology Center at the Tufts-NEMCH
 - Advocated for measures (state funding of PCA care, etc.) to allow individuals with disabilities to reenter the community and play an active role
 - Worked closely with members of the Massachusetts congressional delegation, including Sen. Edward Kennedy.

Elmer C. Bartels and BCIL

Elmer Bartels, a quadriplegic himself, receiving Distinguished Service Award from Easter Seals in Washington DC



BCIL was established as a Group Residential Program sharing PCA's and other resources at the apartment complex located at the School of Theology, Boston University in 1974.

- Started Transitional Living Centers focused on Independent Living Skills training for long term independent living in the community.
- Now completely phased out of group living arrangement. Provides skills training and assists with PCA hiring and management.

Dr. Murray Freed

- One of Donald Munro's students was Dr. Murray Freed.
- I was one of his students...
- Dr. Freed was an injured veteran of WW II's Battle of the Bulge.
- Dr. Freed created the New England Regional Spinal Cord Injury Center at University Hospital/ Boston Medical Center.
- He started practice in 1956 and the Center officially opened with a Federal Model Systems grant in 1973.

SCI Model Systems

- Vietnam Era veterans with SCI increased the SCI population and added to the cohort.
- US Federal Government gave grants in 1973 to 13 hospitals to develop integrated, regionalized systems to offer multidisciplinary care to people with SCI from the moment of injury through the lifespan.
- These institutions allowed for development of treatment protocols, databases, statistically proven best practices and experienced care teams to deal with a very high intensity but low incidence diagnosis.
- Regional model was extremely important to limit duplication of effort and division of labor.

Models Systems and NERSCIC

- The model systems stressed educating the patient to cope with their altered physiology. They used the power of peer and family support. They worked with and coordinated with local resources.
- Dr. Freed worked with local resources including Liberty Mutual Insurance, the Massachusetts Rehabilitation Commission (under Dr. Elmer Bartels) and BCIL

Model Systems

- The Model Systems have since expanded to cover other conditions including traumatic brain injury.
- What we have learned has allowed us to offer better care to people with all kinds of conditions, including childhood onset conditions like CP and acquired conditions like MS, strokes, etc.
- NERSCIC
 - NERSCIC was based at BMC from 1973 through July, 2012 when it was closed by the hospital. It was a regional resource for patients with spinal cord injuries at all levels of care.

NERSCIC - SCI Care Then and Now

- “F5,” as it was affectionately known, was a unique place. It was a cross between a hospital, a school and a boot camp. It cared for patients who were healthy enough stay out of the ICU. Anyone with a chronic SCI and any other acute medical problem was assigned a bed there. People with new injuries were transferred there as soon as they were healthy enough to leave the ICU.

NERSCIC - SCI Care Then and Now

- The ward was designed to eliminate architectural and personal barriers. Nursing protocols were built around appropriate bladder and bowel management. Equipment was designed to prevent skin breakdowns and improve ease of use for patients.
- By design, folks with new injuries were placed in the same room with folks who had been injured for many years. Patients and families learned to problem solve together.

SCI Care Then and Now

- Life expectancy increased and people with SCI returned home and reentered the community.
- By the time of discharge they were experts in their own care and could talk anyone through it- with or without a medical background.

SCI Care Then and Now

- Insurers at first recognized the value of this approach.
- At one time Liberty Mutual sent anyone in the U.S. with an SCI to Boston to be cared for by Dr. Freed and his team.
- After discharge they returned home and Dr. Freed's team served as a resource for their local caregivers.
- F5 was a medical-surgical unit with a rehabilitation focus.

SCI Care Then and Now

- Rising health care costs changed the way care was delivered. This has happened in a very short period of time.
- At BMC F5 was "zoned" as a medical/ surgical unit within an acute care hospital rather than as a rehabilitation unit. This allowed people with new and longer term injuries to be cared for together seamlessly no matter what the medical issue. However, this kind of high quality care was very expensive.

Limits of the Health Care System

- DRG's and Managed Care were implemented to reduce health care costs. The search was on to deliver care in less expensive settings.
- Lengths of stay were shortened.
- Rehab units were restricted to people with new injuries. If a medical problem arose, the person was discharged from rehab back to the acute hospital med-surg unit and then readmitted when stable.
- Sometimes they developed new problems in the acute hospital...

