

POST-POLIO HEALTH 10th International Conference
INTERNATIONAL

Living with Polio in the 21st Century

April 23-25, 2009

Friday, April 24, 2009

Session F1, 9:30–10:45 am
through
Session F4, 2:45–4:00 pm

This book belongs to

POST-POLIO HEALTH
INTERNATIONAL

POST-POLIO HEALTH INTERNATIONAL
INCLUDING INTERNATIONAL VENTILATOR USERS NETWORK

ROOSEVELT
WARM SPRINGS



POST-POLIO HEALTH INTERNATIONAL
INCLUDING INTERNATIONAL VENTILATOR USERS NETWORK

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www.post-polio.org
info@post-polio.org
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QUESTIONS from the audience will be submitted to the speaker/moderator in writing unless otherwise announced in the session.

Post-Polio Health International (PHI) thanks the presenters for providing the excellent information contained in the daily program books.

If you share this information, we respectfully ask that you acknowledge the presenter and that the information was disseminated at PHI's 10th International Conference: Living with Polio in the 21st Century (April 2009). PHI will incorporate additional information presented at the conference and make it available to attendees and others at a later date. Details will be published in *Post-Polio Health* and on www.post-polio.org.

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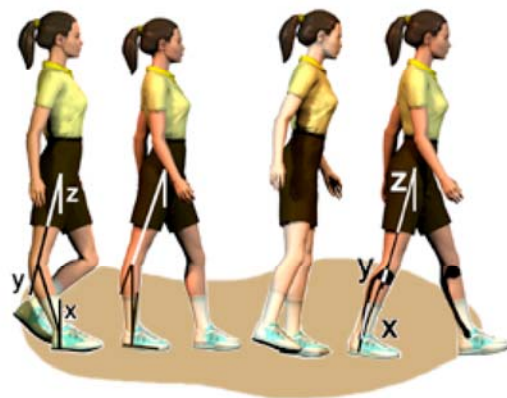
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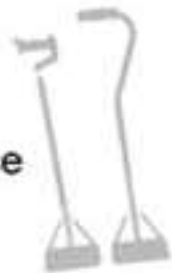
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EXHIBITORS

Visit the following companies in Georgia Hall during these hours:

Friday, April 24 from 11:30 am–7:00 pm

Saturday, April 25 from 8:30 am–1:30 pm



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Welcome to the Roosevelt Warm Springs Institute for Rehabilitation.

Whether you have been here before or this is your very first time on our campus, we are thrilled to have you here as our guests. As you may know, we are the “living legacy” of FDR’s vision for healing, so as you enjoy your symposium you will notice patients and students coming and going, and that we are very much a living and breathing rehabilitation center. We have been providing rehabilitation for 81 years, and you will also note that parts of our campus show our age.

We are not a modern conference center like you may find in downtown Atlanta, but we have something that they don’t. My hope for you during your visit is that you experience what we call the “Spirit of Warm Springs,” which refers to our caring and compassion. We are very proud of our historic legacy, and I encourage you to reflect on that as you travel around and across our campus. Franklin D. Roosevelt never learned to walk by coming here, but I believe it made him a better man and a much better President. So on behalf of all of us who come to work here every day in pursuit of the same mission “to empower individuals with disabilities to achieve personal independence” as FDR did, welcome to this place of healing. May you enjoy your conference and fully enjoy your stay with us.

Greg Schmieg
Executive Director, RWSIR

From Post-Polio Health International (PHI):

Welcome to the tenth in our series of international conferences.

PHI's goal for these conferences has always been threefold: First, we aim to promote the face-to-face exchange of authoritative, up-to-date information about the late effects of polio and independent living with its consequences. Second, we aim to sustain a productive network of active polio survivors and healthcare professionals with relevant expertise – by providing a forum in which these two groups can inform each other and interact. Third, we aim to disseminate the results of our conferences to all those interested polio survivors and medical professionals who are unable to attend.

We are honored to have this conference at Roosevelt Warm Springs Institute for Rehabilitation (RWSIR). RWSIR's place in the history of physical medicine and rehabilitation is a prominent one indeed. It began with Franklin Delano Roosevelt, and with the idea of rehabilitation as a cooperative venture between medical professionals and polio survivors. From its beginnings, like PHI, it has also been dedicated to helping people develop and sustain the functional abilities necessary for independent living with a physical disability.

This event was made possible by the dedicated labors of many staff members at RWSIR. To all of them, we owe our thanks. We also thank Carolyn Raville, founder of the North Central Florida Post-Polio Support Group, for suggesting a post-polio conference at RWSIR.

Thank you for joining us to learn about "Living with Polio in the 21st Century."

Lawrence C. Becker
Chair, Board of Directors, Post-Polio Health International

Acknowledgements

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Carolyn Raville, Founder, North Central Florida Post-Polio Support Group, Ocala, Florida
Greg Schmieg, Executive Director, Roosevelt Warm Springs Institute for Rehabilitation (RWSIR),
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Christy Osborn, PT, Retreat On-Site Program Coordinator, Bay Cliff Health Camp, Big Bay, Michigan
Reenae White, Camp Dream Coordinator, RWSIR, Warm Springs, Georgia

Special Acknowledgement

Denise Burson, Executive Secretary, RWSIR
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Program / Friday, April 24, 2009

8:30 am – 1:30 pm

Registration in GEORGIA HALL

8:30 am – 9:30 pm

Continental Breakfast

9:30–10:45 am

SESSION F1 OPTIONS

Demonstration and Discussion of a Post-Polio Examination: Don't Forget Breathing, Part 2

ROOSEVELT HALL AUDITORIUM

Frederick Maynard, MD, UP Rehabilitation Medical Associates, Marquette, Michigan

Brenda Butka, MD, Vanderbilt Stallworth Rehabilitation Hospital, Nashville, Tennessee

William DeMayo, MD, John P. Murtha Neuroscience and Pain Institute (JPMNPI), Johnstown, Pennsylvania

Martin Wice, MD, Medical Director, St. John's Mercy Rehabilitation Hospital, St. Louis, Missouri

Warm Springs During the Epidemic Years: Not the Usual Story

SCHOOLHOUSE 105

David W. Rose, Archivist, March of Dimes, White Plains, New York

Michael Shadix, Librarian, RWSIR, Warm Springs, Georgia

Daniel J. Wilson, PhD, Muhlenberg College, Allentown, Pennsylvania

Demonstration and Discussion of a Bracing Evaluation

MEADOWS CLASSROOM

David P. Guy, PT, MS, Scottsdale, Arizona

Marmaduke Loke, CPO, Dynamic Bracing Solutions, Inc., San Diego, California

Mark Taylor, MLS, CPO, FAAOP, University of Michigan, Ann Arbor, Michigan

Research Progress

SCHOOLHOUSE 111

PHI Research Grant: Progress on a Biomarker for PPS

Rahnuma Wahid, PhD, Manager Analytical Immunology, Sanofi Pasteur, Swiftwater, Pennsylvania, formerly University of Arkansas for Medical Sciences, Little Rock, Arkansas

Summary of Post-Polio Research at University of Amsterdam

Frans Nollet, MD, PhD, Academic Medical Center, University of Amsterdam, Amsterdam, The Netherlands

Aging with a Disability: Policy Lessons Learned from Polio

VRU AUDITORIUM

Fernando Torres-Gil, Associate Dean for Academic Affairs at the School of Public Policy and Social Research, University of California, Los Angeles

11:30 am – 1:30 pm

Lunch on Your Own at the RWSIR Cafeteria. Vegetarian available. (Attendees will choose from Session F2 or F3 and eat lunch during the other time slot.)

11:15–12:30 pm

SESSION F2 OPTIONS

Finding Causes of and Managing Fatigue, Part 1

VRU AUDITORIUM

Frans Nollet, MD, PhD, Academic Medical Center, University of Amsterdam, Amsterdam, The Netherlands

Daria Trojan, MD, Physical Medicine and Rehabilitation, Montreal Neurological Institute and Hospital, Montreal, Quebec, Canada

Martin Wice, MD, Medical Director, St. John's Mercy Rehabilitation Hospital, St. Louis, Missouri

**Making the Tough Decisions:
Palliative Care and End-of-Life
Decisions**

SCHOOLHOUSE 111

Lawrence C. Becker, Fellow, Hollins
University, Professor of Philosophy Emeritus,
College of William & Mary, Roanoke, Virginia
Fernando Torres-Gil, Associate Dean for
Academic Affairs at the School of Public Policy
and Social Research, University of California,
Los Angeles

**Anesthesia Update: Separating Fact
from Fear**

ROOSEVELT HALL AUDITORIUM

Selma H. Calmes, MD, (Ret),
Olive View/UCLA Medical Center,
Sylmar, California

**Demonstration and Discussion of a
Seating Evaluation**

MEADOWS CLASSROOM

Rene James, PT, RWSIR,
Warm Springs, Georgia
Trina Ouzts, PT, RWSIR,
Warm Springs, Georgia

**Benefits and Techniques of Aquatic
Therapy**

SCHOOLHOUSE 105

Cynthia Henley, PT, Miami, Florida
Kathryn Wollam, PT, Coral Springs, Florida

1:00–2:15 pm

SESSION F3 OPTIONS

**Current Epidemics: Status, Lessons
and Tasks**

SCHOOLHOUSE 111

John Fitzsimmons, Centers for Disease Control
and Prevention, Atlanta, Georgia
Ann Lee Hussey, Chair, Polio Survivors
and Associates Rotary Action Group,
South Berwick, Maine

**Using Assistive Technology for
Personal Independence**

SCHOOLHOUSE 105

Samantha Massengale, OTR, RWSIR,
Warm Springs, Georgia

**Exercise: The Kinds, the Methods and
the Benefits**

MEADOWS CLASSROOM

Merete Bertelsen, PT, The Danish Society of
Polio and Accident Victims, Rodovre, Denmark
Frederick Maynard, MD, UP Rehabilitation
Medical Associates, Marquette, Michigan

**Cardiovascular Complications and
Prevention Tips**

VRU AUDITORIUM

Sunita Dodani, MD, MSc, PhD, FAHA,
Director, Center for Outcome Research
and Education (CORE), Associate Professor,
Department of Internal Medicine,
Kansas University Medical Center,
Kansas City, Kansas

**Communicating with Your Physician:
Techniques that Work**

ROOSEVELT HALL AUDITORIUM

William DeMayo, MD, John P. Murtha
Neuroscience and Pain Institute (JPMNPI),
Johnstown, Pennsylvania

Barbara Duryea, MSN, RN, CPHQ, John P.
Murtha Neuroscience and Pain Institute
(JPMNPI), Johnstown, Pennsylvania

William Stothers, The Center for an Accessible
Society, San Diego, California

2:45–4:00 pm

SESSION F4 OPTIONS

Finding Causes of and Managing Fatigue, Part 2

VRU AUDITORIUM

Frans Nollet, MD, PhD, Academic Medical Center, University of Amsterdam, Amsterdam, The Netherlands

Daria Trojan, MD, Physical Medicine and Rehabilitation, Montreal Neurological Institute and Hospital, Montreal, Quebec, Canada

Martin Wice, MD, Medical Director, St. John's Mercy Rehabilitation Hospital, St. Louis, Missouri

Effective Family Communication: Do We? How Can We Improve?

ROOSEVELT HALL AUDITORIUM

Annamarie Barber, RN, Polio Survivors & Friends of East Central Illinois, Charleston, Illinois

Linda Bieniek, CEAP, LaGrange, Illinois

Exercise and Activity: How Much and What? Let's Get Practical

MEADOWS CLASSROOM

Merete Bertelsen, PT, The Danish Society of Polio and Accident Victims, Rodovre,, Denmark

John G. Fan, MD, Hutchinson Clinic, Hutchinson, Kansas

Complementary and Alternative Medicine: What You Don't Know Can Hurt You

SCHOOLHOUSE 105

Barbara Duryea, MSN, RN, CPHQ, John P. Murtha Neuroscience and Pain Institute (JPMNPI), Johnstown, Pennsylvania

Assisted Living Communities for Survivors

SCHOOLHOUSE 111

Sue Burgess, Atlanta Regional Commission, Atlanta, Georgia

4:30 – 6:30 pm

Story telling and pizza in GEORGIA HALL

7:00 – 9:00 pm

Film Night in ROOSEVELT HALL

AUDITORIUM and VRU AUDITORIUM

SESSION F1

Demonstration and Discussion of a Post-Polio Examination: Don't Forget Breathing, Part 2

Frederick Maynard, MD, UP Rehabilitation Medical Associates,
Marquette, Michigan

Brenda Butka, MD, Vanderbilt Stallworth Rehabilitation Hospital,
Nashville, Tennessee

William DeMayo, MD, John P. Murtha Neuroscience and Pain Institute (JPMNPI),
Johnstown, Pennsylvania

Martin Wice, MD, Medical Director,
St. John's Mercy Rehabilitation Hospital, St. Louis, Missouri

Post-Polio Patient Assessment

Frederick Maynard, MD, UP Rehabilitation Medical Associates,
Marquette, Michigan

I. History

A. Chief Concerns: eg. Pain, fatigue, new weakness, change in function

B. Polio History

1. Age and severity during first month; historical year
2. Early rehabilitation highlights and timeframes of recovery
3. Residual disability at maximum recovery or after 2 years
4. Any rehabilitative surgeries and/or History of device/brace use
5. More recent or later (>15 years) changes in strength or function
6. Current motor functional capacity

C. Past General Medical History

1. Chronic conditions
2. Injuries
3. Surgeries
4. Timing of above in relation to PPS symptoms

D. Current Health

1. Review of Systems: pain, fatigue, new weakness, breathing or swallowing problems, sleep, weight change
2. Current medications

E. Family & Social History

1. Lifestyle Assessment relative to health & wellness
2. Psychological & social stressors

F. Review Relevant Medical, Laboratory & Imaging Reports

II. Examination

**A. Observe Function: seating/standing/walking postures and capacities—
do fully clothed and with usual devices/methods**

B. Formal Range of Motion assessment of joints & muscles

C. Strength assessment of key functional muscle groups (modified MMT)

D. General and/or focused Orthopedic Exam

1. Structural deformities of neck, back, chest, limbs
2. Joint Instability
3. Leg Length Discrepancy

E. General and/or focused Neurologic Exam

1. Muscle tone and bulk (?atrophy)
2. Reflexes
3. Sensation
4. Co-ordination
5. Mental status & affect

F. Provocative Pain Examination

1. Can pain be reproduced during the exam?
2. Does pain occur with active and/or passive movements, or with pressure?

G. Focused Evaluation of Gait or other Functions

1. With and without devices
2. Challenged

III. Planning

A. Is More Information Needed?

1. Lab Studies: eg. CBC, thyroid, blood sugar, etc.
2. Further X-Rays or Imaging Studies
3. Electrodiagnostics: EMG, Conduction studies
4. Pulmonary Function Studies and Arterial Blood Gases
5. Sleep Studies
6. Rehab.Team Evaluations: PT, OT, CR, Psych/social work, orthotics, dietician
7. Medical evaluations: Orthopedist, Neurologist, Internist (pulmonologist, cardiologist), ENT, Psychiatrist, Surgeon
8. Medical Records/Reports: eg. Primary Care Physician, original polio care, reconstructive surgery operative reports, etc.

B. Preliminary Goals Presented and Discussed with Patient (and family)

C. Short-term and Long-term Goals Agreed to by Patient & Physician

D. Treatment Plan Outlined and Agreed To

For Example:

1. Weight Loss Plan
2. Use Bi-PAP at night
3. Obtain orthosis (brace) and follow with PT to learn correct use & adjust
4. PT for Individualized Exercise Program
5. Pain Management Plan
6. Counseling & anti-depressant use
7. OT for energy conservation plan

Respiratory Evaluation

Brenda Butka, MD
Division of Allergy, Pulmonary and Critical Care Medicine
Vanderbilt School of Medicine
Vanderbilt Stallworth Rehabilitation Hospital

Symptoms and Examination

Breathing: how do you know you have a problem?

- shortness of breath
- fatigue
- headaches, especially in the morning
- grogginess
- “sleep attack”—need to nap more often
- edema

History

- polio history, including iron lung or respiratory problems
- respiratory symptoms
- recurrent pneumonias
- sleep
- swallowing, especially if associated cough
- cough
- nasal or “sinus” problems
- other elements of complete history

Examination

- oxygen saturation—normal is >95%
- voice: “wet”, hoarse, nasal
- chest expansion
- diaphragm excursion
- scoliosis
- auscultation: listen to lungs for abnormal sounds
- heart exam
- edema

Chest X-ray: maybe, especially if smoker

Pulmonary function tests, especially

- vital capacity: “largest breath you can take”
- MIP/NIF: “how hard you can suck”
- MEP: “how hard you can blow”

Arterial blood gases: rarely

- if oxygen saturation is low

Physiology

Breathing

- pulls in oxygen = fuel
- blows off carbon dioxide = waste
- maintains acid-base balance (with kidneys)

Respiratory system

- brain signals
- nerve carries signal
- muscles help keep airway open

- muscles inhale/exhale gas
- lungs transmit gas into and out of blood
- feedback system
 - oxygen sensors
 - carbon dioxide sensors
 - stretch/"work" sensors

Respiratory failure

- low oxygen
 - secretions
 - damaged lungs
 - high carbon dioxide decreases "room" for oxygen
- high carbon dioxide
 - not enough ventilation/air moving through lungs

Shortness of breath is NOT the same as respiratory failure

- athletes' exertion produces shortness of breath
- panic attack produces shortness of breath

Polio affects breathing

- muscle weakness
- scoliosis
- obesity
- sleep disordered breathing
- bulbar muscle dysfunction
- aspiration

Muscle Weakness

Muscle weakness

- diaphragm: inspiration
- chest wall: some inspiration and cough
- abdominal muscles: cough

Concerns with muscle weakness:

- "pulmonary hygiene" = cough = secretion management
- ventilatory support

Cough

Cough = "queen of pulmonary hygiene": goal is to produce effective cough

Elements of cough

- inspiratory volume
- expiratory power
- close/release vocal cords ("glottis") to build up pressure

Cough: Glottis closure

- can cap trach
- otherwise hard to intervene

Cough: Volume

- main muscle is diaphragm
- measure vital capacity on pulmonary function tests
- if less than 50%, may need assist

Cough: Volume assist: goal is to boost inspiratory volume to normal

- breath stacking
 - glossopharyngeal breathing
 - stacked Ambu breaths
 - have to be able to occlude expiratory port
 - use volume ventilator to stack breaths

-Cough Assist unit

- delivers single large breath, pressure-limited
- goal is pressure of 40 cm water or more
- be SURE to get an automatic unit!

Interfaces between equipment and human being, depending on oral muscle strength

- mouthpiece
- lip seal
- face mask: less efficient, but much better than nothing
- tracheostomy

Cough: Expiratory power

- muscles are mainly abdominals
- measure peak flow on pulmonary function tests
- some measure cough peak flow
- if less than 5 liters per second, may need assist

Cough: Expiratory assist (after obtaining adequate volume)

- manual assist cough: similar to Heimlich maneuver
- Cough Assist unit
 - switches from breath in to suction/breath out
 - VERY effective in right patients

Vibrating vest

- does not provide volume or expiratory power
- very useful in other conditions
- sometimes used with muscle weakness if patient can't use Cough Assist

Ventilation

Ventilatory support

- noninvasive (NIV)
- invasive/trach

What can ventilatory support do for you?

- prolong life
- increase energy
- decrease respiratory infections/hospitalizations

Noninvasive Ventilation

Noninvasive ventilation criteria

- sleep-disordered breathing/sleep lab
- dx neuromuscular disease +
 - vital capacity less than 50% OR
 - NIF less than -60 cm H2O
- do NOT need sleep study if you fit these criteria

NIV equipment

- mostly Bipap WITH backup rate
- sometimes volume ventilator with mouthpiece during the day

NIV interfaces

- mouthpiece
- nasal mask
- full face mask
- oral interface

Negative pressure ventilation

- cuirass or "iron lung" variations
- less efficient than current positive pressure modalities

Invasive Ventilation/Tracheostomy

Invasive ventilation/tracheostomy

- respiratory failure in spite of noninvasive ventilation
 - bulbar muscle involvement
 - scoliosis
- acute failure/pneumonia
- secretion management

Demythologizing trachs:

- can usually talk, often while being actively ventilated
- may not be on ventilator all the time anyway
- can eat

Advantages of tracheostomy ventilation

- secure airway
- access for secretion management
- no mask/mouthpiece in the way for eating and perhaps talking
- volume ventilators have batteries and alarms = VERY portable

Volume ventilators

- small
- batteries for 6-8 hours
- we use Newport HT50, sometimes Pulmonetic
- no longer need to rebuild wheelchairs to accommodate vents!

Mobility

- skydiving
- horseback riding
- sledding
- travel

Sleep Disorders

Sleep disorders

- obstructive
 - bulbar muscle dysfunction
 - obesity
 - small jaw
- central
 - disordered brain signals
- other sleep disorders

Sleep disorders: evaluate in sleep lab by sleep specialists

- home sleep study inadequate

Swallowing

Swallowing

- aspiration risks
 - concerns if coughing with eating or drinking
 - recurrent pneumonias
- swallow evaluation by speech therapy

How does one assess an individual for the post-polio syndrome?

**Martin Wice, MD, Medical Director
St. John's Mercy Rehabilitation Hospital, St. Louis, Missouri**

The first thing I do when I examine polio survivors is to get a very detailed medical history from the time they had polio through their entire recovery process and then their new decline. I conduct a detailed physical examination, including a neuromuscular and functional evaluation. Tests are performed not so much to prove one has the post-polio syndrome (no test can do this), but to rule out other problems which can masquerade for it. Tests include blood work (including a CBC, chemistry profile, thyroid screen, CPK, and ANA), and a vital capacity (a breathing screen).

If I have cause for concern about breathing, I request a blood gas, which checks for oxygenation and for CO₂ retention. I may request a sleep study I may also do a special barium "cookie" swallowing study if swallowing is a problem. I may do electrodiagnostic testing of the arms and legs, not to prove that someone has the post-polio syndrome, but to look for other problems – carpal tunnel syndrome, radiculopathy – which may explain someone's symptoms. I also may request appropriate radiological testing such as x-rays of joints that are hurting to look for arthritis or for fractures. I may request an MRI scan of the spine to make sure nothing else is masquerading for the post-polio syndrome.

Other tests can be requested depending on what is found during the physical examination. Depending on the results of the above-mentioned tests, I will arrange appropriate referrals.

It is important that the patient and his/her family get the most out of the evaluation. It is to bring in all relevant information including a completed patient profile, if sent, records of past evaluations, test results, treatments and treatment results and to have their questions in writing with someone to help record the answers.

Warm Springs During the Epidemic Years: Not the Usual Story

David W. Rose, Archivist, March of Dimes, White Plains, New York

Michael Shadix, Librarian, RWSIR, Warm Springs, Georgia

Daniel J. Wilson, PhD, Muhlenberg College, Allentown, Pennsylvania

Friends and Partners: The Legacy of Franklin Roosevelt and Basil O'Connor in the History of Polio

David W. Rose, March of Dimes Archivist

David Rose has been Archivist of the March of Dimes since 2001. He is a Certified Archivist of the Academy of Certified Archivists, and he oversees the preservation and organization of the documents, photographs, and films of the March of Dimes Archives in its national office in White Plains, New York. He is author of the first photographic history of the March of Dimes in the Arcadia Images of America series published in 2003. David is a writer, amateur mycologist (the study of mushrooms), and contributing editor to Fungi Magazine for which he writes a regular column. He has been Consulting Archivist to the New York State Museum and the North American Mycological Association. He is also an advisor to the Jonas Salk Legacy Foundation. David holds a Masters degree in Anthropology from the New School for Social Research (New York, NY) and a Bachelor's degree in Anthropology and Philosophy from Case Western Reserve University (Cleveland, Ohio).

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Among the multitude of Franklin Delano Roosevelt's enduring accomplishments is his creation of the March of Dimes, founded as the National Foundation for Infantile Paralysis (NFIP) in 1938. FDR created the NFIP by presidential proclamation on September 23, 1937 to "lead, direct, and unify" the fight against polio. The new foundation quickly became a beloved institution through its popular March of Dimes fund-raising campaigns and through which it claimed the conquest of polio with the Salk vaccine licensed on the tenth anniversary of FDR's death, April 12, 1955. In 1958, with polio on the wane, the foundation re-invented itself by launching an adventurous program directed at birth defects. As the birth defects programs developed through the 1960s, the foundation's mission expanded through the burgeoning fields of genetics and perinatology, evolving into its present mission, strongly characterized by a campaign against premature birth launched in 2003. These later developments, which FDR could not have foreseen, continue and thrive as part of his permanent legacy.

While the story of FDR's creation of the NFIP and the first March of Dimes radio campaign in 1938 that deluged the White House in dime donations has often been told, the person who orchestrated these campaigns that revolutionized volunteerism and fund-raising in the United States has been nearly lost to history. Basil O'Connor (1892-1972), FDR's former law partner, who also played key roles in the Georgia Warm Springs Foundation and the President's "Brains Trust" in the 1930s, led the NFIP as president for over three decades, from 1938 to 1972. During that period he served, simultaneously, as head of the American National Red Cross (1944-1949) and was instrumental in creating the Salk Institute for Biological Studies in 1960. Roosevelt and O'Connor are the only two non-medical honorees in the Polio Hall of Fame at Warm Springs, Georgia; and yet there is no complete biographical treatment of Mr. O'Connor's life that can validate his historical importance as "the architect in the fight against polio."

In actuality, Roosevelt and O'Connor together set the groundwork for the massive campaign to end the polio epidemics in the United States through the Georgia Warm Springs Foundation and the NFIP. Well-known is O'Connor's initial reluctance to spearhead the efforts to create the Georgia Warm Springs Foundation, but his loyalty to FDR superseded any initial hesitation he may have had. O'Connor eventually supported FDR's interest in Warm Springs whole-heartedly, and he became a passionate spokesman for the polio cause. Their relationship matured not only through the mutual interest in Warm Springs, but through myriad channels of advice that O'Connor provided for FDR after he became President in 1933. Though FDR served as president of the foundation until his death in 1945, often spending time at his home there, the "Little White House," it was O'Connor who directed the foundation during the Roosevelt years, serving as treasurer and chairman of its Executive Committee and ultimately succeeding FDR as president.

The NFIP was founded in 1938 in part to establish a non-partisan basis for polio fund-raising and research beyond the confines of Warm Springs. Realizing that the problem of polio could not be effectively addressed by a local institution like the Georgia Warm Springs Foundation, FDR issued a proclamation on September 23, 1937 to create the NFIP. In his proclamation, FDR focused on the need to create a national organization to approach the problem of polio in a holistic fashion. He stated that the Georgia Warm Springs Foundation had devoted its efforts “almost entirely to the study of improved treatment of the after effects of the illness” whereas the new foundation would attack “every phase of this sickness.” Of course, O’Connor assumed responsibility for leading the NFIP even though he continued to manage the program at Warm Springs.

The formative years of the NFIP coincided with a period of global war, and raising funds for polio in a wartime economy found stiff competition from war bond drives. Yet, in the patriotic climate of support for the President and American armed forces, Hollywood favored the March of Dimes. MGM mogul Nicholas Schenk chaired the Motion Pictures National Committee March of Dimes Drive, ensuring industry support from the highest level. As a result, the March of Dimes had a monopoly on movie theater fund-raising during the war as thousands of theaters were authorized to permit collections that preceded a film. Popular movie stars like Judy Garland, Mickey Rooney, and Greer Garson appeared in March of Dimes trailers and films. Patriotism, the global war, the fight against polio, and the dominance of the film medium at the time all converged to make the March of Dimes extremely popular and successful despite the war. As an ending to the war began to emerge as a real possibility, FDR appointed O’Connor as President of the American Red Cross in 1944. O’Connor’s visits to the Pacific and European theatres of the war for the Red Cross provided critical experience to him for the logistical complexities of the Salk polio vaccine field trial to come.

After President Roosevelt’s death on April 12, 1945, Basil O’Connor succeeded Roosevelt as president of the Georgia Warm Springs Foundation, headed the Roosevelt Memorial Commission, and continued to lead both the NFIP and the American Red Cross (until 1949). O’Connor led the Roosevelt Memorial Postage Stamp ceremonies at Warm Springs in August 1945 with a speech, “Nothing Could Conquer Him,” a title which summarized O’Connor’s admiration of FDR as president, commander-in-chief, and fighter against polio. O’Connor promoted FDR’s legacy at every opportunity. FDR’s influence on the history of disability, polio, and the independent living movement has been repeatedly demonstrated. Through O’Connor, the March of Dimes willingly accepted FDR’s legacy and actively promoted its mission in the aura of FDR’s colossal reputation as the first and only disabled president. The foundation steadfastly and symbolically honored the memory of FDR in traditions such as the annual visit to FDR’s gravesite in Hyde Park by each new national March of Dimes poster child. This practice endured at least until Eleanor Roosevelt’s death.

Historian Saul Benison has commented on the historical significance of the NFIP which illustrates the role of ordinary Americans in the fight against polio. Benison said: “In 1937 . . . President Roosevelt became convinced that polio could only be conquered through a broad and sustained program of scientific education and research. The organization of the NFIP was in essence the first step toward the realization of that goal. It was also something more. At a time when deadly assaults had already been launched against the human spirit and life itself in Europe, the new Foundation . . . stood as an affirmation of the value of conserving human life and dignity. Ordinary people everywhere recognized this quality and quietly and emphatically made its cause their own.” However, behind this realization lay the spirit of Warm Springs and the March of Dimes, and the two men – friends and partners – who were most responsible for formulating their vision and realizing their success.

March 23, 2009 / David Rose / March of Dimes Archives

Warm Springs During the Epidemic Years: Not the Usual Story

**Mike Shadix – Librarian, Roosevelt Warm Springs
Warm Springs, Georgia**

Wild and Wonderful Warm Springs – FDR loved fun. The patients and staff of the Georgia Warm Springs Foundation did not let him down. A visit from FDR always included a special evening of entertainment. This segment will give an overview of patient and staff hi-jinks over the years that were really part of the Warm Springs philosophy of rehabilitation. This segment will also provide an introduction to people who loved Warm Springs and established homes here. Despite all the fun, Warm Springs did have a bit of a dark side in that it was a racially segregated facility during the polio era. This segment will conclude with a look at how that segregation and racism played out at a facility devoted to the rehabilitation and inclusion of all people with disabilities.

Georgia Warm Springs: The Untold Story

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Almost every biography of Franklin D. Roosevelt and every history of polio celebrates Warm Springs as the ideal place in which to be rehabilitated from the crippling disease. Numerous accounts depict an almost resort like atmosphere infused with Roosevelt's sense of fun. Some narratives make it sound as though those who avoided polio during the epidemic years and thus had no need of Warm Springs' services were missing out. There is no doubt that the atmosphere at Warm Springs was different, and better, than at most of the rehabilitation facilities where polio patients went to learn to breathe, and sit, and walk again. While it is worth celebrating Roosevelt's gift to polio survivors some eighty years after its founding, I also want this afternoon to suggest that not every polio patient who passed through Warm Springs found it to be Oz or paradise.

The Warm Springs experience in the period from the late 1920s through the 1950s could be complex and sometimes difficult. Part of one's experience in the Georgia woods was shaped by what came before. How old you were when you went to Warm Springs made a difference, as did the severity of one's paralysis. Family relations and one's contact, or, more likely, lack of contact with family during one's stay made a difference as well. In our well connected and well traveled world it is sometimes hard to remember just how hard it was to get to Warm Springs fifty or sixty years ago and how hard for patients to stay in regular touch with their families. Without dwelling unduly on the negative, I would like to sketch a more complicated picture of polio rehabilitation at Warm Springs during the epidemic years.

This presentation will look briefly at individuals who found it difficult to adjust to the program and culture of Warm Springs, at the difficulties faced by younger children, at the painful work of rehabilitation, at the racial segregation practiced at the Foundation and at other problems that surface in the memoirs of polio survivors who were treated at Warm Springs.

Demonstration and Discussion of a Bracing Evaluation

David P. Guy, PT, MS, Scottsdale, Arizona

Marmaduke Loke, CPO, Dynamic Bracing Solutions, Inc., San Diego, California

Mark Taylor, MLS, CPO, FAAOP, University of Michigan, Ann Arbor, Michigan

Bracing Evaluation (A Thorough Preparation)

David P. Guy, PT, MS, CPT USA (ret), Physical Therapist

In 1968 I was injured in Vietnam. The injury was several compression fractures of my lumbar spine. As a result of the injury I sustained considerable weakness and decreased sensation in both of my legs. After 4 spine surgeries my problems decreased but I still was unable to pick up my toes when walking – what we call a foot drop. My surgeon called together a team of people that included himself, an orthotist and a physical therapist. I was also asked to attend the meeting. At this meeting I was assessed, from what seemed to me, to be every angle. Then each of the professionals offered their suggestions as to what was the best treatment for me. Surgery to fuse my ankle was discussed; strengthening exercises for my legs was discussed; and, bracing was discussed. The decision was made that a brace was the best answer for my problems. The surgeon, however, stated that there was some preliminary treatment that needed to be provided as I was being evaluated for the brace. First, he stated that the focus should be on me as a person and not just my legs and problems walking. Since I still had spine related problems and was wearing a brace that went from my hips to my shoulders, he wanted to see a comprehensive assessment of many factors. Those factors included my motion, strength, balance, stability, endurance, joint alignment, cardio-pulmonary status and psychological preparation for more treatment and the use of another device in addition to the spine brace I already had. I had to admit that this was not what I was taught in my physical therapy training. In my training, I was told the orthotist would do an assessment of the “joint” problem and, then, provide a device to “fix” that problem. Nowhere was it discussed that there might be other data that needed to be collected and assessed by a team of professionals. I was indeed fortunate in the caring I received. I now am able to walk and run with good strength and without the need of a device.

My point in relating this story is that anyone who is being considered as a candidate for bracing should also be provided with a thorough assessment prior to the time a brace is prescribed. It is only after thorough assessment is completed that the alternatives can be listed and examined. There are alternatives to bracing and those alternatives need to be discussed with feedback provided by the patient. As in my case, there were and are several alternatives. Surgery, sometimes, is the appropriate answer. At other times, doing nothing is the right response. The only way to lessen errors is to first complete a full assessment. Unfortunately, we professionals all too frequently look only at the presenting problem and not the person who has the problem. We also need to do a whole person assessment and relate that assessment to the unique environment in which that the person lives.

In the same vein, there is a need to complete some preparation treatment prior to bracing if that is the choice made by the assessment team. Often, a patient is provided a brace and expected to be able to do a whole host of things that they couldn't do before. It might be more appropriate if the treatment team first assured that other simultaneously existing problems are eliminated or minimized before the brace is provided. For example, many polio patients may benefit from bracing because of problems with their feet and ankles. These same people may also have been sitting most of the time and have really decreased endurance and fatigue quickly in any walking activity. These same people may have limited motion in their chest and decreased breathing capability. They

may have a scoliosis and have great difficulty standing straight. If they are older, they may have arthritis that causes pretty severe pain in many other joints. They may have skin problems with either hyper or hypo sensitivity of their skin or they may have some skin wounds caused by decreased circulation. The list could be endless. What is important is that everyone is unique and each patient deserves the opportunity to reduce these associated problems before the brace is applied. Doing so will assure a better result from the bracing and with that, improved function.

In this presentation I will focus on the pre-brace treatment that could and should be provided. The first and most important component to thorough care is communication. The patient, physicians, therapists and orthotists need to discuss the patient's problems and response to treatment on a regular basis. The primary physician should get feedback from other treating physicians to present to the team. A plan for care needs to be developed with everyone's input. The plan should specify goals that need to be achieved prior to brace application. Examples of those goals are as follows:

1. Reduce hip flexion contracture
2. Increase chest expansion to more than 2 inches
3. Increase endurance to tolerance of 15 minutes of activity
4. Increase trunk stability
5. Decrease weight by 10 pounds
6. Increase ability to shift center of mass side to side and front to back

The goals are very patient specific and should be based not only on the patient's particular problems but also on the specific bracing system that will be used. At a minimum, the program should include the following:

1. Flexibility exercises for all joints
2. Strengthening exercises
3. Breathing exercises
4. Conditioning cardiovascular exercises
5. Balance training if able
6. Relaxation training

The majority of these exercises can be taught by a physical therapist in one to three treatment sessions and then the patient can continue the program at home. If done at home, there is a need to call the therapist to report problems and success.

Preliminary treatment should also include what should and should not be expected to result from brace use. What specific improvements in function will result from brace use? What might the patient experience from brace use that needs to be reported to the orthotist? What is the "break in" period and what must the patient tolerate initially that will resolve later? Are there specific activities that need to be completed with the brace on to assure maximum benefit? How long should the brace be worn per day? Does the patient need to continue the exercises now with the brace and, if so, what exercises?

As you can see from these questions, the patient has a critical role. It is only with frequent and complete patient communication that the best brace fitting can be achieved. The patient also needs to know that the initial brace may need to be modified as a result of feedback provided by the patient or other team members.

Once the brace is provided, it is extremely important for the patient to follow up with the physical therapist for gait training. The patient should not expect that the brace without training will meet established goals. The gait training also includes several factors and might require several weeks of therapist treatment.

As a result of this comprehensive assessment and treatment the patient should expect to achieve the maximum benefit from the brace without any severe side effects. A little work at the beginning of new brace use can result in many happy years of increased function.

Assessment for Polio Bracing is part of an Individualized Walking Solution (Orthotic Evaluation)

Marmaduke Loke, CPO, Dynamic Bracing Solutions, Inc., San Diego, California

Introduction: Efficiency in standing and walking from point A to point B is the underlying issue for most polio survivors. To gain efficiency one must solve many issues to enable the polio survivor the ability of standing hands-free to accomplish a daily task and/or reduce upper extremity involvement for locomotion. A more detailed assessment and individualized solution development process is required to help the client to overcome fatigue, address balance issues, and provide the stability for improve efficiency.

Assessment starts the process, and it is a process! The Assessment is key in developing a solution. One cannot fix what one does not recognize. The solution must be developed from A-Z to provide optimal potential gains for each person. The future of polio bracing will be the development of comprehensive walking solutions, not just braces. The assessment process is much more involved than traditional methods. Solving human pathomechanics is a true 3D problem and the “Complex Puzzle” must be solved in each of the three dimensions. Besides lower extremity issues, many polio survivors also have upper extremity, spinal, and pelvic weaknesses that can affect sitting, standing and their locomotion. The assessment must include all issues in order to develop a meaningful solution.

Content:

Each polio survivor is unique. There may be similarities, but more often differences or specific attributes, set each polio survivor apart from the next. The old adage, walk a mile in my shoes (if this were possible) would clearly describe this uniqueness.

The first step of the process for the orthotist is collecting all the critical data from the physician(s), physical therapists, gait labs, and most importantly from the polio survivor. Video of a survivor’s gait from different angles must be secured and then analyzed frame-by-frame to properly assess the obvious and finite details of all the gait deviations in each of the three dimensions. A walking solution is developed to plan for success and enable a better quality of life. The solution should improve the potential of an individual.

Collection and reviewing of the documentation from all involved healthcare professionals with open communication, encourages good insight and valuable data.

Biomechanics is the study of normal and efficient gait. Pathomechanics is the study of biomechanics gone wrong. Each polio survivor has his or her unique pathomechanics that culminate into their signature gait pattern. Solutions to the signature pathomechanics are in the minute details. The causes of each pathologic detail must be recognized and followed with a series of decisions to reestablish them to as normal a biomechanical profile as possible.

The solution must address each bone in three dimensions. The medical field knows these dimensions as the sagittal, coronal (frontal), and transverse planes; we will categorize them as Triplanar.

Assessment Components:

Documentation:

Physician(s), Physical Therapists, Gait labs, X-rays, etc.

Video Filming & Evaluation:

Triplanar evaluation of pathomechanics

Manual Evaluation (Orthotist):

Confirm data collected

Assess alignment (realignment) possibilities

Formulate final solution development

Psychological Assessment:

Motivation

Ability to understand, agree and follow the treatment plan

Security Issues:

Recognizing the underlying Security Issues

Mechanical Profile:

Determine and define the mechanical profile

Goal:

Develop a solution-based standing and walking plan to improve efficiency.

Video analysis of each person's gait by the orthotist will provide a greater understanding of the individual's pathomechanical gait deviations. Video is a critical tool used to recognize and assess the small details that must be solved to enable better alignment, balance and efficiency. Video provides more data that can be gathered by normal observation. It also serves as documentation in evaluating before and after outcomes.

The orthotic manual evaluation is important to confirm data collected from other professionals and from the individual, i.e.; "my foot is fused". We often find a once fused foot will have more range of motion than thought. The manual assessment offers more information for the orthotist to utilize in their solution development.

Assessment of motivation and the ability to understand, agree, and follow the treatment plan are key factors in improving the success rate. Checking the expectations of an individual is important to determine whether they are realistic.

To improve an individual's success, the underlying security issues of the polio survivor must be addressed. The security issues are those that elicit fear, instability, and energy consuming compensations. Solutions must include finding a balance to overcome the security issue and allow for efficient mobility.

The mechanical profile is understanding the patterns of structural deviations. The orthotist then needs to devise a counter to the deviations, with corrective forces, to improve alignment and balance. The mechanical profiles vary in complexity, and solutions must vary as well.

The solution development must take into consideration all of the data, the polio survivor's goals, and the structural deficits and functional deficits to be solved. It must incorporate true Triplanar control, under full weight bearing, while employing a better understanding of polio survivors and the progressive nature of Post-Polio Syndrome. The orthotic solutions of the future will do a better job of preventing deformities and surgeries, reducing or preventing painful joints, offer better alignment and balance, free up upper extremities for useful tasks, and allow a better quality of life than can be found from traditional bracing systems.

Conclusion: DynamicBracingSolutions™ obviously has a very different and involved assessment process. A wealth of information is available on our web site: www.DynamicBracingSolutions.net. Also review the "What's New in Orthotics" in this publication.

Bracing Evaluation (Orthotic Evaluation)

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Evaluation for orthotic management involves several areas of assessments. These areas include but are not limited to: patient's cognitive status, physical environment, health status (including cardiovascular condition) muscular – skeletal condition, age, education and etc. Gathering information from these assessments require adequate time and commitment from health care professionals who have responsibility for and the opportunity to work with polio patients.

Practitioners must understand they need obtain a clear picture of the muscular-skeletal conditions of polio patients. This includes not only observing their gait patterns but getting hands on evaluation knowledge of joint range of motion, skin conditions, muscle strengths and if any discomfort is present. From this information, practitioners can make decisions on how to best gather data for the provision of a custom made orthotic device. Sometimes a combination of casting and tracing techniques along with gait evaluations are appropriate clinical activities for gathering such knowledge.

Proprioception is usually present with the polio population unless there is some underlying pathological condition that limits it. Practitioner need to understand that there probably is hypersensitivity with the affected extremity thus requiring a gentle approach when handling these extremities. Communicating with the patient at this time is helpful in obtaining their feedback concerning their level of sensitivity and location of discomfort.