SCI Care Then

- Care shifted away from the hospital inpatient setting and towards rehabilitation specialty hospitals and even some skilled nursing facilities.
- BMC could no longer afford a geographically distinct SCI unit.
- In 1999 the designation changed to a rehabilitation unit and SCI patients with other medical problems were admitted to general medical units.

SCI Care Now

In July, 2012 BMC closed the last rehabilitation unit within an acute hospital in Massachusetts.

- We are now in a new period of rapid change.
- And again we are in a period where danger and opportunity come together.

SCI Care Now

- “Necessity is the mother of invention!”
- Our predecessors responded to the issues of their day by creating systems to deliver the highest quality care possible to people with complicated disabling conditions.
- These systems emphasized wellness and taught people how to manage their medical issues in order to take their rightful places in the community.
- Now it is our turn to innovate.

Crisis- Danger + Opportunity

- There are new opportunities to deliver high quality care to people with chronic conditions
- It is up to all of us to make sure that the next chapter in the medical care of people with disabilities represents forward progress.

Changes in MA Health Care

- MA is implementing a global payment system instead of fee for service which could revolutionize the way chronic conditions are managed.
- As long as global payments are high enough to cover costs they could allow providers enough flexibility to make investments in the right equipment and meds to prevent rather than respond to known problem areas.

What Now?

- There are multiple working groups now exploring best ways to care for people with disabling chronic conditions
- Models are being developed and expanded to coordinate care statewide as well as nation wide.

What Now?

- The Office of Health Care Innovation and CMS are looking at different models of care.
- There are only 3 practices in the country who concentrate on the needs of those with disabilities.
- One is located in NY, one is in Wisconsin and one is here in Boston. That practice is BCMG.

BCMG Model

- BCMG (Boston's Community Medical Group) was formerly a program within The Urban Medical Group
- Co- Founded by Dr. Marie Feltin, Dr. Robert Master and Mary Glover, ANP-BC
- Worked closely with BCIL to provide follow-up medical care for people with many disabilities after discharge from acute care and rehabilitation units.

BCMG Model

- Delivers community based primary care to people with complex disabilities
- Multidisciplinary team approach includes physicians, NPs, PAs, Behavioral health professionals, PT, OT, SLP, social workers and other disciplines as needed.
- Upon enrollment, each patient is assigned to a primary doctor and nurse practitioner or physician's assistant.

BCMG Model

- BCMG offers home visits from NP/ PA's as first line care.
- MDs make home visits or see patients in the office as indicated by the condition. Specialists are consulted as needed.
- Team meets regularly to review patient care plans
- Model is being expanded now and will hopefully be used nationwide

BCMG Model

- Home visits form the backbone of care to make the care accessible to patients.
- The challenge is bringing this model to outlying areas as nurses can travel only so far.
- Stay tuned!!!

BCMG Model

- BCMG expansion
Now part of CMA (Community Medical Alliance)
- BCMG name is changing to CCC
(Commonwealth Community Care)

The name may change, but the
commitment to care will not.

Commonwealth Community Care

- Prototype of the "patient centered medical home."
- This model is being explored by many different entities.
- In the last year I have been asked to sit on 2 different advisory boards (unrelated to CCA) to develop PCMH in different parts of the state.

Pros and Cons of the New System

- That's great, but now where do I go for my medical care?
- What does all this mean to you????

Pros and Cons of the New System

- New emphasis on the "patient centered medical home" validates and reinforces the rehab model
- Team approach with the patient at the center
- Each member of the team has a different area of expertise to offer

Pros of the New System

- Community based care allows for home visits and better access to care
- NP becomes the first “go to” person and helps you choose the best person on the team to help solve the problem
- Regular team meetings allow team members to “pick each other’s brains” to solve problems

Cons of the New System

- Large influx of new patients all at once means that you may be seeing someone without a lot of experience with SCI in particular
- Not a new issue- in the regionalized model people returned to their home community after rehab and resumed their relationship with their local doctors
- Details are still being worked out - things keep changing. This gives us a chance to be part of the solution.