Gait observation can be extremely helpful in determining where discrepancies are and what type of compensations are required to provide stability and strength for ambulation. Gait observation can be done pre and post hands on evaluation to have a deeper appreciation for the forces involved for upright stability. A competent practitioners will evaluate a patient's gait from two positions, lateral (sagittal) and front to back (frontal/coronal) views. From the gait evaluation, a practitioner can better comprehend the motions being used for stability and ambulation. Observance of the activities happening at the foot/ankle complex, knee, hip, low back and trunk is valuable in determining and designing for orthotic management.

Documentation of what is observed and what a practitioners hears also becomes a valuable tool is assessing and planning for orthotic management. Document what the patient says and their response to any questions you may have concerning their ability to ambulate and perform their necessary tasks for daily living and providing. What a practitioner hears and sees during the evaluation process can be extremely helpful as these correlate to the actions taking place. For example, if you hear a foot slap type of noise, it cues the practitioner to look for weakness about the anterior part of the ankle.

History also becomes a valuable tool in orthotic management. Has there been previous orthotic intervention? How successful has this intervention been? If orthotic intervention was not successful, try to find out the reasons why. What caused the patient to discontinue the use of their orthotic device? Was it pain, weight, peer pressure or something else? How long has this intervention been used? During post orthotic intervention it is good to know the patient's likes and dislikes of orthotic use and do they have any ideas of thoughts concerning present and future orthotic use such as, changing orthotic design and or materials.

Obtaining patients' views, goals and suggestions concerning orthotic management can be very valuable in helping design a future course for orthotic use. With the knowledge obtained from a complete and thorough evaluation, a well trained practitioner should be able to offer an appropriate orthotic design and discuss this with the patient. It is always important to provide options so the patient has the opportunity to decide for themselves which orthotic

route to take. Allowing the patient to participate in the decision process will also create a higher rate of acceptance with the proposed orthotic management. Describing this intervention in detail including the advantages and disadvantages/consequences of using such intervention will assist in a greater understanding and success of the care to be provided.

Devise a plan that will address the orthotic needs and allow the patient to approve the plan. Let them know that there is no law that commits them to 24 hour use of the device. Share your orthotic plans with others, listen to the ideas of your peers, research what has been done in the past. Take time to do your homework to help you prepare for all possible options. Communicate your plans/goals to referral sources, physical therapists, occupational therapists, family members and if necessary, third party pay. Through this communication, take advantage of suggestions, ideas and limitations pertaining to your orthotic plan. Then, proceed with your orthotic intervention as a team remembering the patient is the most important part of the team and will be the team member along with their families members who will be affected by the outcome of this investment.

Research Progress

Regulatory T cells as a Biomarker of Post-Polio Syndrome

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There are large numbers of polio survivors today who contracted acute paralytic poliomyelitis prior to the advent of widespread vaccination programs against poliovirus (PV). What is under appreciated is the fact that polio survivors are many years later at risk of developing new neurological deterioration, a condition recognized in the late 80's as post-poliomyelitis syndrome (PPS). PPS is a slowly progressive disease in individuals previously affected by paralytic poliomyelitis that is characterized primarily by new muscle weakness and atrophy. Diagnosis of PPS is time-consuming and complicated by the need to rule out other diseases that could explain the new symptoms. The ability of a physician to diagnose a specific disease can be significantly aided by the availability of one or several disease biological markers (termed biomarkers). No biomarker(s) has been identified for PPS as yet that could assist in providing a definitive, easy and rapid diagnosis.

Disease biomarkers are measures of biological parameters indicative of a disease process. They are useful because they can assist in diagnosis or provide a means of monitoring the disease as it progresses and the effectiveness of different therapies. The study conducted at the University of Arkansas for Medical Sciences (UAMS) was, therefore, designed to answer a simple question: Are there signs or changes in the immune system (that is an immunological signature) that can be linked to Post-polio Syndrome (PPS)? If so, these changes in the immune system could be potentially used as a biomarker to diagnose PPS quickly and efficiently and to possibly provide clues as to the causes of PPS.

In this study there were 3 groups of individuals – (1) healthy individuals who never had disease associated with poliovirus and were vaccinated with the polio vaccine, (2) stable polio survivors, who suffered from poliomyelitis and may have had the vaccine but currently do not have symptoms associated with PPS, and (3) individuals with PPS. The goal was to determine whether the types of immune cells and their functions observed in individuals with PPS were different from those from healthy individuals or individuals with stable polio.

The data from the study show that PPS individuals have higher levels of antibodies and regulatory T cells circulating in their blood than healthy age-matched individuals, while stable polio individuals have variable levels of these immune components, which overlap with both the PPS and the healthy individuals.

The data from this study suggest that there is possible immune dysregulation occurring within polio survivors (both stable and PPS individuals). Importantly, however, there was a lack of sufficient data from stable polio subjects. This lack of sufficient data from stable survivors makes it difficult to make definitive conclusions regarding the role of regulatory T cells (and/or antibodies) as an easily available diagnostic marker for PPS. The cause for the increased levels of the immune components (antibodies and regulatory T cells) is currently unknown.

The observations from this study do, however, suggest that there is a problem with the immune responses in polio survivors, which could contribute to PPS. Whether immune components have a direct role in the initiation and progression of PPS or merely indicate the presence of a problem with the immune system in these individuals is unclear at this time.

Research Progress

Summary of Post-Polio Research at University of Amsterdam

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The research on post-polio syndrome in Amsterdam started in 1989 and was initiated by professor Marianne de Visser, neurologist. From that time on increasing numbers of Dutch patients with post-polio syndrome came to Amsterdam and were also seen in the Department of Rehabilitation. In 1993 funding was obtained for a PhD research project of Frans Nollet. Since then post-polio research has continued in Amsterdam, led by Marianne de Visser, Anita Beelen and Frans Nollet, resulting in 27 peer reviewed scientific papers up till now. PhD theses were written by Barbara Ivanyi in 1999, Frans Nollet in 2002, Herwin Horemans in 2005 and Merel Brehm in 2007. At present 3 PhD students are doing research Janneke Stolwijk-Swüste, Fieke Koopman and Irene Tersteeg and a fourth one will start soon. What has been studied so far and what is presently being studied?

Research has been focused on clinical studies. Some results are summarized according to the topics that have been studied over the past years and can be categorized as:

- I - epidemiological and longitudinal studies
- II - diagnostic studies
- III – physiological studies
- IV- intervention studies
- V - methodological studies

Epidemiological and longitudinal studies

Polio victims from the last large epidemic in The Netherlands in 1956 with almost 1800 cases were studied 39 years later. In this population-based study among 260 respondents almost 60% experienced signs of new

weakness, increased disabilities and handicaps and diminished health-related quality of life. The use of devices and adaptations had increased.(8,12)

A cohort of 103 polio patients was followed for six years. 27 of them had stable polio and 76 post-polio syndrome.(7,14) It appeared that health-related quality of life of the patients with PPS was lower compared to the stable functioning polio individuals. Over the years physical functioning did not change much. However, it appeared that the severity of paresis at baseline was a prognostic factor for decline in physical functioning in six years. These results supported the concept of overuse, that a (slow) decline in muscle mass, as a late effect of polio, may lead to a decline in physical functioning as the reduced muscle capacity becomes less able to meet the demands of daily physical activities.

In a systematic review of the literature we concluded that so far no conclusions can be drawn from the literature with regard to the functional course or prognostic factors in late-onset polio sequelae.(23) The rate of decline in muscle strength is slow, and prognostic factors have not yet been identified. Long-term follow-up studies with unselected study populations and age-matched controls are needed, with specific focus on prognostic factors. Therefore we are presently conducting a longitudinal study involving 168 polio individuals.(26) This study focuses on the effects of aging and co-morbidity on functioning over time. Individuals ranging in age between 45 and 85 have been included and in contrast with many other studies, co-morbidities are not excluded but its influence on the time course is studied as this reflects what happens in reality with aging. At the moment the participants in the study have been followed for 5 years. Some results have been published. Age and co-morbidities were found to be negatively associated with physical functioning and physical independence. The influence of these factors on the changes over time are being analyzed at present. More publications from this cohort-study will follow in the next years.

Diagnostic studies

The value of muscle computed tomography (CT) was studied. It was shown that muscles of post-polio patients experiencing new muscle weakness showed significantly more CT scan abnormalities compared with stable post-polio patients.(5) Muscle CT scan evaluation was considered a useful adjunct to muscle strength assessment and is now routine procedure in clinical practice. Furthermore, sleep complaints were inventoried. It appeared that up to half of post-polio patients reported complaints of disordered sleep, which was likely to influence daytime functioning. This was not further analyzed.(4) At present we are doing research on this in the aging study in collaboration with pulmonologists from the Center for Home Ventilation in Utrecht.

Physiological studies

Aspects of muscle function and exercise capacity were studied. It appeared that exercise capacity of polio individuals was mainly determined by the available muscle mass. No convincing evidence as found for a poor cardio respiratory condition. Results were comparable to normally active healthy controls.(11) We confirmed reports from others that polio individuals, especially those with post-polio syndrome may have difficulty with activating their muscles and are thus not fully able to recruit the available capacity.(13, 19) A clinical relevant finding is that the energy cost of walking is directly related to the severity of polio residuals.(24) This implicates that in case of two severely affected legs walking may cost twice (or even more) energy as compared to healthy people. Together with a reduced muscle mass this implies that 'one has to do more with less' substantiating the concept of overuse as a major cause of post-polio complaints. However, it appeared that only those individuals with severely reduced walking ability, reduced their walking activity in daily life.(22)

Intervention studies

In 2003 we reported a study on the effects of pyridostigmine (a drug that improves neuromuscular transmission) on fatigue, muscle strength and functioning in post-polio syndrome.(15) Unfortunately, we found no effect, which was in line with the results published earlier by Trojan et al. Our hope was that an effect could be found with different outcomes in polio individuals with proven neuromuscular disturbances.(10) However, this was not the case. Since, some limited effects were found, a potential benefit of pyridostigmine can not entirely be ruled out. However, that would require another study, accounting for individual differences in drug uptake. At present no such study is undertaken.

Another area of interventions is innovation and biomechanical optimization of custom-made leg braces. We demonstrated that the energy cost of walking can be reduced substantially by improving braces.(27) A chapter on state-of-the-art carbon composite orthoses for post-polio syndrome was written for the latest edition of the Atlas of Orthoses and Assistive Devices by the American Association of Orthopedic Surgery issued in 2008. At the moment, a grant has been obtained to write a clinical prescription guideline. Research on the innovation of braces is ongoing in collaboration with orthopedic technicians and industry.

Methodological studies

In scientific research it is important to investigate the measurement properties of the instruments that are applied: questionnaires, time scored tests, strength tests, (electro)physiological measurements and so on. A number of papers have been published in this area. It appears that strength measurements with a hand-dynamometer, but also in a fixed chair-dynamometer show large variations and are not very sensitive to detect small changes over time in individuals.(9,19) This implies that it is not easily possible to conclude that strength has really declined in evaluating a person with post-polio syndrome over time. It appears that walking tests and measurements of energy consumption are better able to detect individual changes, although the sensitivity to detect change is less in polio individuals than in healthy controls.(21,24) In a recent paper, we recommended the Medical Outcomes Study Short Form 36 scale Physical Functioning and a 2-min walk test at self-selected speed to be used as core qualifiers for physical functioning, the major increasing disability in late-onset sequelae of poliomyelitis, to assess perceived physical performance and walking capacity in research and clinical practice.(29)

Research in progress

At present we are following up the cohort that is focusing on aging and co-morbidity. These studies are being done by Janneke Stolwijk-Swüste and Irene Tersteeg and supervised by Anita Beelen.

Another study is an intervention study to reduce fatigue and improve functioning. Two different strategies are being investigated physical exercise and a cognitive behavioral approach. This study is part of a larger project involving also other neuromuscular disorders, coordinated by senior-researchers Anita Beelen and Kimi Uegaki. This study is being done by Fieke Koopman and a second PhD student will be involved.

Finally, studies are ongoing regarding orthotic devices and clinical guidelines involving senior-researchers Merel Brehm and Carine van Schie.

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Aging with a Disability: Policy Lessons Learned from Polio

Fernando Torres-Gil MSW, Ph.D.

The concerns of older people and people with disabilities have risen on the nation's political agenda. This political elevation reflects decades of advocacy, lobbying, and public awareness of people with social, economic, health, and physical vulnerabilities. Debates about entitlement programs such as Medicare and Medicaid illustrate the growing public awareness of those important issues. But the real test of how this country responds to the needs of people with disabilities will occur as two important demographic trends come to fruition: the aging of the Baby Boom population and the aging of people with long-term disabilities such as cerebral palsy, spinal cord injury, polio, and multiple sclerosis. Public policy actions, especially in the health area, will have major repercussions for both of these populations. Thus it becomes important for aging interest groups, disability organizations, and people of all ages with disabilities to pay close attention to political decisions and public policy actions over the next several years. Such actions will largely determine the extent of public benefits and services and possibly quality of life for people aging with disabilities.

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SESSION F2

Finding Causes of and Managing Fatigue, Part 1

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Summary

Fatigue is the most frequently mentioned complaint of people with post-polio syndrome (PPS). And fatigue is often severe. However fatigue is not very specific and a prominent complaint in many neuromuscular disorders, in many chronic diseases such as multiple sclerosis, in oncology and even on itself in chronic fatigue syndrome. How to understand fatigue in PPS and how to deal with it is the aim of the two fatigue sessions.

In Session I the focus will be on the magnitude of the problem of fatigue in PPS, the different forms of fatigue and the factors playing a role in fatigue in PPS. In Session II the focus will be on the assessment and treatment of fatigue in clinical practice and what people with PPS can do to reduce fatigue.

Contents

Session I on Friday 11.15 - 12.30 AM covers the following topics:

- the problem of fatigue in PPS; prevalence and severity
- types and definitions of fatigue in PPS
- the mechanisms and factors contributing to fatigue in PPS

Session II on Friday 2.45 - 4.00 PM covers the following topics:

- how to assess fatigue in PPS
- how to treat fatigue in PPS
- energy conservation techniques

Causes of fatigue

Fatigue is mentioned by up to 80% of people with post-polio syndrome and the scores on fatigue questionnaires are often high, indicating severe fatigue. But, what is fatigue? Fatigue can be defined as 'a persistent, subjective sense of tiredness that interferes with usual functioning'. This refers to the general feeling of fatigue, however local muscle fatigue is also often present and is among the symptoms to define post-polio syndrome: 'new muscle weakness or abnormal muscle fatigability'.

In post-polio syndrome fatigue is most frequently related to physical factors.

Local muscle fatigue

Local muscle fatigue is the decline in the ability of the muscle to generate force. Several factors have been identified that may play a role in this:

- I - Failure to drive muscles from the central nervous system due to alterations in the central nervous system to activate the nerve cells due to polio - the precise mechanism is not understood;
- II - Transmission failure from the nerves to the muscle fibers due to the fact that nerve connections with muscle fibers that were formed in the recovery phase after the acute polio are of less quality and therefore less able to sustain the transfer of the signal from the nerve to the muscle;
- III - Decreasing capacity of the muscles due to post-polio syndrome to meet the physical requirements needed to execute daily life activities. The muscles that slowly decline in strength have to work at an increasing level of their maximal capacity and this will be inversely related to the duration physical activities can be maintained.
- IV - A decrease in endurance properties of muscles. Muscles that are chronically used at a certain load, especially leg muscles, change their properties towards endurance, however not fully. Shortages of relevant enzymes have been reported.
- V - Especially less and not affected muscles may be chronically under loaded in daily life and suffer from disuse. As a consequence they are less loadable.

General fatigue

General fatigue, the feeling of being tired, may have several causes.

- I - People with post-polio syndrome may feel fatigued due to the fact that they are constantly acting above or in the upper range of their physical capacities. This may result in a chronic state of exhaustion. It is important to realize that movement efficiency is often reduced. This implies that walking may cost twice (or even more) the energy of normal walking in case of two affected legs.
- II - Brain alterations due to polio virus damage have been suggested as a possible cause of general fatigue.
- III - Recent studies have demonstrated signs of chronic inflammation in the cerebrospinal fluid in PPS. This may also play a role in fatigue.
- IV - Deconditioning of the cardio respiratory system. Persons with post-polio syndrome have been found to be deconditioned, or to have a condition comparable to a sedentary life style.
- V - Psychological factors, such as 'giving up the fight', social factors related to the persons life situation, and sleep problems may all contribute to fatigue. However, these are not the main causes of fatigue in post-polio syndrome.

Other causes of fatigue

It is very important to rule out other causes of fatigue. Of course the list of potential causes is very long, but a few common causes such as anemia, hypothyroidism, depression need to be mentioned.

Factors associated with fatigue in PPS

In a recent study, so far unpublished data, several of the above mentioned factors were found to be associated with fatigue. Lower physical functioning, more pain, sleep problems, lower well being and an active coping style were found to be associated with fatigue. Of course, in this study not all potential factors were included.

Pharmacological treatment

No pharmaceuticals have been proven effective in reducing fatigue. Randomized controlled trials (RCT's) in which drugs are tested against a placebo and both investigators and patients are blinded for the intervention are the gold standard to prove effectiveness of interventions. Results from such studies have so far been disappointing in that no drug was found to be effective.

Modafinil, a drug used in narcolepsy, was recently demonstrated as not effective in reducing fatigue in a study by Vasconcelos OM, *Neurology* 2008 confirming the negative results reported earlier by Chan KM in *Muscle and Nerve* in 2006.

Intravenous Immunoglobulines (IVIg) have been studied in two trials by Borg K, in *Lancet Neurology* in 2006 and by Farbu E, *European Journal of Neurology* in 2007. The study by Borg found effect for muscle strength and for 'vitality'. The study by Farbu found an effect for pain. Both studies however found no effect for fatigue.

Pyridostigmine, a drug that improves neuromuscular transmission was demonstrated not effective in two studies, one by Trojan DA in *Neurology* in 1999 and one study by Horemans HL in *Journal of Neurology Neurosurgery and Psychiatry* in 2003.

Other drugs were investigated in only one study involving limited numbers of patients. Negative results were found by Dinsmore S for high-dose *prednisone*, and by Stein DP, for *amantadine*, an anti-inflammatory drug, both published in Annals of New York Academy of Sciences in 1995. A study in 2005 by On AY, demonstrated a significant effect of *lamotrigine*, an antiepileptic drug, supposed to have neuroprotective properties, on fatigue. So far confirmative studies have not been published. Finally, a recent pilot study by Skough K, in 2008, found no effects for coenzyme Q10.

Assessment of and Managing fatigue in individuals with PPS

Assessment

I Medical evaluation

It is very important to start with a thorough medical evaluation to exclude other pathologies as mentioned earlier.

II What is meant by fatigue?

The next thing is to go into a full consideration of the complaint of fatigue. Is it local or general, related to activity and which activities, does it increase over the day, does it respond to rest.

III Are other contributing factors present?

Consideration has to be given to sleep quality, mood disorders and coping styles.

IV What is the activity pattern?

The activities of daily life have to be inventoried. What is the activity level of a person, what kind of work does someone do, what are social and home activities, how is mobility outdoors. Are there any aids being used for walking, mobility in and outdoors and so on.

V What is the social system?

How is the person's social environment, does he or she have sufficient support and understanding at home and work.

VI What are the own perceptions?

How does someone value his or her complaints of fatigue (and other complaints, post-polio syndrome, polio residuals and so on).

VII What are the physical capacities?

What is somebody able to do given the polio residuals and co-morbidities. What is the physical burden of activities such as standing, walking, transfers, stair climbing, and the individuals various activities.

VIII Conclusion

Finally a conclusion can be made on which factors cause or sustain fatigue. These are to be targeted in interventions.

Assessment tools

Tools that may be of value in the assessment of fatigue are validated questionnaires to assess fatigue severity, pain, coping styles, mood, and physical functioning.

Diaries to inventory daily life activity are extremely useful to gain insight in what someone life looks like, in what a person actually does over the days. A common finding is that people with PPS appear to be much more active than they spontaneously report.

Clinical tests may be included to determine the extent of the polio residuals, and capacity tests to assess physical abilities.

Management

The first important thing is that the person obtains insight in the factors contributing to fatigue. The next and crucial thing is readiness to change. Many factors contributing to fatigue are related to behavior and to cognitions. For instance, if someone is constantly overusing oneself, but considers that as normal, it will be impossible to obtain any change in behavior. It is well known that many polio survivors are so-called 'over achievers' who are not easily prepared to reduce their activities. Occasionally, the reverse is also seen that some polio individuals may avoid physical activity, for instance if they think that this may damage muscles, and they may very well be mainly fatigued due to the vicious circle of fatigue, inactivity, physical deconditioning and so on.

To diminish fatigue energy conservation skills are often to be learned. This may be done individual or in group therapy programs. On the other hand regular physical activity is advised to maintain physical functioning. This implies an individual non-fatiguing exercise program that can be easily done at home, or in an (adapted and accessible) fitness setting. Environmental adaptations at home or work, transportation aids, braces and assistive devices may all be needed tailored to the individual's needs. Rehabilitation therapy is therefore usually multidisciplinary organized and may involve physical and occupational therapists, social workers, psychologists, orthotists, shoe technicians and adaptation technicians. Preferably, the effect of multidisciplinary interventions to reduce fatigue should evaluate the achievements obtained after the program and during follow-up.

Making the Tough Decisions: Palliative Care and End-of-Life Decisions

**Lawrence C. Becker, Fellow, Hollins University, Professor of Philosophy Emeritus,
College of William & Mary, Roanoke, Virginia**

**Fernando Torres-Gil, Associate Dean for Academic Affairs at the School of Public Policy
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Palliative Care and End-of-Life Decision-making

Lawrence C. Becker, Fellow, Hollins University, Professor of Philosophy Emeritus,
College of William & Mary, Roanoke, Virginia

Agenda

There are three elements to this session.

One is about tools -- important resources that are in print or online.

Another is about making sure we have acted effectively and proactively on these issues.

And the third will be a freeform exchange of ideas on this subject.

A framework for making decisions

Don't postpone these matters:

Make contingency plans for a variety of possibilities

Name a health-care proxy /durable power of attorney for healthcare

Make an advance directive

Refine all of this in consultation with your physician(s) and make changes as necessary

Things to consider in doing all this planning

End-of-life trajectories

Types of treatment to consider insisting upon or refusing

What you can, and can't, expect to control about your treatment

Contingency planning

Make contingency plans for a variety of *possible* living arrangements

Independent living with *decreasing independence* over time

Assisted living at home; respite care options

Assisted living in a private apartment

Skilled care

Hospice care

Insofar as possible, make these specific plans, about specific facilities

Healthcare proxy

Name a health-care proxy /durable power of attorney for healthcare

Choose someone who will be available when needed

Make sure this person is willing and able to be your advocate

Discuss your contingency plans and the plan for your advance directive

Make sure your physician and local hospitals know who your proxy is

Make this information publicly, and prominently available for healthcare workers

Update this as necessary

Advance directive

Make an advance directive

Use the legally defined form for your state

Make sure it includes the name of your health care proxy

Make sure it contains (or that you add) specific information about when you want, and do not want, various kinds of treatment or palliative care

Make sure you have signed off on the appropriate "no transfer" policy

Make sure you have discussed this thoroughly with your physician and healthcare proxy, and have made it accessible to healthcare professionals

Refine this with your physician

Refine all of this in consultation with your physician(s) and make changes as necessary

Review it all in advance of routine physicals

Review it during receipt of new prognoses about life altering changes

Do not count on being able to make changes during emergencies

Things to consider in doing all this

End-of-life trajectories

Types of treatment

Things you can, and cannot, control about your treatment

End-of-life trajectories

Medical textbooks and discussions of these matters assume that the process of dying is likely be some variation on one of three patterns:

A steep decline from stable functioning to death

A series of stairstep declines and partial recoveries to eventual death

A very gradual decline, or dwindling, from stable functioning to death

Pay particular attention to the level of function starting point.

What does functioning mean at this point? Major organ functioning? Activities of daily living?

CAUTION: medical textbooks on palliative care and discussions of end-of-life matters do not typically focus on how to assess these matters for people who have been living with serious, long-term disabilities.

Types of treatment

Restorative or rehabilitative treatment. Medical treatment is sometimes aimed at full or partial recovery - that is, at restoring our health or the ability to function ; restoring it from the effects of disease, injury, impairment, developmental interruption...

to achieve that aim, you also need ultimately to sustain life. It is perverse to say that "the surgery was a success, but the patient died.") Nonetheless, merely sustaining life is not the ultimate goal of this form of treatment, and in fact this form of treatment may involve serious *risks* to life. (Think about bone marrow transplants.)

Life-sustaining treatment. Medical treatment is sometimes not aimed at recovery, however, but rather is aimed first and foremost at sustaining life.

Emergency and critical care medicine typically operates with an overriding mandate to stabilize the patient first and ask questions later.

If you have been brought to the hospital in extremis, your advance directive may well be overridden until you are stabilized.

To achieve the aims of stabilization and life-sustaining treatment, risks may have to be taken.

But it would be perverse to take *life*-threatening risks (say, on some longshot hope of recovery) if your aim is really first and foremost sustaining your life.

Palliative Care. Good medical treatment always involves caring about, and ameliorating the patient's needs:

minimizing anxiety, fear, pain;

keeping the person clean, comfortable, well nourished;

providing a spiritually nourishing environment;

helping the person carry out his own projects;

and so forth.

[To palliate comes from the late Latin verb palliare, palliat-, meaning to cloak; which in turn comes from the Latin noun pallium, meaning a cloak. The idea is, I suppose, that one can palliate, mask, or cloak pain and suffering -- by making people "comfortable" -- even though the source of the pain and suffering remains.]

When this kind of care takes place in the context of medical treatment -- either restorative or life-sustaining treatment -- we don't typically speak of it as palliative care. Though strictly, of course, it is palliative.

But typically what we mean by palliative care is what goes on (or should go on) when for one reason or another the patient, or others, have decided against "treatment" of either the restorative or life-sustaining forms.

Non-beneficial treatment. Treatment which will be, to a reasonable medical certainty, futile in achieving the treatment goal for which it is sought.

Nonbeneficial treatment becomes a problem in palliative care situations when there is sharp disagreement between the patient (or the patient's advocate) and the treating physicians, or disagreement between physicians, or between insurance companies and the patient, physician, or both.

Some of these disagreements are inevitable, but many of them can be resolved by paying careful attention to the following:

What is the good of the treatment sought?

The patient's tolerance for risk, pain, suffering, and death at a given time, or in a given way can vary enormously depending on which conception of the good life is at issue:

the container conception,

the integrity conception,

or the project conception.

When is it reasonable to expect healthcare professionals to defer to the patient's conception of the good in calculating whether a given treatment will be beneficial or not?

That leaves disputes with insurers.

Whose rights are at stake, and what kind of rights are they?

All three stakeholders in these disputes (patient, healthcare provider, insurer) have rights.

But those rights may be claim rights, liberty rights, powers, or immunities.

For example, a patient may have a claim right against the insurance company for coverage of a standard form of treatment if ordered by a physician, but only a liberty right against physicians that they order such treatment. So in that case, when a physician refuses to order the treatment on the grounds that it is "nonbeneficial" -- even deferring to the patient's conception of the good being sought -- then continued demand for that treatment by the patient is on shaky ground, and probably will not succeed unless it can be shown that the physician is flatly wrong, or unless the patient can find a physician who disagrees with the first one and will order the treatment.

Principles of biomedical ethics

Autonomy (to be respected for all involved, but mostly of concern in preserving the agency of the patient)

Beneficence (applicable to all involved, but mostly of concern in defining the physician's duty to provide genuinely beneficial treatment, and the patient's family/agent's duty to seek genuinely beneficial treatment)

Prohibition of harm (applicable to all involved, but pointedly involved in the physician's duty to do no harm unless it is required by genuinely beneficial treatment, and the patient's duty to consider the consequences for others [including the public health consequences -- including costs], and the family/agent's duty to act in the interest of the patient)

Justice (fairness or equity to all involved, and of special concern when there is reason to believe that one or more of the other three principles principle might not be followed, but also commonly of concern in conflicts between public health goals [including cost] and individual treatment goals)

Palliative Care: some resources

Online resources

International Association for Hospice and Palliative Care

<http://www.hospicecare.com/>

Standards from the US, UK, Switzerland, Spain, Scotland, Romania, Poland, Norway, Moldova, Japan, Italy, Hungary, Canada, Australia:

<http://www.hospicecare.com/standards/>

For the US, in particular, see the standards from 2004 from

JCACHO (Joint Commission on Accreditation of Healthcare Organizations)

National Consensus Project

National Hospice and Palliative Care Organization (US)

<http://www.nhpco.org/> (home page)

Oriented toward healthcare professionals and organizations

Links to their affiliate organizations, including one directly oriented to consumers and their families:

The Caring Connection <http://www.caringinfo.org/Home.htm>

This is an excellent "consumer service" page

American Academy of Hospice and Palliative Medicine
<http://www.aahpm> (for physicians, but with some “patient education information”)
Hospice and Palliative Nurses Association
<http://www.hpna.org/> (for nurses, but with some general standards information)

Medical handbooks

Kuebler, Kim, Debra Heidrich, and Peg Esper (authors). *Palliative and End-Of-Life Care: Clinical Practice Guidelines*, 2nd ed Mosby: 2006. \$48.55

Watson, Max, Caroline Lucas, Andrew Hoy, Joe Wells. *Oxford Handbook of Palliative Care* (Oxford University Press, 2009, \$49.95)

Reflections by (and mostly for) physicians & nurses

Fins, Joseph. M.D. *A Palliative Ethic of Care*. Jones & Bartlett, 2005. \$46.95

Lynn, Joanne et al. *The Commonsense Guide to Improving Palliative Care*. Oxford University Press, 2007. \$27.42

From the patient’s side of things

Kiernan, Stephen P. *Last Rights: Rescuing the End of Life from the Medical System*. St. Martin’s Press, 2006. \$18.94

Well-written investigative journalism with philosophical ambitions.

Legally speaking

Cebuhar, Jo Cline. J. D. *Last Things First, Just in Case... The Practical Guide to Living Wills and Durable Powers of Attorney for Healthcare*. Murphy Publishing, 2006. \$24.95

Doukas, John David, M.D. and William Reichel, M.D. *Planning for Uncertainty: Living Wills and Other Advance Directives for You and Your Family*. 2nd ed. Johns Hopkins University Press, 2007.

Mirarchi, Fernando. D. O. *Understanding Your Living Will*. Addicus Books, 2006. \$11.96

Emergency room physician describes the “codes” to use to make sure your instructions are not misunderstood by medical staff.

Anesthesia Update: Separating Fact from Fear

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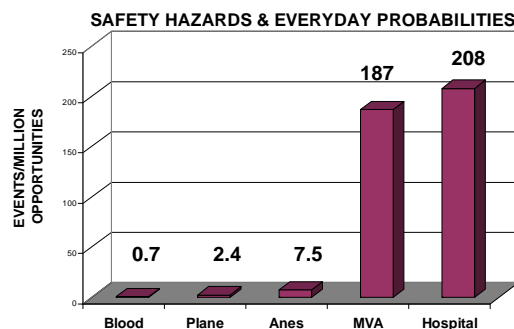
INTRODUCTION:

This talk will briefly review the process of anesthesia care, current anesthesia practice, and how these might relate to post-polio syndrome (PPS) patients having surgery. The goal is to make clear that proper preop planning allows post-polio patients to have surgery and anesthesia with a minimum of risk. Indeed, the risk of anesthesia is much, much less than the risk of death from an error while hospitalized. It also emphasizes that it is not necessary for post-polio patients to keep up with drugs and practices in anesthesia. Anesthesia, like every medical specialty, is rapidly changing, as legions of dedicated researchers and clinicians work to make what we do more effective and safer. It is extremely difficult for anesthesiologists to keep up with all the new drugs and practices; patients can not possibly keep up.

This talk will NOT address pain management, except pain immediately postop. Research has—and is still—finding numerous, complex mechanisms that cause pain, and pain treatment is becoming more and more complicated. Continuing research on pain mechanisms will probably lead to better therapies for PPS patients with pain problems.

THE RISK OF ANESTHESIA:

What is the risk for anyone having anesthesia, and how does this compare it to other risks in our daily lives? The government's Agency for Healthcare Research and Quality looked at this in 2002.



AHRQ data, 2002

(Source: www.webmm.ahrq.gov/dykarchivecase.aspx?dykID=1)

DEFINITIONS:

- **BLOOD:** Getting HIV from transfusion of a single unit of blood
- **PLANE:** Annual number of passenger deaths/number US commercial flights, 1992-2002
- **ANES:** 2002 estimate of mortality from anesthesia
- **MVA:** Deaths/number registered drivers
- **HOSPITAL:** Estimate preventable deaths hospitalized patients/number of hospitalizations

It should be clear where the real risk is: just being in the hospital! The risk of dying from anesthesia is much, much smaller. The focus for worry should move from anesthesia to being hospitalized. Fortunately, a nationwide effort to improve hospital safety is developing, but safety still varies markedly by individual hospital.

ANESTHESIA RISKS FOR PPS PATIENTS:

What do we know about how PPS patients do during anesthesia? Very little! Medical knowledge like this can be measured by looking at the number and type of medical journal publications over time, something easily done on the National Library of Medicine's PubMed data base. (This lists all articles in standard medical journals over time.) Searching for "post-polio syndrome AND anesthesia," 11 articles were found. The first was in 1990. Ten more articles were published in the next 12 years,. Not all were significant/focused only on PPS. There were 3 case reports, 3 letters-to-the-editor on the cases, 1 was a theoretical article with no cases, 1 article was on dental issues, 1 mentioned PPS as part of a larger study of a new drug and 1 was on indications for modafinil (Provigil), not about anesthesia. This is a very small amount of information, really only 8 articles.

Contrast this meager number of articles with those on PPS itself: 946 articles were published since 1990, when the first article on anesthesia was published! So researchers were focused on the bigger problem of what is PPS and what should therapy be. Additionally, few hospitals have many PPS patients coming for surgery, so a significant study of anesthesia complications would be very difficult.

Fortunately, we will get some real data in the next few years. The Mayo Clinic has had an electronic medical record since 1980, and it is often used to study anesthesia complications. So, I convinced my anesthesia friends there to study this. The question is, *“How many and what type of anesthesia complications occur in PPS patients having anesthesia and how does that compare to other patients with a neuromuscular disease and also how do they compare to normal patients?”*

Data gathering is finished and they are half-way through data analysis. They gave me permission to give you some early, preliminary results, as of March 6, 2009. The study covers 1986-2008 and includes all PPS patients having surgery (excludes sedation cases and patients less than 18 yo). There are 779 patients, a very generous sample size, which will make their results very powerful. Data analysis is complete on the first 300/779 patients. No anesthesia complications occurred. It will take other 6-plus months to finish the data analysis, write this up and get it published, so we won't get the final results for awhile. But, I think this is a most hopeful study, and it supports my clinical impression that if a good preop evaluation is done and if surgical, anesthesia and hospital care are competent, PPS patients can have surgery without problems.

PPS patients have asked numerous questions about anesthesia since 1996, when I gave the first talk on this. Many questions have been about normal things that can happen, for example a drop in blood pressure after a spinal anesthetic was placed. This is due to the effect of the spinal anesthetic on nerves controlling blood vessels and is actually not a complication. Well-trained anesthesiologists look for these “complications” and treat them appropriately and promptly. And, some of the most significant “anesthesia complication” questions were actually about complications from surgery and had nothing to do with anesthesia. We have to use great care about what we call “anesthesia complications.”

THE PROCESS OF ANESTHESIA CARE:

Because each patient's anesthesia needs differ, and differ over time as new problems show up, this talk will focus less on specific anesthesia techniques and drugs and discuss how you can hopefully communicate with anesthesiologists about your problems. This is an area of confusion, so the usual process is reviewed here.

Most PPS patients will have surgery in a hospital or an out-patient surgery facility attached to a hospital. (PPS patients should not have anesthesia in physicians' offices, for safety reasons, and that situation will not be discussed.) The anesthesia process is essentially the same, but varies by elective and emergency surgery.

A. FOR ELECTIVE SURGERY:

(1) The surgeon and you decide on surgery. You should state your special problems for anesthesia (sleep apnea or whatever). If you have a request for a particular anesthesiologist, tell the surgeon.

(2) Surgeon's office calls the hospital's scheduling office and schedules time, date and the operation. The special medical problems related to anesthesia should be stated to the scheduling secretary. If there is an anesthesia request, the office secretary should give the information to the scheduling office. (Many hospitals do this process on the web now.)

(3) Anesthesia preop evaluation varies in different institutions. Many hospitals now run a daily clinic for upcoming surgery patients. This is at the hospital; blood work, EKG and chest X-ray can be done at the same time. You receive an appointment, usually from the preop clinic's scheduling office. These clinics are often staffed by specially trained nurses, who follow protocols. Anesthesia residents are also used. An anesthesiologist is always available to the nurse/resident, who would call him/her for complicated patients. The anesthesiologist might suggest special tests or even come to the clinic to examine you. The data on each patient is recorded and reviewed at the end of the day to see if anything is missing. These forms are passed along to the scheduled anesthesiologist, usually the night before. If there is no preop clinic, trained nurses will usually call before surgery to check on your medical history and medications. The answers to those questions are given to an anesthesiologist.

Often, you don't physically see the anesthesiologist until the day of surgery. If your problems are very difficult, for example you need assisted ventilation, appointments can be made well ahead of time for the

Anesthesia Preop Clinic or to see an anesthesiologist. The surgeon's office would facilitate that. Patients with these difficult problems should get evaluations by your pulmonary and post-polio physicians before that preop clinic visit, and you should come with all those records (a pulmonary function test, at least!), so the anesthesiologist has maximum information about you. Be sure you are well-organized and precise when you speak with them ("I've had polio and need or have ---whatever."); they are usually extremely busy and pressed for time.

(4) Hospital operating rooms are chaotic and always in flux, due to emergencies incoming at all hours and also problems possibly occurring in the scheduled operations. As a result, anesthesia staffing is always in flux. The department should do their best to get you your desired staff, but there are times when it just isn't possible. In that case, all the preop information is passed along to the new physician, who should have all the needed information on you.

(5) After surgery, you should get a visit from an anesthesia person, usually a specially-trained nurse or an anesthesia resident. They should ask about your anesthesia experience and if you note any possible complications on this first postop day. Be frank in your responses. They need to know what YOU experienced. This information is typically put into a data base so the department can see how they are doing and compare themselves to national figures.

B. FOR EMERGENCY SURGERY: In a true emergency such as a car accident, there is little choice of hospital or anesthesiologist. The Emergency Room physician will assess you and decide how urgent surgery is. There may be time for your own physician to get involved. The anesthesiologist will talk with you, often in the OR.

You can help by having a MedicAlert bracelet or some other way to identify your health problems and needs. Because of the wide recognition of the MedicAlert program, that is probably the best to use. Also, your companions/spouse should be aware of your needs. Simple wallet cards can provide them with the needed information. This could save your life! It's also helpful to know which are the best hospitals in your geographic area and discuss this with your companions/spouse.

TYPES OF ANESTHESIA:

"What kind of anesthesia is best?" is the question I'm asked most often. The answer is it depends: It depends on your own health problems, including the ones from age-related diseases as well as from polio. It also depends on your wishes and your past experience with anesthesia. It depends on the operation that's planned: Some operations require certain types of anesthesia. It also depends on your surgeon: Some surgeons, for example, just can't operate under local anesthesia. Your anesthesiologist may be particularly skilled in a certain technique, so it can also depend on them.

This calls for discussion as each individual patient comes for each particular operation and at that point in time. After evaluating all these "depends" we can come up with an "Anesthesia Plan." All anesthesia plans should include something for pain relief in the postop period.

There are 3 types of anesthesia:

General anesthesia: You are completely asleep. You receive intravenous drugs and also gases to breathe, by way of a mask or breathing tube.

Regional anesthesia: Only the part of the body being operated on is anesthetized, using local anesthesia injected at the site of surgery, near a major nerve(s) to that area or around or near the spinal cord. The most common types are spinal anesthesia (local anesthesia is given into the fluid around the spinal cord) and epidural anesthesia (local anesthesia is given in the space just before the spinal cord's covering, usually through a small catheter). Regional anesthesia is increasingly popular because pain is actually prevented.

Monitored Anesthesia Care (MAC) The surgeon injects local anesthesia at the surgical site; an anesthesiologist sedates, monitors and makes sure you are comfortable and safe.

Many operations need a certain kind of anesthesia. Common operations and the usual anesthetics are as follow:

Cholecystectomy (removal of the gall bladder, usually done laparoscopically, using a telescope-like instrument inserted into the abdomen through small incisions): Needs general anesthesia because the abdomen is very distended during the operation.

Cataract removal: MAC. The ophthalmologist/anesthesiologist does a nerve block behind the eyeball, anesthesiologist gives sedation so you hold still and are comfortable.

Carpal tunnel release: MAC, usually. Usually done with local injection by the surgeon at the wrist, with sedation added. Can be done with various nerve blocks of arm or general anesthesia.

Orthopedic operations: General/regional, depending on the operation and the surgeon.

Rectal surgery (hemorrhoidectomy, anal fistula): Regional anesthesia has many benefits and is indicated. Sedation can be added.

Urologic surgery (resect the prostate, kidney stone): Simple trans-urethral resection of prostate (TURP) is best done with regional for numerous reasons. Radical prostatectomy calls for general anesthesia because the operation is more extensive and longer. Kidney stone removals are usually done with general anesthesia due to the severe pain.

It is not unusual to combine types of anesthesia: to add sedation to regional cases (to improve patient comfort while lying on the hard OR table), or to do a regional technique and then put the patient to sleep; the regional will be in place at the end of the case to give long-term postop pain relief. Mixed techniques gets the benefits of each.

These recommendations may change in the future. Surgical techniques are changing very rapidly and will lead to less invasive surgery. You may have read about robotic surgery, currently used in prostatic, neurosurgical, cardiac and gynecology operations. You might also have learned about endoscopic surgery. There are some simple ones already, such as laparoscopic cholecystectomy. Soon, we'll have major operations on the GI tract done via an endoscope passed through the mouth—and they'll remove your stomach! Or, they will go through the rectum and remove your colon!

We can also note how anesthesia is advancing. People have very different responses to many drugs, and this can be predicted now, for some drugs, based on genetic studies. In the near future, we will be able to predict ahead of surgery, how you would respond to certain anesthesia drugs, based on your genetic profile. So, we could tailor an anesthetic to each individual patient. I hope you get the sense of how dynamic the practice of medicine is and how rapidly it's changing.

ANESTHESIA SPECIFICS FOR PPS:

In the absence of any significant published information, the following is based on my clinical experience and ideas developed after extensive study of polio and PPS. As more information becomes available, these will change. These are the recommendations on the PPHI web site (www.post-polio.org/ipn/anes.html). I reviewed them and added an additional one, #9, and a comment.