Draw on the Strengths

- So it still all comes down to arming yourself with as much accurate information as you can
- Go to lectures like this one, learn as much as you can
- Best resources - *Paralyzed Veterans of America* , *National Spinal Cord Injury Association (NSCIA)*

Take Charge of Your Health

- In brief, your best bet is to know your own body and be able to articulate your needs and concerns.
- Use all available resources to educate yourself about SCI and its known problem issues.
- Loss of the regional model means that people who know about SCI are scattered in different places.

Take Charge of Your Health

- YOU are the one who knows your own body best.
- In the new world of health care, you may well be the person who knows the most about SCI in the room.
- The good news is that health care providers want to help and are trained to recognize disease patterns.

Opportunities

- New communication platforms (including EMR) increase access to information that was previously locked away
- If you are far from SCI resources, encourage your provider to call a regional center for help

Make the Most of Your Visit

- Be as organized as possible so you can use your time efficiently
- Consider writing down any questions or concerns you have so you can be sure they will be addressed first

Make the Most of Your Visit

- Be sure that all of your most important concerns are addressed at each routine follow-up visit as there may be a relationship between seemingly unrelated symptoms that unlocks the puzzle.

A Great Place to Start

- Dr. Freed used the mnemonic

- **NIBBLES**

NIBBLES

- **N**- Neurologic and Orthopedic Status
- **I**- Integument (Skin)
- **B**- Bladder and urinary tract
- **B**- Bowels and digestive issues
- **L**- Lungs and general medical issues
- **E**- Equipment issues
- **S**- Sexuality and psychological concerns

N- Neurologic and Orthopedic Status

- Has there been any change in your motor or sensory level since your last visit?
- Are you in any pain? If so, where is it and what does it feel like?
- What makes it better? What makes it worse?
- Are there any joint deformities? Fractures? Changes in ROM? Spine deformities? Osteoporosis?

N- Neurologic and Orthopedic Status

- ***Spasticity***- Has there been a change in your level of spasticity?
- If so, in what time period?
- What part(s) of your body are affected?
- Does it interfere with your function or sleeping? Does it hurt?
- Or does it actually help?

N- Neurologic and Orthopedic Status

- Be alert to changes in the baseline pattern and level of your spasticity.
- Spasticity will increase in response to noxious stimuli (anything that would hurt) so it may be the first sign of a problem.

Spasticity- “Sentinel Symptom”

- A change in the level of your spasticity should trigger a search for the cause.
- Most times, the source will be in the urinary or digestive tract.
- It can herald the beginning of a UTI, a stone, a fecal impaction or a pressure sore.

I- Integument

- Skin issues are one of the most devastating and difficult issues after SCI
- It takes very little sustained pressure to cause tissue damage
- Skin ulcers are like icebergs- what you see on the surface may not be the whole picture

Protecting Your Skin

- Pressure Relief is key-
- Frequent turns, physically shifting weight and pressure relief cushions and mattresses are helpful.
- Taking pressure off bony prominences helps prevent deep tissue loss.
- "The price of freedom is eternal vigilance."
- "An ounce of prevention is worth a pound of cure."

What to Do

- Do your pressure reliefs, make sure your equipment is properly maintained.
- Watch your technique during transfers, especially toilet and car transfers.
- At the first sign of breakdown, get off it and call your provider!!

B- Bladder and Urinary Tract

- Neurogenic bladder is present in most, if not all, people with SCI in one form or another and needs to be addressed.
- Before Sir Ludwig instituted the ICP technique, repeated UTIs and renal failure shortened life expectancy after SCI to an average of 18 months.
- Goals of bladder management include-

Goals of Bladder Management

- Prevent the backflow of urine back up into the kidneys.
- Keep pressure within the bladder at optimal levels to protect delicate kidney tissue.
- Limit the number and type of bacteria present in the urine to prevent infection as much as possible.