ANESTHESIA ISSUES FOR POST-POLIO PATIENTS:

1. Post-polio patients are nearly always very sensitive to sedative meds, and emergence can be prolonged. This is probably due to central neuronal changes, especially in the Reticular Activating System, from the original disease.
2. Non-depolarizing muscle relaxants cause a greater degree of block for a longer period of time in post-polio patients. The current recommendation is to start with half the usual dose of whatever you're using, adding more as needed. This is because the poliovirus actually lived at the neuromuscular junctions during the original disease, and there are extensive anatomic changes there, even in seemingly normal muscles, which make for greater

sensitivity to relaxants. Also, many patients have a significant decrease in total muscle mass. Neuromuscular monitoring intraop helps prevent overdose of muscle relaxants. Overdose has been a frequent problem.

3. Succinylcholine often causes severe, generalized muscle pain postop. It's useful if this can be avoided, if possible.

4. Postop pain is often a significant issue. The anatomic changes from the original disease can affect pain pathways due to "spill-over" of the inflammatory response. Spinal cord "wind-up" of pain signals seems to occur. Proactive, multi-modal post-op pain control (local anesthesia at the incision plus PCA, etc.) helps.

5. The autonomic nervous system is often dysfunctional, again due to anatomic changes from the original disease (the inflammation and scarring in the anterior horn "spills over" to the intermediolateral column, where sympathetic nerves travel). This can cause gastro-esophageal reflux, tachyarrhythmias and, sometimes, difficulty maintaining BP when anesthetics are given.

6. Patients who use ventilators often have worsening of ventilatory function postop, and some patients who did not need ventilation have had to go onto a ventilator (including long-term use) postop. It's useful to get at least a VC preop, and full pulmonary function studies may be helpful. One group that should all have preop PFTs is those who were in iron lungs. The marker for real difficulty is thought to be a VC <1.0 liter. Such a patient needs good pulmonary preparation preop and a plan for postop ventilatory support. Another ventilation risk is obstructive sleep apnea in the postop period. Many post-polios are turning out to have significant sleep apnea due to new weakness in their upper airway muscles as they age.

*COMMENT: Postop respiratory failure in these patients can be difficult to manage. The patient's pulmonary physician could help by doing a preop evaluation and being involved in postop ventilatory management. This situation might call for the resources of an ICU in a major medical center.

7. Laryngeal and swallowing problems due to muscle weakness are being recognized more often. Many patients have at least one paralyzed cord, and several cases of bilateral cord paralysis have occurred postop, after intubation or upper extremity blocks. ENT evaluation of the upper airway in suspicious patients would be useful.

8. Positioning can be difficult due to body asymmetry. Affected limbs are osteopenic and can be easily fractured during positioning for surgery. There seems to be greater risk for peripheral nerve damage (includes brachial plexus) during long cases, probably because nerves are not normal and also because peripheral nerves may be unprotected by the usual muscle mass or tendons.

*9. NEW IDEAS/THOUGHTS:

Spinals: Recent studies demonstrating the presence of cytokines in the CNS of PPS patients lead me to be less enthusiastic about using spinal/epidural anesthesia. There is no data on this situation, and there are so many benefits to this regional anesthesia, and they might be suitable in some situations. Lidocaine would not be a suitable drug choice for PPS patients.

Regional anesthesia: Should the peripheral nerves of PPS patients be exposed to local anesthetics, especially for long periods postop? There is no data, but many PPS patients have atrophied peripheral nerves. Perhaps smaller doses of local anesthetics and avoiding continuous postop infusions would be safer.

Above-the-clavicle blocks(supraclavicular and interscalene): These have a high risk for diaphragmatic paralysis and should probably not be used in PPS patients, unless the patient can tolerate a 30% decrease in pulmonary function.

SUMMARY:

PPS patients can have anesthesia and surgery safely, with careful preparation. Anesthesia and surgery is a process that involves anesthesia, surgery and hospital care. For an optimal outcome, ALL must be at high levels of performance and achievement! You, the patient, must work to be sure you get these. Remember, few surgeries are truly urgent and you usually have time to get data from the web, the state's hospital licensing department, the state's medical board and other resources. You should also research the operation and its consequences, to be sure you can deal with them. Don't rush into anything until you're satisfied you'll get the best. You deserve it.

HELPFUL RESOURCES:

ON ANESTHESIA:

1. Post-Polio Health International: www.post-polio.org/ipn/anes.html
2. "Post polio Syndrome and Anesthesia" by David A. Lambert, MD; Elenis Giannouli, MD; & Brian J. Schmidt, MD, The University of Manitoba, Winnipeg, Canada, in the September 2005 issue of *Anesthesiology* (Vol. 103, No. 3, pp 638-644). This article reviews polio, post polio syndrome and anesthetic considerations for this patient population.
3. To learn more about anesthesia: The American Society of Anesthesiologists' (ASA) patient education web site: www.asahq.org/patientEducation.htm. Covers many topics.

ON HOSPITALS:

1. To check out a hospital, start with the Joint Commissions (JCAHO) web site: www.jointcommission.org and click on the Quality Check mark.
2. Check the hospital's web site; many show their surgical results.

ON PHYSICIANS:

1. Check your surgeon and anesthesiologist in the state's medical licensing board web site.

Demonstration and Discussion of a Seating Evaluation

Rene James, PT and Trina Ouzts, PT, ATP,
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I. Introduction

A. Goals of seating and wheeled mobility:

1. **Ultimate goal:** To provide maximum function with minimum pathology
2. Decrease and prevent deformity
3. Decrease the incidence of overuse syndromes
4. Manage pressure
5. Improve natural functions of internal organs (digestion, respiration, swallowing)
6. Enhance mobility
7. Increase comfort
8. Decrease pain
9. Conserve energy
10. Increase sitting tolerance and tolerance to activity
11. Assist in facilitating a positive self image
12. Increase ability to perform self care

- B. Consequences of poor seating
 - 1. Pressure sores
 - 2. Contractures
 - 3. Spasticity
 - 4. Poor function of internal organs
 - 5. Impaired mobility
 - 6. Increased dependency
 - C. Seating and wheeled mobility team members:
 - 1. Client
 - 2. Family members and caretakers
 - 3. Rehab specialists (PT, OT, SLP, audiologist, nurse, rehab engineer, recreation therapist, Physician)
 - 4. Educators
 - 5. Vocational counselor
 - 6. Case manager or social service worker
 - 7. Third party payer
- II. Seating evaluation
- A. Client's goals
 - 1. What does the client want? - A person can be provided with the most perfect wheelchair, made to meet their needs, but if it is not what they want, they will never be satisfied.
 - 2. When and for what purpose will the mobility device be used?
 - 3. User's abilities and plans:
 - a. Activity level
 - b. Prognosis - Is the client likely to get better, worse, or stay the same?
 - c. Functional abilities
 - d. Vocational goals
 - e. Lifestyle
 - B. Medical / surgical history and plans:
 - 1. Past and present medical problems
 - 2. Potential for motor return or decline
 - 3. Height and weight
 - 4. Bowel and bladder function
 - 5. Skin condition past and present
 - a. Condition
 - 1) Intact
 - 2) Current breakdown
 - 3) History of breakdown - areas of past breakdown are more susceptible to future breakdown
 - 4) Condition of skin
 - b. Sensation
 - c. Risk for breakdown - Braden Scale used for predicting pressure sore risk by grading sensory perception, moisture, activity level, mobility, nutrition, and friction & shear
 - 6. Muscle spasms or spasticity
 - 7. Contractures/ ROM
 - 8. Pain
 - C. Cognitive and behavioral status:
 - 1. Acceptance of need to using mobility devices
 - 2. Safety awareness
 - 3. Motor planning problems
 - 4. Level of alertness
 - 5. Problem solving abilities
 - 6. Motivation
 - D. Communication / Language
 - 1. Ability to communicate
 - 2. Use of augmentative communication

- E. Sensory function
 - 1. Vision
 - 2. Hearing
 - 3. Sensory perception
- F. Environmental factors – Home, work, school and recreation:
 - 1. Home environment
 - a. GEM Assessment - A comprehensive home assessment tool used to identify problems and possible solutions for each room of a home and the immediate outdoor area (www.cornellEG.org)
 - b. Width of doorways
 - c. Ramps or curb cuts
 - d. Necessary turning radius
 - e. Bathroom set-up
 - f. Clearance under tables, desks, workstations
 - g. Assistive devices, communication devices used
 - h. Others using the environment
 - i. Distances and surface types required to cover on a regular basis (i.e. college campus v. home bound)
 - 2. School / Vocation
 - 3. Leisure activities
- G. Transportation:
 - 1. Does the client drive?
 - a. Considerations if drives from the vehicle's seat
 - b. Considerations if drives from wheelchair
 - 2. Type of vehicle (2 or 4-door car, truck, van or van with lift)
 - 3. Method of transportation for power wheelchair
 - a. Lock down/tie down used
 - b. Size and style of lift / ramp
 - c. Consider the needed external clearance for the lift or ramp to work
 - d. Consider the needed internal clearance (head clearance, seat to floor height)
 - e. If transported in the back of a pickup or on an exterior lift, the wheelchair is exposed to the environment, which can cause serious damage to the wheelchair
 - f. Some power wheelchairs can be broken down and folded into components, but the components are heavy (50-60 pounds) and unwieldy
 - g. Community transportation
- H. Current and past equipment:
 - 1. Problems and positives about current equipment
 - 2. Appearance in current equipment
 - 3. Past equipment – the good and the bad
 - 4. Tolerance to technology
- I. Functional activities of daily living (Bathing, dressing, toileting, feeding, and grooming)
 - 1. Level of assistance required
 - 2. Tasks that are performed in the wheelchair
- J. Physical assessment
 - 1. Transfers
 - 2. Balance
 - a. Sitting balance
 - b. Standing balance
 - 3. Mobility
 - a. Bed mobility
 - b. Gait
 - c. Wheelchair mobility and management

4. Posture
 - a. Limitations in extremities
 - b. Spinal alignment (scoliosis/ kyphosis)
 - c. Pelvic alignment (obliquity / rotation / lordosis)
 - d. Symmetry v. asymmetry
 - e. Fixed v. flexible deformity
 - f. Note differences in range of motion, and pelvic/spinal alignments when in different positions
5. Range of motion
6. Strength
7. Alignment of trunk to extremities
8. Spasticity – When is it present? What breaks it up?
9. Effect of gravity in different positions
- K. Measurements (Take these in short sitting position)
 1. Seat depth - Measurement from the most posterior aspect of buttocks to behind the knee
 2. Seat width - Measurement of widest aspect of hips or thighs.
 3. Back height - Varies according to person's trunk control
 4. Seat to floor height - The distance from the top of the cushion to the floor
 5. Footrest to seat distance (Lower leg length) - The distance from the back of the knee to the bottom of the shoe
 6. Armrest height - The height at which the person can be seated in the wheelchair on their cushion with their elbows flexed to 90°, and be comfortably supported with an aligned posture
 7. Maximum wheelchair weight to enter home - Power wheelchairs are heavy. If a person lives in an older mobile home or house, the floors may not be able to support the weight of the wheelchair and endanger the patient.

III. Choosing wheelchair and components

- A. Problem list
 1. Risk for breakdown
 2. Postural deformity
 3. Risk for future deformity
 4. Dependent for mobility
 5. Inability to perform effective weight shift
 6. High risk for falls
 7. Unsafe gait
- B. Goals and desired outcomes
 1. Independence
 2. Mobility
 3. Access to community
 4. Safety
 5. Comfort and tolerance
 6. Accommodate needs
- C. When possible, create a simulation of potential wheelchair
 1. Place client in appropriate wheelchair base, cushion, backrest, etc.
 2. Transfer client into the wheelchair and adjust as necessary
 3. Allow client time to try it out and to ask questions
 4. Assess client's ability to maneuver
 5. Make changes, as appropriate
 6. Realize that compromises may need to be made
- D. Things to consider:
 1. Provide symmetry and midline of the head whenever possible
 2. Do NOT take away function for appearance
 3. Do NOT imprison
 4. There is no such things as “use it or lose it” and “no pain, no gain”
 5. Define desirable features before selecting equipment

E. Power versus manual bases

1. Power may be necessary when:
 - a. Unable to propel a manual wheelchair
 - b. Orthopedic injury, overuse syndrome or medical condition which is aggravated when propelling a manual wheelchair
 - c. Vocational or educational needs in hilly areas or in areas requiring being able to go over great distances
 - d. Energy conservation needs – a power wheelchair will conserve energy for activities, not use energy for mobility
2. Environmental considerations
3. Safety considerations
 - a. Safety awareness
 - b. Level of distraction or agitation
 - c. Adequate visual and motor skills

F. Types of manual wheelchairs

1. Heights of wheelchairs
2. Weights of wheelchairs
 - 1) Transport wheelchair (19-29 pounds)
 - 2) Standard wheelchair (>36 pounds)
 - 3) Lightweight wheelchair (28-36 pounds)
 - 4) Ultralightweight wheelchair (14-28 pounds)
3. Rigid v. folding frame

G. Types of power wheelchairs

1. Power Operated Vehicle (POV) = Scooter
 - a. Has a larger turning radius than a power wheelchair
 - b. Does not provide positioning
 - c. Cannot have controls programmed
 - d. Not very portable
 - e. Client should have good balance, good arm control and function, and ability to safely transfer
2. Power assist - Added to manual wheelchair (may void warranty on the wheelchair); Increased the effect of each push so that it is easier to propel a manual wheelchair; Must be able to self propel the wheelchair in a symmetrical manner
3. Power w/c
 - a. Drive wheels
 - 1) Front
 - a) Small turning radius
 - b) Difficult to learn to drive (configuration backward from rear wheel drive)
 - c) Can fish tail when making turns
 - d) Good over uneven surfaces and over obstacles
 - e) Can get close to objects
 - 2) Mid
 - a) Smallest turning radius
 - b) More intuitive to drive
 - c) May rock slightly on casters
 - d) Not very good on rough terrain (i.e. gravel, sand, off road)
 - e) May have problems with steep ramps
 - 3) Rear
 - a) Larger turning radius
 - b) Tends to have more power over uneven surfaces
 - c) Typically have higher speeds
 - b. Power wheelchair controllers

- a) Proportional (i.e. joystick, head drive, chin drive) - Directional movements of the controller produce identical directional movements of the wheelchair; Speed increased in proportion to distance the controller is moved
- b) Microswitch (i.e. sip & puff, single switch) - Activating the switch causes the wheelchair to move in a pre-programmed direction at a pre-programmed acceleration and speed; Course correction requires either accessing a second switch or 2 switches together; It is difficult to use and requires training

H. Reclining and tilt systems

- 1. If a person is unable to adequately perform a weight shift and to reposition themselves, they will require some system to prevent skin breakdown and discomfort
- 2. Recliners and tilt in space systems are available for manual and power wheelchairs

I. Seating systems

- 1. Considerations
 - a. Pressure reducing properties
 - b. Maintenance requirement
 - c. Ability to accommodate postural deformities
 - d. Comfort
 - e. Ease of transfers
 - f. Balance and stability
 - g. Moisture and heat resistance
 - h. Cushion weight
 - i. Cost, durability, trial and return policy, warrantee
- 2. Types of cushions
- 3. Types of backs
- 4. Custom systems - Used when positioning needs cannot be met by standard available systems (i.e. significant postural asymmetries)

IV. Funding

- A. All funding sources have their own rules and regulations
- B. Medicare is one of the strictest in their regulations and set the bar for many other funding sources
- C. Medicare requirements for mobility equipment
 - 1. Manual wheelchairs
 - a. Has a mobility limitation that significantly impairs mobility related activities of daily living activities:
 - 1) Prevents ability to accomplish
 - 2) Cannot accomplish safely
 - 3) Cannot accomplish in a reasonable time
 - 4) Limitation not resolved with a cane or walker (Client unable to functionally walk)
 - 2. Funding sources coverage of power mobility
 - a. Has a mobility limitation that significantly impairs mobility related activities of daily living activities:
 - 1) Prevents ability to accomplish
 - 2) Cannot accomplish safely
 - 3) Cannot accomplish in a reasonable time
 - 4) Limitation not resolved with a cane or walker (Client unable to functionally walk)
 - 5) Limitation not resolved by an optimally configured manual wheelchair (Client unable to functionally propel a manual wheelchair)
 - b. Coverage criteria for POV
 - 1) Home is accessible to POV
 - 2) Can safely work the controls of a POV
 - 3) Client's weight is within limit
 - 4) Client is willing to use equipment
 - 5) Can safely get in and out of a POV
 - 6) Can safely sit in a POV without additional support.

- c. Coverage criteria for power wheelchair
 - 1) Cannot meet coverage criteria for POV
 - 2) Home accessible to power wheelchair
 - 3) Has willingness and ability to use
 - 4) Pt's weight is within limit of the device
 - 5) Power wheelchair coverage significantly improves mobility related activities of daily living participation
 - 6) Client's weight is within limit
 - 7) Client is willing to use equipment

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Benefits and Techniques of Aquatic Therapy

Cynthia Henley, PT, Miami, Florida, and Kathryn Wollam, PT, Coral Springs, Florida

Almost any person regardless of age or physical condition can benefit from exercise and improve their fitness level. Fitness is defined as adapting to the environment so as to be capable of surviving. A state of physical fitness offers enough energy to perform daily duties with energy left at the end of the day to enjoy leisure time. Fitness exercises are designed to improve endurance. This increased stamina is achieved by making the heart and lungs stronger and more efficient. Additionally, exercise can help decrease blood glucose levels, decrease the risk of cardiovascular disease, control weight, improve quality of sleep and develop a sense of well being.

Challenges of Exercise: Exercise can be a challenge for individuals with a history of polio. The appropriate balance between overuse and disuse must be achieved. It is essential to have an exercise program that is tailored to the individual's specific muscle test in order to be safe and effective. Extremities used in strengthening exercise must be able to move through complete range of motion against gravity. It is important to adhere to the following general exercise guidelines for polio survivors and avoid excessive fatigue.

General Exercise Guidelines for Polio Survivors:

- Check with your doctor before beginning any exercise program.
- Do not use muscles with strength of 3/5 or less for conditioning or strengthening exercise. These muscles must work all day to fight gravity in basic activities of daily living. Attempting to strengthen these muscles may cause overuse and increased weakness.

- Start a conditioning program slowly. Often 3-5 minutes of conditioning is all that can be initially tolerated. If needed, start with one-minute intervals with rest periods and SLOWLY build up endurance. Watch for signs of overuse.
- Strengthening exercise can be done with muscles of strength greater than 3/5. In other words, that muscle must be able to move the joint through full range of motion against gravity. However, remember to start with minimal number of repetitions (5-7) within tolerance. Increase resistance and number of repetitions cautiously. Watch for signs of overuse. As a general rule, muscles that have a grade of 3/5 or less should be protected and not exercised. Grade 3+/5 muscles can be exercised with caution; grade 4 –4+/5 can be exercised moderately; and grade 5/5 muscles can be exercised more vigorously.

Aquatic exercise is very beneficial, as the buoyancy of the water will help to support weak muscles and decrease joint stress while it can also provide resistance to strong muscles. Remember to start slowly (15-20 minutes) and avoid the tendency to overdo in the pool, because it is easier to move in the water.

Signs of Overuse: Although you may feel mild fatigue after exercise, you should not experience the signs of overuse. These signs of overuse can occur within 24-48 hours after too strenuous exercise or a very active day. Pacing activities and modification of the exercise routine is necessary if these occur.

- Muscle cramps or spasm
- Muscle twitching
- Muscle pain
- Extreme fatigue

Aquatic therapy was often utilized during the recovery phase from the original polio. Water is the great equalizer. It allows people to move in ways that they cannot move on land. The buoyancy of water greatly enhances the ability to move and provides resistance based on speed of movement in the water. Further, water exercise offers the ability to improve flexibility, strength, muscle tone and aerobic condition. Water can facilitate a workout that can be tailored to each person's strength.

Physical Properties of Aquatic Therapy:

There are physical properties of water that make exercise less difficult and painful, while increasing its effectiveness. These properties are buoyancy, hydrostatic pressure, relative density, fluid resistance and turbulence.

Buoyancy is the upward pressure exerted by a fluid in which a body is immersed. Archimedes' Principle states that when a body at rest is fully or partially immersed in a fluid, it experiences an upward thrust equal to the weight of the fluid displaced. Buoyancy and gravity constantly oppose each other and reach equilibrium when you float partially immersed. The vertical body is typically at equilibrium when immersed to neck level. Buoyancy can provide support or resistance. As an assist, buoyancy is used to decrease gravitational forces placed on weak limbs that are less able to bear weight. There is less strain on the muscles and joints, requiring less effort to move underwater. Buoyancy adds a challenge to stronger muscles and offers resistance when a floatation device is pushed or held submerged underwater.

Pascal's Law defines ***hydrostatic pressure*** as fluid pressure exerted equally on all surface areas of an immersed body at rest at a given depth. Hydrostatic pressure helps return the blood to the heart, causing it to work more efficiently under less pressure. The water surrounding the body helps circulate blood from the legs to the heart, often reducing any swelling in the ankles and feet. Once swelling is reduced, joint tenderness may decrease and range of motion can improve. Additionally, hydrostatic pressure offers mild resistance around the ribcage. Breathing with the trunk immersed in the water is a form of exercise. Although this can help strengthen people with respiratory involvement, it should be approached with caution. Simply being immersed in water has a positive therapeutic effect on our bodies.

Relative density is the relation of the mass of an object to the mass of an equal volume of liquid at standard temperature and pressure. It determines whether or not an object sinks in the water. Simply stated, if an object is denser than water, it will sink. Muscle tissue is denser than fat. People who are lean and muscular will tend to sink; those with more adipose tissue tend to float. Swollen extremities retain fluid and that fluid is lighter than muscle tissue; giving those body parts a lower relative density and tendency to float. Therefore, it takes less effort to raise weak or swollen extremities than it does to lower them in the water. Muscles that are paralyzed or have atrophied due to polio will have lower relative density and will tend to float.

Fluid resistance is the force that opposes the motion of an object through a fluid. Basically you have to push your way through the water and it slows you down. Fluid resistance is beneficial in aquatic therapy as it supports and helps to hold you in position while also offering resistance to movement. The fluid resistance of water makes it a perfect environment to perform balance exercise. On land, resistance is felt in only one direction, which leads to an over development of some muscles and under utilization of others. Fluid resistance also increases sensory awareness and allows time to react and learn how to maintain proper balance in a gentle environment.

Turbulence is the random motion of the water as it responds to a disturbance. A person or limb moving through the water creates changing pressures and turbulence. This swirling effect in the water can provide therapeutic benefits of massage and resistance. The gentle massage can increase circulation and reduce pain. The sensation of water on the skin overloads the peripheral nerves. This causes the brain to ignore other signals, such as pain, that your body is sending. Changing the speed and direction of motion can alter turbulent forces. The use of equipment, such as aquatic gloves or paddles, is another way to increase turbulence.

Benefits of Aquatic Therapy:

In addition to the benefits of general exercise, aquatic exercise offers unique physical and physiological benefits. The buoyancy of water decreases the weight and stress on the joints, encouraging freedom of movement. Movement and functional activity are more comfortable in water because the pull of gravity on the body is not as strong as on land. Water supports the body, reduces joint stress, and provides resistance and assistance to movement, allowing improved mobility, strength, and function.

Water provides a number of unique properties making it an excellent environment for rehabilitation.

Benefits:

- Increased cardiovascular function - resistance of the water aids in controlled conditioning.
- Reduced stress on joints - buoyancy reduces the stressful effects of gravity on the body.
- Improved muscle strength and tone - resistance of the water aids in gentle muscle strengthening.
- Increased range of motion and flexibility - the support of the water allows effective stretching.
- Increased balance and coordination - balance can be challenged in a safe environment.
- Pain modulation - turbulence and the support of the water decrease pain.
- Decreased edema - the hydrostatic pressure of water decreases swelling.
- Improved posture and trunk stability.
- Promotes relaxation.
- Improved metabolism and calorie burn for weight control.
- Increased circulation - hydrostatic pressure increases venous blood return to the heart.
- Respiratory benefit - hydrostatic pressure offers resistance around ribcage during respiration.
- Improved kidney function - increases blood flow to kidneys, renal clearance and diuretic effect.

Precautions:

- Medical clearance is required prior to initiating any exercise program.
- Cardiac precautions should be taken into account.
- Pool temperature can affect exercise tolerance. The temperature of the water is a personal preference. Recommended temperatures range from 85-94 degrees. Cool water is often not well tolerated and will tap your energy quickly. Warm water temperature helps relax the muscles, however be cautious with excessively warm pools to avoid becoming overheated.
- The exercise guidelines specific to post polio hold true for aquatic exercise.
- Medications that cause drowsiness should be avoided.
- Aquatic exercise is contraindicated with skin infections, rashes, open wounds, sores, stitches or contagious diseases.
- Allergies or reactions to pool chemicals should be considered.
- Avoid aquatic exercise during illness. (fever or cold).
- Urinary tract infection or incontinence (lack of bowel or bladder control) prohibits aquatics.
- Get out of pool immediately with any signs of distress, shortness of breath, or dizziness.
- Supervision during aquatic exercise is a must. Never go in alone. Keep a cell phone nearby.
- Safe access to the pool (parking, lifts, rails, ramps, wheelchair accessibility).
- Surfaces around pools tend to be slippery and dangerous for anyone with a tendency to fall.
- Sun exposure, climate changes and lightning are considerations (indoor vs. outdoor pool).
- Don't overdo, aquatic exercise can be deceptive. Fifteen minutes is enough initially.

It may take some time for you to determine the correct amount of exercise for your individual needs. Schedule a specific time to exercise. Try different times to see what works best. Do not exercise when tired. Pace your activities on busy days. Don't exercise right before bed; it can stimulate and interfere with sleep. Breathe normally during exercise: count out loud; exhale with effort. Complete the exercise with correct form and proper posture to prevent injury. Better to do fewer repetitions with good technique and control, than to exercise with sloppy form. It is important to replenish fluids.

Aquatic Therapy Techniques:

Techniques of aquatic therapy will be discussed and demonstrated in the actual session. A booklet of aquatic exercise ("Ready, Wet, Go" by K. Wollam, PT and C. Henley, PT) will be given to participants in attendance at the session. Their philosophy of aquatic exercise for polio survivors, which includes the need for a formal assessment and manual muscle test (MMT) to appropriately plan an individualized program, will be emphasized. The volunteer participants have been evaluated by the presenting physical therapists prior to the aquatic therapy demonstration. These therapists use the water to work towards an individual's goals as listed in the benefits of aquatic exercise based on the evaluation.

Additional aquatic therapy techniques may prove beneficial to polio survivors depending on the evaluation, MMT, assessment and goals. These techniques, however, will not be discussed in depth and are beyond the scope of this presentation. Techniques such as Ai Chi (deep breathing with concepts of TaiChi, Shiatsu and Qigong in shoulder depth water), Feldenkrais (gentle movement and directed attention to improve movement and enhance human function), Lyu Ki Dou ("Floating Life Energy Pathways") and Pool Massage focus on the relaxation benefits of aquatic therapy. BackHab (an aquatic walking program), Proprioceptive Neuromuscular Facilitation (therapeutic exercise that includes three components of motion) and Water Pilates (core strength and spinal alignment) emphasize active exercise and resistive properties of water. Other techniques in the literature include Ai Chi Ne, Bad Ragaz, UCT, Watsu, Water Yoga, Wassertanzen and Yogalates. Additionally, the Burdenko Method and Halliwick Concept include methods of swim training for people with disabilities.

Types of Exercise:

Warm up exercises gently increase the heart rate and respiratory rate. They also prepare the body for exercise by gently loosening the major muscle groups and joints. An adequate warm up can decrease the risk of injury.

Stretching and range of motion exercise help lubricate the joints and prepare the nervous system. Stretching is an important part of any fitness program. Shortened muscles can lead to muscle imbalance. For example, spending a lot of time in a seated position can cause tightness in the legs making it difficult to stand straight. Weak shoulders and tight chest muscles can cause forward flexed posture yielding neck pain or making it difficult to breathe. Aquatic stretching can assist in proper positioning for stretching. Hold stretch position ~15-20 seconds and don't bounce into the stretch.

Resistance exercise helps increase muscle strength. Resistance can be achieved during aquatic exercise by increasing the speed that the limb moves through the water or by adding equipment. This causes increased turbulence and greater resistance. Slowly progress the exercise program by gradually increasing speed and repetitions over time.

Aerobic exercise challenges the cardiovascular system. Aquatic exercises can be performed in deep water (using a floatation belt or Styrofoam noodle for support) including bicycle or jogging movements to increase heart rate. Upper extremity exercises can be performed in the shallow water to increase heart rate as well. Over time, this type of exercise improves endurance and stamina helping to offset fatigue.

Cool down is much like the warm up phase and returns the body to the resting state. The cool down helps prevent post-exercise soreness and reduces the risk of injury.

Progressing Your Program:

Once an appropriate level of exercise is established, fitness is maintained with a consistent program. To advance the program, it is important to progress cautiously and remember the signs of overuse. Some ideas to progress the program are listed. Choose only one variation at a time to advance the program.

- Add repetitions to the current exercise routine, beginning with 1-2 per week.
- Add new exercises to the routine, no more than 1 new exercise per week.
- Work in more shallow water for balance and gait activities to decrease buoyancy. Shallow water is more challenging to balance and trunk control.
- Increase the speed of exercise under water to increase the resistance. Deeper water provides more support at slow speeds and more resistance at fast speeds.
- Exaggerate arm swing, step height or step length during gait activities.
- Increase the time of conditioning exercise (i.e. pool walking, arm cycling or bicycling) 2-3 minutes per week. When swimming laps, find a comfortable stroke, use your strong extremities and swim the width of the pool. Progress to swim the length of the pool, add laps to tolerance.
- Add equipment to increase the resistance in the water.

Equipment:

Equipment can be utilized to provide flotation or resistance, assist or challenge balance or offer protection from the elements. Aquatic equipment can be purchased online or at pool, sports and toy stores.

- Flotation devices provide flotation while allowing freedom of movement of limbs:
 - noodles, kickboards, water belt, arm rings, flotation vest, flotation ring
- Balance can be assisted or challenged in the water:
 - water walker, noodles
- Resistance can be increased by the addition of simple equipment:
 - aquatic gloves, foam dumbbells, hand paddles, fins, kickboard
- Protect your body from the elements:
 - wetsuit for cold intolerance
 - solar protection clothing, hat/visors and sunscreen in outdoor pools
 - water shoes protect skin from abrasion, particularly important for diabetics

Enjoy the relaxing and invigorating qualities of aquatic exercise. Keep it fun. Vary the exercises to prevent boredom or exercise with a partner. Approach the exercise program with patience and consistency to reap the benefits of an improved condition with less fatigue, better endurance and functional gains. Avoid excuses and do something special for yourself!!!

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SESSION F3

Current Epidemics: Status, Lessons and Tasks

John Fitzsimmons, Centers for Disease Control and Prevention, Atlanta, Georgia

Ann Lee Hussey, Chair, Polio Survivors and Associates Rotary Action Group,
South Berwick, Maine

Using Assistive Technology for Personal Independence

Samantha Massengale, OTR, RWSIR, Warm Springs, Georgia

A. ASSISTIVE TECHNOLOGY RESOURCE GUIDE

1. Catalogue Company

a) Physical Challenges

- Sammons Preston. www.sammonspreston.com
Voice: 1800 323 5547
- Parsons A.D.L Website: www.parsonsadl.com

Voice: 1800 263 1281

- Portable rolling shower: <http://www.shower-anywhere.com/Roll-in-Shower-Stall.aspx>
- Step in tub: <http://walkintubdepot.com/index.php?cPath=2>
- Incline platform wheelchair lifts:
<http://www.universalaccessibility.com/products/AmeriGlideaipl.html>.
(800) 470-893
- Electric leg bag emptier. <http://www.rdequipment.com/>. Phone/Fax: 508-362-7498

b) Low vision

- LS&S: products for the visually impaired and hard of hearing;
www.LSSPRODUCTS.com
- Voice: 1800 468 4789
- MaxiAides: www.maxiaides.com
- Voice: 1-800-522-6294
TTY: 1-800-281-3555

c) Hearing Devices

- Beyond Hearing Aides: www.beyondhearingaides.com
- Voice\TTY: 800-838-1649
- Sound Bytes: www.soundbytes.com.
- Toll Free: (888) 816-8191 | TTY: (516) 937-3546
- Harris Communications: www.harriscomm.com.
Voice (800) 825-6758
TTY :(800) 825-9187

d) Computer and Ergonomic Related Technology

- Options of Info Grip: computer access technology only
- Enable Mart: computer and telephone tech
- Website: EnableMart.com Tel # 1888 640 1999
- Goldtouch www.goldtouch.com
- Contour designs www.goldtouch.com
- Ergonomic concepts www.ergoconcepts.com

- Kinesis Computer Ergonomics www.kinesis-ergo.com
- Work rite ergonomic www.wrea.com
- Dragon Naturally Speaking. Voice activated computer access www.nuance.com, office Depot

e) Home Automation Devices:

www.smarthome.com
www.exponenta.com

2. Vehicle Modification

- National mobility Dealers Association www.nmeda.org
- National Highway Traffic Safety Administration www.nhtsa.dot.gov

3. Websites:

- Abledata.com, (listing for all types of AT product information and vendor information)
- Techable.org (gives you products available, vendor info)
- iltech.org/catalogue.htm (list of catalogue companies and telephone number)
- www.headsets.com

4. Local Durable Medical Stores: sell durable medical equipment like tub benches, shoe horns etc.

5. Technology Shows: Exposure the latest technology

- Touch the Future
- Medtrade

6. Rehabilitation and independent Living Centers: provide assistive technology products and services.

7. Stores: Home Depot, Office supplies stores, Sears and Wal-Mart: sells bathroom equipment, ergonomic office equipment, automation devices.

8. Charity Organization

- Friends of Disabled Adults: free new or refurbished adapted devices, wheelchairs, ambulation, and bathroom equipment. Ramps and home modification
 4900 Lewis Road, Stone Mountain, GA 30083
 (770) 491-9014.
- Reboot computer program: free or discounted rates on refurbished computers.
 Tel # 770-934-8432

9. Non- profit Organizations

- Tools for Life, www.gatfl.org. It is GA technology program: Has 4 Assistive Technology centers in the state of GA.

The Tools for Life Assistive Technology Resource Centers (ATRCs) are "hands-on" learning centers for demonstration, education and evaluation of products available on the market today. They are also a resource for Georgians with disabilities, families, friends, health care professionals and other professionals who are interested in seeing, learning and experimenting with new and existing assistive technology devices and equipment. ATRCS). AT services include: evaluation, demonstrations, training, loan library, acquisition.

- Job accommodation network: <http://janweb.icdi.wvu.edu/>. Tel# 800-526-7234
- State independent Living Centers in your state. Provide Assistive technology services

B. FUNDING SOURCES FOR ASSISTIVE TECHNOLOGY

Refer to the Tools for Life website for comprehensive list. www.gatfl.org

Home Modification:

- Friends of Disabled Adults and Children (FODAC): Ramps and home modification for people in Metro Atlanta area. Ramps for Champs
- FODAC: 4900 Lewis Road, Stone Mountain, GA 30083 (770) 491-9014.
- Brain Injury and Spinal Cord Trust Fund: Awards up \$15000. Tel # 1888 233 5760
- State Alternative Financing Programs. A low interest credit union loan. Including rental home Modification. See Attached Handout.
- State Independent Living Centers.
- GA Department of Community Affairs: Disability Housing Coordinator. Office of Special Housing Initiatives. Contact information: 404 327 6864
- Social Security: Plan to Achieve Self Support(PASS), Impaired Related Work Expense(IRWEP)
- First Hand Foundation: Grants for Children 18 yrs and younger (sometimes up to age 21) for DME, AT, vehicle modifications and more. <http://www.cerner.com/firsthand/default.aspx>

Computer Related

- GA Reboot computer program: free or discounted rates on refurbished computers. Tel # 770-934-8432
- GiveTech.org: Gives away computer input devices that allow individuals with quadriplegia to use computers. www.givetech.org
 - Travis Roy Foundation: Grants for specific modifications or AT awarded to paraplegic and quadriplegics due to *injury*. Grants typically range from \$4,000- \$7,000 <http://www.travisroyfoundation.org/pages/grants.html>
 - First Hand Foundation: Grants for Children 18 yrs and younger (sometimes up to age 21) for DME, AT, vehicle modifications and more <http://www.cerner.com/firsthand/default.aspx>
- State Alternative Financing programs. A low interest credit union loan. See Attached Handout

- Brain Injury and Spinal Cord Trust Fund: Awards up \$15000. Tel # 1888 233 5760

Vehicle Modification

- Vocational rehabilitation
- Social Security (Work related technology): PASS, IRWEP programs
- Brain Injury and Spinal Cord Trust Fund: Awards up \$15000. Tel # 1888 233 5760
- State Alternative Financing programs. A low interest credit union loan. See Attached Handout
- Joni and Friends, Christian Fund for the Disabled: Funds for AT, rehabilitation, special treatment, educational opportunities. CFD up to \$2,500
<http://www.joniandfriends.org/outreach/fund.shtml>

Personal Care Devices

- FODAC. Contact information; 770- 491-9014
- State Independent living centers
- Joni and Friends, Christian Fund for the Disabled: Funds for AT, rehabilitation, special treatment, educational opportunities. CFD up to \$2,500
<http://www.joniandfriends.org/outreach/fund.shtml>
- First Hand Foundation: Grants for Children 18 yrs and younger (sometimes up to age 21) for DME, AT, vehicle modifications and more
<http://www.cerner.com/firsthand/default.aspx>

Low vision

- The Association of Blind Citizens: ATF will provide funds to cover 50% of the retail price of adaptive devices or software. Deadlines: June 30th and Dec 31st
http://www.blindcitizens.org/assistive_tech.htm
- Joni and Friends, Christian Fund for the Disabled: Funds for AT, rehabilitation, special treatment, educational opportunities. CFD up to \$2,500
<http://www.joniandfriends.org/outreach/fund.shtml>
- First Hand Foundation: Grants for Children 18 yrs and younger (sometimes up to age 21) for DME, AT, vehicle modifications and more.
<http://www.cerner.com/firsthand/default.aspx>
- State Alternative Financing programs. A low interest credit union loan. See Attached Handout
- Brain Injury and Spinal Cord Trust Fund: Awards up \$15000. Tel # 1888 233 5760
- Newline: Newline®, a nationwide newspaper service for the blind, will utilize telephone lines and digitized voice synthesizer systems to provide blind and severely visually impaired people daily access to a variety of newspapers. National Federation of the Blind at 410-659-9314.
- Georgia's Project Independence for the Older Blind or Visually Impaired: 55 and older. Provides services throughout the state of GA to senior adults experiencing vision loss. Rehabilitation specialists provide instruction in your home environment and in group settings. Peer support groups are available to discuss mutual problems and concerns of vision loss in a supportive setting. A low vision evaluation in designated clinics around Georgia will provide assessment and training to help you remain independent in your own home. Other services may include orientation and mobility training, as well as daily living skills training. Services are

available to eligible seniors regardless of income for little or no cost. (770) 432-7280 or (800) 726-7406.

Hearing Devices

States with **telecommunication distribution** programs:

Telecommunications Equipment Distribution provides a variety of free specialized telecommunications equipment to qualified applicants who have difficulty using a standard phone. For those who qualify, staff also offers assistance selecting telecommunications equipment and training on how to use it properly.

* States in Blue have a website

- Arkansas :: 501 686-9693 V/TTY
- Connecticut :: Text Telephone Loan Program 860-242-4974 (V/TTY)
- Georgia : 404-292-5312 voice/TTY, 800-541-0710 voice/TTY, 404- 299-3642 FAX
- Hawaii :: TRS 808-546-4611 (V)
- Indiana :: TTY Program 317-469-0803 (V/TTY) Telecommunications Relay Service 808-546-4611 (V)
- Kansas :: (785) 234-0200 (Voice) (785) 234-0207 (TTY)
- Mississippi :: Project S.T.A.R.T. 601-987-4872 (V/TTY)
- Nebraska :: 402-471-0225 (V) 402-471-0213 (TTY)
- North Carolina :: 919-773-2994 (TTY) 800-999-5737 (V/TTY)
- North Dakota :: 701-328-8950 (V) 701-328-8968 (TTY)
- Ohio :: No Distribution Program
- Oklahoma :: 1-800-833-8973 VTTY 405-522-7930 VTTY
- Rhode Island :: 401-276-0875 (voice/relay) 401-861-6677 (TDD)
- South Dakota :: 605-773-4547 (TTY) 605-773-3195 (V)

Other

- Kate Kimberly Foundation: Grants for individuals with SCI for the purchase of adaptive sports, recreation and exercise equipment
 - Grants typically range from \$1,000 to \$4,000 <http://katekimberlyfoundation.org/>
 - Modest Needs: Grant for individuals who need just a bit of assistance with monthly bills and other things. www.modestneeds.com

Exercise: The Kinds, the Methods and the Benefits

Merete Bertelsen, Physical therapist
Rehabilitation Center at The Danish Society of Polio- and Accident Victims
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Presentation

I work at a Rehabilitation Center for polio and accident victims in Copenhagen, Denmark.

The Rehabilitation Center is owned and run by the patient organization called The Danish Society of Polio- and Accident Victims. The Society employs all staff members, but the counties pay for the treatment, so all assessment and treatment is free of charge for the patient.

I am going to tell you about a study we did from 2002 to 2005, comprising 50 polio survivors who were referred to us for the first time. Dr. Maynard has now told you a lot about how to exercise, and we work according to the same principles in Denmark, so the results of this study will give you an impression of the benefits of exercising. But bear in mind that the intervention in this study was not only exercising. It was a multidisciplinary intervention with social and psychological counseling, technical aids etc. The study was published in the Journal of Rehabilitation Medicine, January 2009.

The 2 aims of the study were:

To describe the problems of patients with late effects of polio who were referred to the clinic for the first time

To describe the intervention and the results of the treatment after 3 months and at one year follow up

We tested the patients 3 times. First time was before they started any treatment, the second time was 3 months after the start of treatment and the third time was 15 months after start of treatment.

Tests

There were 3 kinds of questionnaires.

The Short Form 36 (SF-36) is a questionnaire which measures 8 different dimensions of quality of life. We also used the Multidimensional Fatigue Inventory-20 questionnaire, which measures 5 different dimensions of fatigue. We developed a third questionnaire with questions about polio related issues and how big an impact the polio problems had on their daily activities.

Functional capacity was tested in functional tests. The 6 minute Walk test which measures how far you can walk in 6 minutes, when you walk as fast as possible, The Timed Stands Test which measures how fast you can get in and out of a chair 10 times without using your arms. The Functional Reach Test, where the polio survivor has to reach as far forward as he can without moving his feet. At last we made the polio survivors climb the staircase at the center, and we measured time used to reach the top and return.

The physiotherapists were asked to register which kinds of treatment they gave to each participating patient.

Population

The study population consisted of 30 women and 20 men; the mean age was 58; 10 of the persons came from other countries; 23 were still working and 27 were retired; They contracted polio between 1930-1985, 20 of them in 1952/53 in the big epidemic; Their average BMI was 28 (20-60). The borderline of being overweight is 25 in Denmark.