Goals of Bladder Management

- Prevent incontinence to keep skin dry and prevent odor
- Limit the amount of time that foreign bodies are present in the bladder- they increase infection and risk tumors
- Prevent formation of stones
- Prevent infection
- Early detection and treatment of poor kidney function or tumors

Treatment Options

- Medications to reduce high bladder pressure and promote urine flow
- Adequate fluid intake
- Intermittent Catheterization
- Suprapubic Tube and Foley Catheter- should be used as a last resort
- Botox - limited applications
- Urinary acidifiers to create a hostile environment for invasive bacteria

Screening

- Baseline Urodynamics to determine pressure levels and timing of muscle contractions.
- Renal Ultrasound every 2-3 years
- Urinalysis and Culture to assess UTI symptoms
- Be alert to symptoms of spasticity or AD
- Check blood work as needed

B- Bowel

- Neurogenic bowel is present in most, if not all, people with SCI in one form or another.
- Maintaining continence is a goal that can be reached but it requires a structured bowel care regime and a carefully balanced diet.

B- Bowel

- Let your provider know if you are having accidents, AD symptoms, increased spasticity, dark, tarry stools or rectal bleeding
- People over 50 or who have a positive family history of colon cancer or polyposis should be screened with colonoscopy just like the general population

L- Lungs, Cardio, General Medical

- Breathing issues, circulatory issues, screening for lipid disorders and diabetes
- Risks for these are increased in SCI
- If your spinal cord level is above T6 tell your provider about AD episodes
- Follow general principles for recommended screenings including STD / chlamydia, lipid disorders, diabetes, colorectal, breast, cervical and other cancers

L- Lungs, Cardio, General Med

- Immunizations
- Nutrition and Weight Management
- Obesity is a major risk!
- Regular Exercise
- BP Checks

E- Equipment

- Mobility- Wheelchair, hand held assistive devices, braces, shoes, adapted vehicles.
- ADLs- Adaptive equipment including electric beds, pressure relief mattresses, shower/commode chairs, pressure relief cushions, reachers, splints, utensils, ECU's.

E- Equipment

- Vocational Equipment- Computers, voice activated software, speech synthesizers, magnifiers, TDD devices, etc.

S- Sexuality, Psychological Adjustment

- Neurogenic sexual dysfunction
- Fertility / STD's
- Adjustment to Disability
- Depression, substance abuse screening
- Family Stress
- Community re-entry

Conclusions

- Staying well after SCI is possible but it takes work and commitment on everyone's part.
- Current changes in health care present challenges and opportunities for us to work together to make wellness an achievable goal.

Resources

- **PVA- Paralyzed Veterans of America-** excellent series of monographs available as PDF files or in print. These review topics like Neurogenic Bowel, Neurogenic Bladder, Autonomic Dysreflexia, etc. in plain English for consumers as well as health care providers.
- **ASIA- American Spinal Injury Association-**
- For people with and without medical backgrounds. They maintain accepted standards so research results can be uniformly applied. Education for patients and providers.

Resources

- **Christopher and Dana Reeve Foundation**
- **MISSION STATEMENT:** The Reeve Foundation is dedicated to curing spinal cord injury by funding innovative research, and improving the quality of life for people living with paralysis through grants, information and advocacy.

Resources

- **Travis Roy Foundation**

MISSION STATEMENT

The Travis Roy Foundation is dedicated to enhancing the life of individuals with spinal cord injuries and their families by providing adaptive equipment and to finding a cure through increased funding of research, resulting in self-reliance and the ability to be as independent as possible

Resources

- **NSCIA- National Spinal Cord Injury Association**

- **Mission**

- Our mission is to improve the quality of life of all people living with spinal cord injuries and disorders (SCI/D).
- We provide active-lifestyle information, peer support and advocacy that empower individuals to achieve their highest potential in all facets of life.

Resources

- Model Systems websites
- Yes You Can Manual

- Peer Experiences
- You may be able to help others!

Q&A

- Contact information- Susan Biener Bergman, M.D.

- Commonwealth Community Care (BCMG),
BMC- 850 Harrison Ave., Dowling 5108, Boston, MA
02118, 617-638-7062. Susan.bergman@bmc.org

- Framingham Office- 600 Worcester Rd., Suite
LL3, Framingham, MA, 508-405-4566