18 persons – normal weight,

20 persons – overweight,

11 persons – obese.

Polio related problems in the study group

The major problems of the patients were not surprisingly: Outdoor walking, climbing stairs, fatigue; pain, anxiety for the future and acceptance of the new situation.

The 6 min Walk Test showed that the polio survivors in this study walked significantly slower than the reference values of the Danish population.

The Timed Stands Test showed that the polio survivors in this study used almost twice the time for performing the test than the reference values.

Approximately half of the polio survivors had problems with their balance and 7 had risk of falling.

Intervention

The treatment was based on each person's individual needs and expectations. Not two patients received the same treatment, because polio survivors are all unique with different problems.

The most frequently used treatments in the individual physiotherapy in this study was:

Individual exercise	37 patients
Massage	36 patients
Stretching	33 patients
Home exercise:	33 patients
Exercising in fitness center:	43 patients
Fitness class:	2 patients
Warm water exercising:	17 patients
Polio education:	35 patients

35 polio survivors joined the polio education program where polio survivors and their relatives are educated in polio issues, principles of exercising, technical aids – what kind of technical aids that are available for their needs, social matters and psychological reactions to the need of changing lifestyle as polio problems arise. But the greatest thing about this “polio education” is that the polio survivors get to meet other polio survivors and to get the opportunity to exchange experiences with each other.

In this study the patients received 15 physiotherapy treatments in average. There is a wide span from 3 to 41 treatments, because some patients only needed some advice and others needed many treatments. They had more severe problems that took longer time to deal with. In average they were treated for 14 weeks, and of course there was a wide span here too.

Many of the patients continued exercising after the individual treatment was ended. Even after one year 22 of the 50 patients were still exercising in the fitness center and 22 of them were exercising somewhere outside PTU. It seems that exercising did them good, since so many continued to exercise.

The intervention at our center is multidisciplinary and below is showed how many of the 50 polio survivors who consulted the other professionals.

	Number of polio survivors
Social worker	15
Psychologist	3
Technical aids therapist	20
Doctor – in addition to the first consultation	12
Dietician	8
Orthotist	25

The results of our intervention at the clinic

The quality of life questionnaire SF-36 shows a significant improvement in the dimensions Bodily Pain, General Health and Vitality. In General Health the improvement stays even at the one-year follow up.

The Fatigue questionnaire showed a significant improvement in the dimension called Physical fatigue. None of the improvements remained at the one-year follow up.

The 6 minute Walk Test showed a significant improvement in walking distance and it remained at the one-year follow-up. 12 of the 50 patients received some kind of walking aid i.e. a brace or a cane. Of course this also improves the ability to walk faster.

The Timed Stands Test showed a significant improvement in the time used for performing the test and the improvement remained at the one-year follow up.

The Climbing Stairs Test showed a significant improvement at the 3 months test, but it didn't maintain at one-year follow-up.

In our polio related questionnaire we asked the patients to consider how their total situation was at the 3 months test and the one-year follow up. 35 polio survivors felt better or a lot better all things considered after 3 months treatment and 27 polio survivors at one-year follow up.

The conclusions of our study are listed here:

The patients with late effects of polio had a lower level of functioning, experienced more fatigue and had more pain compared to values for the Danish population

The patients can benefit from an individually planned multidisciplinary intervention with emphasis on physiotherapy

The patients experience less pain or copes better with the pain after intervention

The improvement remains at one year follow up

Another way of showing the results is to show them in percent:

6-min. Walk test 10,6% improvement

Timed Stands Test 12,9% improvement

"Vitality" from SF-36 7% improvement

"Bodily Pain" from SF-36 20% improvement

"Physical fatigue" MFI-20 10% improvement

These improvements were all statistically significant

The results of this study are based on several different treatments but the main intervention was exercising, so I will dare to say that exercising is a major reason for the improvements experienced by these polio survivors.

The study was performed with my two colleagues Susse Broberg and Ellen Madsen and was published in Journal of Rehabilitation Medicine 2009,41: 85-87

The benefits of exercising are multiple:

- Improvement/maintaining strength level or diminishing the polio related loss of strength
- Improvement of functional capacity and balance
- Weight control
- Reduces hypertension, risk of heart disease, risk of diabetes, depression
- Improved sense of well being

Other studies on exercising:

I will supplement my own study by telling you shortly about a few other studies made on exercising in polio survivors.

Strength, endurance, and work capacity after muscle strengthening exercise in postpolio subjects. Agre et al Arch Phys Med Rehabil 78: 681 1997

- Mondays and Thursdays subjects performed three sets of four maximal isometric contractions of the quadriceps held for 5 seconds each. On Tuesdays and Fridays subjects performed three sets of 12 dynamic knee extension exercises with ankle weights

- Conclusion: This home exercise program significantly increased strength, endurance, and isometric tension time without apparently adversely affecting the motor units or the muscle, as the EMG and CK variables did not change.

Effects of resistance training in combination with coenzyme Q10 supplementation in patients with post-polio. Skough, K et al. J Rehabil Med 2008, oct; 40 (09) 773

- A total of 14 patients with post-polio syndrome participated in a 12-week muscular resistance training, 3 days/week 2 groups : Q10 and placebo

- Results: There was no significant difference between the coenzyme Q10 and placebo groups regarding muscle strength, muscle endurance and quality of life.

- Muscle strength, muscle endurance and quality of life regarding mental health increased statistically significantly in all 14 patients.

Low- intensity alternate-day exercise improves muscle performance without apparent adverse affect in polio patients, Agre et el. Am J Phys Med Rehabil 75; 50, 1996

- 12 patients performed six to ten repetitions of a 5-s duration knee extension exercise with ankle weights – increasing weights according to their strength gain during a period of 12 weeks.

- Conclusion: Performance was significantly improved, as demonstrated by an increase in the amount of weight the patients lifted in the exercise program from 7 to 11 kg in average

No evidence was found to show that this program adversely affected the motor units or the muscle as the EMG and CK did not change.

Short term effects of aerobic exercise on functional capacity, fatigue, and quality of life in patients with post-polio syndrome. Oncu et.al. Clin Rehabil 2009 feb; 23

- Thirty-two patients were divided into two groups for either hospital- or home-based aerobic exercise programme

- Conclusion: Fatigue and quality of life were both improved in the home and hospital exercise groups. An increase was also found in the functional capacity in the hospital exercise group. A regular exercise programme is beneficial to patients with post-polio syndrome.

Cardiorespiratory responses to aerobic exercise training in humans with postpoliomyelitis sequelae Jones et al. JAMA 1989

- Cardiorespiratory responses of 16 patients to a 16-week aerobic exercise program at 70% of maximal heart rate

- Exercising on cycle ergometer in average 20 minutes 2-3 times a week

- Conclusion: The aerobic training program employed in this study is a safe, short-term procedure and that patients with postpolio sequelae respond to training in a manner similar to healthy adults.

You can find abstracts and in some cases the full text on the internet.

I hope this has given you some inspiration to either make exercise programs to your polio patients if you are a professional, or if you are a polio survivor, I hope you will give it a try and see for yourself that exercising in most cases do something good for you.

Exercise: The Kinds, the Methods and the Benefits

Frederick Maynard, MD, UP Rehabilitation Medical Associates, Marquette, Michigan

Role of Exercise in Post-Polio Health and Wellness

What is Holistic Health & Wellness?

Critical Components of a Healthy Body

- Nutrition
- Exercise/Activity
- Rest/Sleep

Controversies about Exercise for Post-Polios

- Is it GOOD or BAD?
- Type & intensity of exercise
- Methods of exercise
- Which muscles?
- What if you have PPS?

Definitions

- Exercise – planned, structured, repetitive bodily movement.
- Physical Activity – movement occurring during daily activities.
- Therapeutic Exercise – done for a specific health purpose.

“Common Sense” FACTS

- Inactivity rapidly leads to weakness and deconditioning.
- Over-exertion can lead to injury, pain and overuse weakness.

So, is exercise Good or Bad?

- Devil in the detail
- Is apple pie good or bad?
- Anecdotes abound.

“Sustaining controversy as a means of discrediting findings that cause economic or social discomfort is one of the greatest sins of science.” – T. Colin Campbell

Type and Intensity of Exercise

- Flexibility exercises
- Strengthening exercises
- Conditioning/endurance exercises

Flexibility Exercises

- Maintain optimal lengths of muscles.
- Take muscle to point of tightness and hold.
- Important for pain management.
- Avoid over stretch of elongated/weak muscles.
- Maintain full ROM of joints.

Strengthening Exercises

- Isotonic
- Isometric
- Isokinetic

Key Principles of Strengthening Exercise

- Use “low” reps: 5-8 to start
- Use “high” resistance: 60% of 3 rep max
- Advance slowly: 2 reps every 3-4 days
- Dr. J. Perry’s Rule: If pain or fatigue occur, reduce by ½.

Normal Fatigue Thresholds

- 16% max – continuous use possible
- 37% max – 50/50 rest/activity balance
- 70% max – 90/10 rest/activity balance

Which muscles to target?

- Those with therapeutic goal
- 5 Point Classification System (Halstead)
 1. No clinical polio (no sxs, NI EMG)
 2. Sub-clinical polio (no sxs, benign EMG)
 3. Clinically stable (no sxs, EMG+, chronic weakness)
 4. Clinically unstable (new weakness, EMG+)
 5. Severely atrophic polio

Methods of Exercise – Strengthening

- Free weights
- Theraband
- Machines
- Body weight
- Targeted movement

Conditioning Exercise Principles

- For ↑ endurance of specific muscles, use “high” reps, “low” resistance
- For whole body endurance, aim for Target Health Rate
- Lower the % target heart rate, longer the exercise bout
- Interval training key for post-polios
- If any heart disease, monitoring needed to begin

Methods of Exercise – Endurance

- Walk/Treadmill
- Stationary Bike/Rowing Machine
- Elliptical
- Aerodyne Bike
- Arm Ergometer
- Free Weights/Body Weight
- 3-4-training bouts weekly to reach goals
- 2-3 training bouts weekly to maintain

Exercise and PPS

- No universal definition of PPS
- Diagnosis of Exclusion
- Exercise approach same but more careful and limited (begin 30% max)
- Activity/Exercise habits before new weakness noted must be honestly described
- Stress, General Health and Lifestyle are critical issues

Factors Leading to Perception of Loss of Strength

- Unawareness of strength loss from acute polio
- Aging process
- Weight gain
- Poor nutritional habits
- Underactivity; deconditioning
- Overactivity; over use
- Poor pacing skills

PHI's Task Force Recommendation on Exercise

- Individualized Exercise Program (IEP) can enhance health and functional activity tolerance of polio survivors
- Professionals with knowledge of PPS & exercise should design and supervise IEPs.
- Two-month minimum needed before transition to self-directed program.
- Follow general principles of low/moderate intensity, slow progression and pacing.
- Consider rotation of exercise type:
 - Less frequent bouts
 - Longer duration of time (weeks/months) to achieve goals

Pain and Exercise

- Muscle Pain vs. Joint Pain
- Muscle pain occurring with daily activity may require some modestly painful strengthening exercise to resolve.
- Vicious cycle of:

Pain ← Disuse

↓ ↖

Weakness
- Fear avoidant attitude toward pain & activity is major problem in US population.

Acute and Chronic Stress & Strain Syndrome

- Muscle
- Tendon
- Myofascial
- Joint
- Ligament

Nothing Ventured/Nothing Gained

- Honest & timely communication with professionals involved with training
- Use of Adaptive Equipment
- --Start exploring uses before you have to
- --May solve one problem but create others
- --Goals are essential

Exercise Studies – Conclusions

- Some muscles can improve strength and/or endurance.
- Some post-polios can improve fitness.
- Interval training and pacing are essential to success.
- Goals for exercise should be clear.

Cardiovascular Complications and Prevention Tips

Sunita Dodani, MD, MSc, PhD, FAHA, Director, Center for Outcome Research and Education (CORE), Associate Professor, Department of Internal Medicine, Kansas University Medical Center, Kansas City, Kansas

Communicating with Your Physician: Techniques that Work

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The single most important way you can stay healthy is to be an active member of your own health care team. One way to get high-quality health care is to find and use information and take an active role in all of the decisions made about your care.

Research has shown that patients who have good relationships with their doctors tend to be more satisfied with their care—and to have better results. Here are some tips to help you and your doctor become partners in improving your health care.

Give information. Don't wait to be asked!

You know important things about your symptoms and your health history. Tell your doctor what you think he or she needs to know.

It is important to tell your doctor personal information—even if it makes you feel embarrassed or uncomfortable.

Bring a “health history” list with you, and keep it up to date. You might want to make a copy of the form for each member of your family.

Always bring any medicines you are taking, or a list of those medicines (include when and how often you take them) and what strength. Talk about any allergies or reactions you have had to your medicines.

Tell your doctor about any herbal products you use or alternative medicines or treatments you receive.
Bring other medical information, such as x-ray films, test results, and medical records.

Get information.

Ask questions. If you don't, your doctor may think you understand everything that was said.

Write down your questions before your visit. List the most important ones first to make sure they get asked and answered.

You might want to bring someone along to help you ask questions. This person can also help you understand and/or remember the answers.

Ask your doctor to draw pictures if that might help to explain something.

Take notes.

Some doctors do not mind if you bring a tape recorder to help you remember things. But always ask first.

Let your doctor know if you need more time. If there is not time that day, perhaps you can speak to a nurse or physician assistant on staff. Or, ask if you can call later to speak with someone.

Ask if your doctor has washed his or her hands before starting to examine you. Research shows that handwashing can prevent the spread of infections. If you're uncomfortable asking this question directly, you might ask, "I've noticed that some doctors and nurses wash their hands or wear gloves before touching people. Why is that?"

Take information home.

Ask for written instructions.

Your doctor also may have brochures and audio tapes and videotapes that can help you. If not, ask how you can get such materials.

Once you leave the doctor's office, follow up.

If you have questions, call.

If your symptoms get worse, or if you have problems with your medicine, call.

If you had tests and do not hear from your doctor, call for your test results.

If your doctor said you need to have certain tests, make appointments at the lab or other offices to get them done.

If your doctor said you should see a specialist, make an appointment.

Remember, quality matters, especially when it comes to your health. For more on health care quality and materials to help you make health care decisions, visit <http://www.ahrq.gov/consumer/pathqpack.htm>

SESSION F4

Finding Causes of and Managing Fatigue, Part 2

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Summary

Fatigue is the most frequently mentioned complaint of people with post-polio syndrome (PPS). And fatigue is often severe. However fatigue is not very specific and a prominent complaint in many neuromuscular disorders, in many chronic diseases such as multiple sclerosis, in oncology and even on itself in chronic fatigue syndrome. How to understand fatigue in PPS and how to deal with it is the aim of the two fatigue sessions.

In Session I the focus will be on the magnitude of the problem of fatigue in PPS, the different forms of fatigue and the factors playing a role in fatigue in PPS. In Session II the focus will be on the assessment and treatment of fatigue in clinical practice and what people with PPS can do to reduce fatigue.

Contents

Session I on Friday 11.15 - 12.30 AM covers the following topics:

- the problem of fatigue in PPS; prevalence and severity
- types and definitions of fatigue in PPS
- the mechanisms and factors contributing to fatigue in PPS

Session II on Friday 2.45 - 4.00 PM covers the following topics:

- how to assess fatigue in PPS
- how to treat fatigue in PPS
- energy conservation techniques

Causes of fatigue

Fatigue is mentioned by up to 80% of people with post-polio syndrome and the scores on fatigue questionnaires are often high, indicating severe fatigue. But, what is fatigue? Fatigue can be defined as 'a persistent, subjective sense of tiredness that interferes with usual functioning'. This refers to the general feeling of fatigue, however local muscle fatigue is also often present and is among the symptoms to define post-polio syndrome: 'new muscle weakness or abnormal muscle fatigability'.

In post-polio syndrome fatigue is most frequently related to physical factors.

Local muscle fatigue

Local muscle fatigue is the decline in the ability of the muscle to generate force. Several factors have been identified that may play a role in this:

- I - Failure to drive muscles from the central nervous system due to alterations in the central nervous system to activate the nerve cells due to polio - the precise mechanism is not understood;
- II - Transmission failure from the nerves to the muscle fibers due to the fact that nerve connections with muscle fibers that were formed in the recovery phase after the acute polio are of less quality and therefore less able to sustain the transfer of the signal from the nerve to the muscle;
- III - Decreasing capacity of the muscles due to post-polio syndrome to meet the physical requirements needed to execute daily life activities. The muscles that slowly decline in strength have to work at an increasing level of their maximal capacity and this will be inversely related to the duration physical activities can be maintained.
- IV - A decrease in endurance properties of muscles. Muscles that are chronically used at a certain load, especially leg muscles, change their properties towards endurance, however not fully. Shortages of relevant enzymes have been reported.
- V - Especially less and not affected muscles may be chronically under loaded in daily life and suffer from disuse. As a consequence they are less loadable.

General fatigue

General fatigue, the feeling of being tired, may have several causes.

- I - People with post-polio syndrome may feel fatigued due to the fact that they are constantly acting above or in the upper range of their physical capacities. This may result in a chronic state of exhaustion. It is important to realize that movement efficiency is often reduced. This implies that walking may cost twice (or even more) the energy of normal walking in case of two affected legs.
- II - Brain alterations due to polio virus damage have been suggested as a possible cause of general fatigue.
- III - Recent studies have demonstrated signs of chronic inflammation in the cerebrospinal fluid in PPS. This may also play a role in fatigue.
- IV - Deconditioning of the cardio respiratory system. Persons with post-polio syndrome have been found to be deconditioned, or to have a condition comparable to a sedentary life style.
- V - Psychological factors, such as 'giving up the fight', social factors related to the persons life situation, and sleep problems may all contribute to fatigue. However, these are not the main causes of fatigue in post-polio syndrome.

Other causes of fatigue

It is very important to rule out other causes of fatigue. Of course the list of potential causes is very long, but a few common causes such as anemia, hypothyroidism, depression need to be mentioned.

Factors associated with fatigue in PPS

In a recent study, so far unpublished data, several of the above mentioned factors were found to be associated with fatigue. Lower physical functioning, more pain, sleep problems, lower well being and an active coping style were found to be associated with fatigue. Of course, in this study not all potential factors were included.

Pharmacological treatment

No pharmaceuticals have been proven effective in reducing fatigue. Randomized controlled trials (RCT's) in which drugs are tested against a placebo and both investigators and patients are blinded for the intervention are the gold standard to prove effectiveness of interventions. Results from such studies have so far been disappointing in that no drug was found to be effective.

Modafinil, a drug used in narcolepsy, was recently demonstrated as not effective in reducing fatigue in a study by Vasconcelos OM, *Neurology* 2008 confirming the negative results reported earlier by Chan KM in *Muscle and Nerve* in 2006.

Intravenous Immunoglobulines (IVIg) have been studied in two trials by Borg K, in *Lancet Neurology* in 2006 and by Farbu E, *European Journal of Neurology* in 2007. The study by Borg found effect for muscle strength and for 'vitality'. The study by Farbu found an effect for pain. Both studies however found no effect for fatigue.

Pyridostigmine, a drug that improves neuromuscular transmission was demonstrated not effective in two studies, one by Trojan DA in *Neurology* in 1999 and one study by Horemans HL in *Journal of Neurology Neurosurgery and Psychiatry* in 2003.

Other drugs were investigated in only one study involving limited numbers of patients. Negative results were found by Dinsmore S for high-dose *prednisone*, and by Stein DP, for *amantadine*, an anti-inflammatory drug, both published in Annals of New York Academy of Sciences in 1995. A study in 2005 by On AY, demonstrated a significant effect of *lamotrigine*, an antiepileptic drug, supposed to have neuroprotective properties, on fatigue. So far confirmative studies have not been published. Finally, a recent pilot study by Skough K, in 2008, found no effects for coenzyme Q10.

Assessment of and Managing fatigue in individuals with PPS

Assessment

I Medical evaluation

It is very important to start with a thorough medical evaluation to exclude other pathologies as mentioned earlier.

II What is meant by fatigue?

The next thing is to go into a full consideration of the complaint of fatigue. Is it local or general, related to activity and which activities, does it increase over the day, does it respond to rest.

III Are other contributing factors present?

Consideration has to be given to sleep quality, mood disorders and coping styles.

IV What is the activity pattern?

The activities of daily life have to be inventoried. What is the activity level of a person, what kind of work does someone do, what are social and home activities, how is mobility outdoors. Are there any aids being used for walking, mobility in and outdoors and so on.

V What is the social system?

How is the person's social environment, does he or she have sufficient support and understanding at home and work.

VI What are the own perceptions?

How does someone value his or her complaints of fatigue (and other complaints, post-polio syndrome, polio residuals and so on).

VII What are the physical capacities?

What is somebody able to do given the polio residuals and co-morbidities. What is the physical burden of activities such as standing, walking, transfers, stair climbing, and the individuals various activities.

VIII Conclusion

Finally a conclusion can be made on which factors cause or sustain fatigue. These are to be targeted in interventions.

Assessment tools

Tools that may be of value in the assessment of fatigue are validated questionnaires to assess fatigue severity, pain, coping styles, mood, and physical functioning.

Diaries to inventory daily life activity are extremely useful to gain insight in what someone life looks like, in what a person actually does over the days. A common finding is that people with PPS appear to be much more active than they spontaneously report.

Clinical tests may be included to determine the extent of the polio residuals, and capacity tests to assess physical abilities.

Management

The first important thing is that the person obtains insight in the factors contributing to fatigue. The next and crucial thing is readiness to change. Many factors contributing to fatigue are related to behavior and to cognitions. For instance, if someone is constantly overusing oneself, but considers that as normal, it will be impossible to obtain any change in behavior. It is well known that many polio survivors are so-called 'over achievers' who are not easily prepared to reduce their activities. Occasionally, the reverse is also seen that some polio individuals may avoid physical activity, for instance if they think that this may damage muscles, and they may very well be mainly fatigued due to the vicious circle of fatigue, inactivity, physical deconditioning and so on.

To diminish fatigue energy conservation skills are often to be learned. This may be done individual or in group therapy programs. On the other hand regular physical activity is advised to maintain physical functioning. This implies an individual non-fatiguing exercise program that can be easily done at home, or in an (adapted and accessible) fitness setting. Environmental adaptations at home or work, transportation aids, braces and assistive devices may all be needed tailored to the individual's needs. Rehabilitation therapy is therefore usually multidisciplinary organized and may involve physical and occupational therapists, social workers, psychologists, orthotists, shoe technicians and adaptation technicians. Preferably, the effect of multidisciplinary interventions to reduce fatigue should evaluate the achievements obtained after the program and during follow-up.

Effective Family Communications Do We? How Can We Improve?

**Annie Barber, RN, Polio Survivors & Friends of East Central Illinois, Charleston, IL
Linda Bieniek, CEAP (retired) La Grange, IL**

Why is **communicating effectively** especially important for polio survivors and family members? Because as human beings, we each need acceptance, respect, love, and support to thrive. Communicating provides us with opportunities to express and accept these invaluable gifts. Most importantly, our connections can support and energize us to enjoy life's beauty during both good and difficult times.

When polio survivors experience losses of physical abilities, lifestyles, careers, connections, and financial resources, these changes often impact family members' lives as well. Each of us needs to communicate honestly, clearly, and sensitively about our needs and desires to make sure that our relationships are supportive and respectful of each other.

As a polio survivor and daughter of a polio survivor, we share examples of our communication challenges and offer strategies for gaining awareness of communication styles and improving our relationships with our natural or chosen family.

Communication Challenges That We Have Faced

"Speaking up about my physical limitations and needs when I developed post-polio syndrome was one of the greatest communication challenges that I have faced. Although in my job, I was assertive at intervening for other employees with disabilities, I was shocked at my own self-consciousness with men and my inability to ask for assistance at work. I grew anxious, depressed, and self-critical about my avoidance and the changes that my physical condition forced me to make in my life. By practicing what I professionally promoted, I invested in very effective psychotherapy! By working through feelings and limiting beliefs from early polio and family experiences, I learned to face myself with compassion and to communicate honestly about my needs. This also enabled me to ask my mother questions about my childhood--in non-accusing ways. Recently, while we watched the documentary on "Polio: An American Experience," she cried throughout the program. Afterwards, when I asked about her sadness, she revealed that she felt guilty about that period. I am grateful that I was able to thank her for all the ways she supported me and to encourage her to forgive herself for her limitations."

Linda Bieniek, Polio Survivor & Ventilator User, Life & Career Coach

“My father had polio when he was 12. I believe polio comprehensively influenced almost every moment of his life afterwards. As I was a nurse, sometimes Dad chose to allow me to partner with him to seek healthcare solutions. We experienced some very challenging times as we changed roles and he became more dependent and needy. He vacillated between appearing as a rigid, demanding, in-control man and a needy, frightened young boy. Neither of these were the strong, loving, devout, passionate, overworking Dad familiar to me. I found that communicating with my Dad had become, now more than ever, extremely important and yet extremely complex. The more Dad revealed to me about his experiences as a boy, the more I understood the reasons for his strong reactions. Then I was able to provide him with comfort and support through his devastating days of being bedfast again. If I had known some of the strategies we share, they might have eased some of the tensions during that period. I know they are helping me with my children.” **Annie Barber, R.N., Daughter of Polio Survivor, Post-Polio Support Group Leader**

“Communication, both verbal and non-verbal, is the ‘stuff’ that initiates, builds, maintains, and destroys relationships,....Effective communicators attend to the nonverbal aspects of space, energy, and time as well as to their choice of words and actions as they move from situation to situation, building and strengthening relationships.”
Connecting with Self and Others, S. Miller et al

What Are Your Relationship Goals?

The first step to becoming aware of how to improve your communication with a specific person is to clarify your goals: ***What kind of relationship do you WANT with this person? What do you WANT to change in your relationship? What do you WANT to gain from communicating with this person?*** Respond to these questions using **positive words that apply to you**. Remember, you only have control over what you can realistically do--how you communicate, listen, and respond to the other person. You cannot control how the other person responds. You can, however, use your insights and the approaches described in this article to plan how to deliver your messages and gain the best results possible.

Do You Communicate Honestly and Directly?

In some families, communicating honestly and directly is or was not considered appropriate. In other families, such as when a parent had an addiction, family members may not have felt safe speaking the truth for fear of reprisals. Now, as adults, we have the opportunity to express ourselves honestly with trustworthy individuals and also to recognize when to be discreet with a person. In order to understand your ability to express yourself honestly, take a few moments and note “yes” or “no” to these questions:

1. Do you say “yes” to requests when you want to say “no?” Do you avoid expressing your opinion when it differs from that of others?
2. Do you request what you need without feeling guilty?
3. When you get frustrated by a person’s behavior do you communicate your needs to the person? Do you avoid the person? Criticize the person doing the behavior? Or complain to someone else?
4. When someone offends you, do you tell the person? Or do you get angry and either avoid the person or say nothing, but feel resentful inside?

Using an approach known as HODSA, the acronym for **honest, open, direct, sensitive, and appropriate**, will enable you to decide how, where, and when to communicate to gain the results you want. The following questions are a checklist for ensuring that your messages reflect these qualities:

- **H--Honest:** Is what you want to say the truth about your thoughts feelings, or experiences?
- **O--Open:** Does your message and body language invite dialogue? What level of openness do you want to share with this person? Is he/she trustworthy? What does your intuition say?
- **D--Direct:** Are you stating your message clearly and concisely?
- **S--Sensitive:** Is what and how you plan to communicate sensitive to the person’s feelings, circumstances, and limitations? What about your body language?

- **A--Appropriate:** Are you choosing an appropriate moment and place to address this subject? Will the timing or setting of your interactions cause too much distress for the listener and interfere with your goals? Is your message appropriate given your roles?

In addition, nothing can replace the value of seeking feedback. Whenever you want to verify or confirm that you are getting your point across, request feedback from your listener. Ask open-ended questions such as, "Please tell me what you think I am saying;" "Please tell me what you think I mean by that;" or "How is this coming off to you?"

Does Your Body Language Reflect Your Good Intentions?

Most people can tell whether we are sincere about what we say by how we look and sound. Body language offers us another way to communicate our positive intentions. When we reflect honesty, openness, sincerity and sensitivity, we build trust and encourage cooperation. Does your eye contact, body posture, gestures, tone of voice, pace of speaking, and facial expressions invite openness? Seek feedback from a trustworthy friend to learn if your body language matches your verbal messages.

How Intimately Do You Share With Others?

Awareness provides us with insights about ourselves, others, and our interactions. Examining the terms below may help you become aware of the different levels of communication that you engage in. When you share information only on the sensory level that means you are revealing very little personal information. People who engage with each other only on this level are not very intimate with each other. On the other hand, if you are able to consistently express what you want, and then use that information to enact changes that meet your needs and desires, you are achieving a high level of intimacy, and often greater satisfaction in relationships.

Becoming familiar with these levels can help you to become attuned to your own comfort level and also can challenge you to share yourself with more depth, detail, and clarity. The more comfortable you become with expressing thoughts, feelings, and wants, the more courage you can gain for creating positive changes in your life.

Sensory Information: Verbal and non-verbal data based on the five senses of sight, smell, sound, touch, and taste. *I observed, sense, heard, etc "I see you have a red face."*

Thoughts: Thoughts are the meaning that we give to information and experiences. For example: *"I believe, perceive, think, expect, interpret, and see possibilities for...."* *"I think you look angry."*

Feelings: Emotional reactions, often to the differences between what we expect and what we actually experience. *"I feel sad, mad, afraid, glad, disappointed, etc "I'm worried that I disappointed you."*

Wants: Are what **you want to DO, to BE, or to HAVE.** *"I intend, desire, need, value...."* Hidden agendas such as retaliating or gaining control are negative objectives. *"I want to show you my gratitude."*

Actions: What we do are our behaviors---in the past, present, or future. *"I plan, achieved, will solve, resolved, will negotiate, am developing...."* *"I plan to listen more carefully next time."*

At what level of this awareness spectrum do you find yourself most comfortable? Do you share deeper levels of awareness with anyone? With whom do you communicate intimately and want to?

Do You Take Responsibility For Your Needs By Being Assertive?

Communicating assertively means taking ownership of our thoughts, feelings, and experiences while respecting the feelings of others. Beginning a statement with "I" rather than "you" is a straightforward approach that invites open and direct exchanges. Saying, *"I disagree,"* rather than, *"You're wrong"* is not blaming or accusatory, and as a result, can reduce defensiveness and conflicts. If you have a hard time turning down requests, respond by

simply saying, *"No, I can't do that now"* instead of giving a long explanation of the reasons that you can't fulfill the person's request before saying "No."

As humans, we all have needs which may conflict with another person's behavior. When this happens, asking the person to change a specific behavior is important for protecting the well-being of each individual and integrity of the relationship. If we avoid communicating directly and honestly about our feelings and needs, we risk revealing them indirectly, perhaps even passive-aggressively, impacting both parties negatively.

Use the four-step framework below to compose a clear and direct request for an individual to change a behavior. The above section on awareness offers useful terms that you can use to fill in the blanks:

"I feel _____ when _____ because _____. I need _____."

Step 1: *I feel.* Take ownership for how you feel about the person's behavior by saying: *"I feel frustrated..."*

Step 2: *When.* Concisely state the person's specific behavior that interferes with your needs. *"...when you keep talking while I am reading..."*

Step 3: *Because.* Describe the effect of the person's behavior on you. *"...because I feel ignored."*

Step 4: *I need.* State what you want the person to do or change. *"I need quiet time to relax and read."*

Do You Listen With an Open Mind and Heart?

How we listen is also essential to communicating effectively. Paying attention to the other person's verbal and non-verbal messages with an open mind and heart contributes to understanding, respect, and trust in our relationships. The questions below reveal traits of *ineffective* listening. If you answer "yes" to any of these, consider this an opportunity to change that pattern and to learn to listen attentively!

- Do you have definite opinions and need to be "right?"
- Do people say that you talk too much or get defensive?
- Do you interrupt others when they are speaking? Or finish their sentences?
- Do you change the subject when you are uncomfortable with a topic or person?
- Do you fully focus on what a person is saying? Or do you let your mind drift off and think about the subject or to another unrelated subject or person?

How Do You Come Across with Family Members?

Next, we encourage you to be honest and CIRCLE all the words in the table below that describe how you have communicated with different family members. Often, we express ourselves differently depending on the individual, circumstances, topic, and sometimes, how we feel that day! Also, take a minute to place an "X" over words that others might use to describe the way you communicate with them. Insights that you gain can equip you to consciously decide how you WANT to interact in the future.

Communication Styles				
Direct	With Avoidance	Expressive	Playful	Inconsistent
Irreverent	Aggressive	Passive	Kind	Sporadic
Abrupt	Inquisitive	Passive-Aggressive	Sensitive	Minimal
Humorous	Respectful	Indirect	Sarcastic	Effusive
Honest	Open	Humble	Patronizing	Overwhelming
Bossy	Demanding	Critical	Accusing	Flooding
Clear	Concise	Verbose	Defensive	Compulsive
Cynical	Diplomatic	Emotional	Sincere	Need-To-Know
Cold	Dramatic	Apologetic	Loving	Patient
Annoyed	Angry	Gentle	Haughty	Timid/Hesitant
Vulgar	Childlike	Cocky/Smart	Oppositional	Encouraging

For polio survivors: *How do you communicate with family members about the following issues?*

- ❖ Your needs and feelings related to changes caused by the late effects of polio?
- ❖ How your current condition and having had polio has affected your life?
- ❖ How your early polio experiences have impacted your life?
- ❖ Their (family members') present day needs and feelings and/or their own past experiences?

For family members: *How do you communicate with the polio survivor about the following issues?*

- ❖ Your own needs, feelings, and life experiences?
- ❖ The effects on your own life of the person contracting polio and/or developing its late effects?
- ❖ Your reactions to what the person has shared about past and present polio-related issues?
- ❖ What you want to know about the person's early polio experiences or present condition?

For polio survivors and family members:

- ❖ What do you do to become aware of your own feelings, needs, and desires?
- ❖ What "hot button" issues trigger intense reactions such as anger, anxiety, hurt, defensiveness, or avoidance? Have you considered seeking professional assistance to resolve them?
- ❖ How do you stay calm and focused when another person overreacts?
- ❖ Who is/are a trustworthy person(s) that you can turn to for constructive feedback and support during stressful family situations?

How Can You Plan To Express Yourself?

We recommend that you take time to note your answers to the questions below before approaching a family member to gain the results that you WANT. Your answers can assist you in deciding how to best communicate with the person. For complex and sensitive issues, also use the questions in the next exercise to plan your approach. These questions are all worth spending your time on!

- 1) With whom do you WANT to communicate?
- 2) What kind of relationship do you WANT with this person? What do you want to change?
- 3) What do you WANT to communicate? What is your message?
- 4) What do you WANT to gain from communicating with this person? For example:
 - a) What do you want to change or have happen?
 - b) What do you want to know?
- 5) How does this person usually communicate with you? Select descriptions from the "**Communication Styles**" box on Page 4.
- 6) What obstacles may interfere with your ability to gain a successful outcome with this person?

This question can help you recognize what you can change and what factors are out of your control. Possible obstacles include but are not limited to addictions; depression/ behavioral health condition; cognitive limitations; unresolved fears, traumas and "hot button" issues; and also mean-spirited, manipulative, abusive, or controlling personalities.

- 7) How, when, and where will you approach this person to gain the results that you WANT after considering his/her communication style, listening skills, biases, and triggers?

How Can You Respond To Challenging Personalities?

Some individuals have personalities that will not only interfere with communicating effectively but also may cause conflicts within the family (See question #6 on “obstacles” above). The reasons for their personality patterns vary. Some behaviors relate to medical conditions such as having a bipolar condition or an addiction. Even with these conditions, individuals can change many of their behavior patterns. However, they must want to make changes and be willing to seek professional assistance. Your role is not to diagnose or fix the person. Instead, you use the strategies in this article along with these suggestions to take care of yourself and your family:

Gain Knowledge

Understanding a person’s condition and behaviors along with your own reactions is especially important when interacting with challenging personalities. For example, a person who was abused or lost a parent as a child may have difficulty trusting others. Your understanding of this pattern can help you recognize that when the person criticizes you, this may be his or her way of creating distance and not of attacking you. Learn what triggers you and the other person and the reasons. Identify what contributes to conflicts or unproductive exchanges. The same advice holds for a medical condition such as bipolar condition. Likewise, if a polio survivor has not worked through anger and fears from early polio experiences, the person may use alcohol to numb uncomfortable feelings. Learning about the effects of traumas and chemical dependency can help you understand the person’s behaviors and find effective ways to encourage the person to seek therapeutic resources to improve his or her relationships patterns.

Focus On Your Positive Goals and Values

Set positive goals about how you want to interact with this person. Be clear about your priorities. Think of the person in compassionate terms, for example, “ill” versus “crazy” or “self-destructive” versus “cruel.” This can help you approach the person with understanding versus anger and defensiveness. Remind yourself of your values and affirm your good intentions. Focus on what you can do and say—what is in your control. Know that you have options of how to respond. Consider imagining yourself sending the person kind wishes or blessings (HeartMath approach). Imagine a protective clear shield between you and the other person to deflect any name-calling or accusations from feeling like a personal assault. Stay objective in absorbing what the person says. Pray for yourself and the person.

Use Good Judgment in What You Say and Do

Communicate clearly and specifically. Choose your battles and your words carefully. State your boundaries: “No, I will not be able to...” “I can do this, but not that.” Stay calm and focused so that you do not fall into the trap of criticizing the person or resorting to saying the person is “crazy” or a “burden.” Be discreet about what you share with the person and with others about the person. Avoid using generalizations and judgmental words. Affirm the person’s good behaviors. Ask the person to be specific about what he or she wants. Limit contact and time to necessities. Be clear about roles, responsibilities, and consequences. Feed back what you understand he or she wants. Take time outs if the conversation becomes too heated or unproductive.

In all situations, gain support from trustworthy individuals. Consider joining a support group on-line if you can’t attend in person. Make sure that you eat, sleep, and exercise (as much as you are able) well. Find ways to relieve stress and boost your energy. Use laughter, a good cry, movies, books, music, art, yoga, relaxation techniques, meditation, spending time outside and in Nature, playful games, and simple pleasures to calm and energize you. Be resourceful and seek assistance from volunteers at local churches, organizations, and college programs. Face yourself with kindness and forgiveness. Seek beauty and goodness. Use spirituality and humor to gain perspective of your situation within the big picture of life!

What Else Can You Do?

If after practicing these strategies, you still experience distress and difficulties gaining positive results from communicating with family members, consider exploring the following resources:

- Books, DVDs, websites, workshops on: communication skills, relationships, resolving conflicts, stress management, polio memoirs, and living well with the late effects of polio: www.post-polio.org/edu/aboutpol/books, Interpersonal Communications, Inc., HeartMath.
- Coaching: Obtain referrals from coachfederation.org or The NLP & Coaching Institute: 1-800-767-6756. Interview coaches by phone to find the professional who matches your needs.
- Counseling & Therapy: Assess website profiles and interview therapists over the phone: GoodTherapy.org; PsychologyToday.com; NetworkTherapy.com. Check backgrounds.
- Call Linda Bieniek, Life and Career Coach and retired Certified Employee Assistance Professional, at 708.354.3640 for professional “assessment and referral” services that match your needs with suitable coaches, counselors, therapists, and/or other resources.
- Read *What Psychotherapists Should Know about Disability* by Rhoda Olkin, Ph.D., and ask a coach, counselor, or therapist whom you work with to read it.
- Interfaith (Community or Care) Partnerships in the US provide visitations and assistance to individuals with chronic health conditions and also support for caregivers.

In conclusion, as polio survivors and caring supporters our lives are full of subtle and difficult changes, fears, opportunities for personal growth, disappointments, role reversals, and unexpected triggers. In these relationships, communication is paramount, yet very complex. We hope these suggestions will equip you to tend to your own and each other’s needs to maximize the beauty of being people who really listen, love, and care for each other. May your interactions enrich your relationships and lives!

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Exercise and Activity: How Much and What?

Let's Get practical

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I work at a Rehabilitation Center for polio and accident victims in Denmark. The Center is owned and run by a patient organization called: The Danish association of Polio and Accident Victims. All staff members are employed by the organization, but the counties in Denmark pay for the treatment, so all assessments and treatments are free of charge for the patients.

878 polio survivors were treated at our clinic in 2008. Around 300 polio survivors exercise on a regular basis in PTU once or twice a week in our training center or in the warm water pool. 10,5% of the polio survivors are immigrants. Around 50 polio survivors are annually referred to the center for the first time. Most of them are elderly Danes who have managed to live without our help until now, but we also get a lot of immigrants from third world countries who have polio. They are often much younger and have a lot of social and language problems on top of the polio difficulties.

We have 7 wheel chair accessible apartments where polio survivors from other parts of the country can stay while they attend a 1 or 3 week program at the center.

The center has a multidisciplinary team to take care of the polio survivor comprising: Doctor, physical therapists, technical aids therapists, social workers, psychologists, nurse assistants, dietician and a private orthotist, who is coming once a week. It is necessary to have a doctor's referral to our clinic. Before coming to the clinic the polio survivor is asked to fulfill a questionnaire about his or her social conditions (work situation / housing), the acute and stable phase and the actual problems that have made the patient come to the clinic. The doctor makes an examination of the patient, and she considers if there could be other differential diagnoses, which could cause the symptoms of the patient. She can then refer the patient to different professionals at the clinic or to additional tests at a hospital. Almost all the patients are referred to physiotherapy.

When all the relevant professionals have assessed the polio survivor, a conference is held where all assessments from the multidisciplinary team are presented and we agree on which recommendations should be given to the patient. It is important that we all work in the same direction and of course the plan is made in cooperation with the polio survivor. When there are complicated matters, the patient participates in the conference.

Some polio survivors need changes in their home or at the place of work. Our technical aids therapist can visit the polio survivors home together with the therapist from the county in order to find the best adjustments. Some polio survivors need to save their energy, so they need technical aids, bandages or help with housecleaning. If the patient has a seating problem we can measure the pressure of the buttocks in the seat, which makes it easier to find the right cushion for the wheel chair.

We also have a polio education program where polio survivors and their relatives can learn about polio issues, exercising principles, technical aids and psychological reactions to the need of changing lifestyle as polio problems arise. I could tell a lot about what all the professionals do but I will focus on the physiotherapy and especially how we deal with exercising according to the title of this session.

The physiotherapist uses a check scheme to make a thorough anamnesis and examination of the patient. We use this to be sure that we get all necessary information about the patient and his or her condition before we make a treatment plan.

If the main problem is pain we consider the cause of the pain. Is it overuse of the body structures or is it a more diffuse pain in the polio muscles. Depending on which kind of pain the patient has, we use a variety of pain treatments: Exercise, acupuncture, laser therapy, medication, massage, relaxation, energy conservation, bandages, aids, etc.

If the patient experiences a decrease in strength we always make a manual muscle test. We know that the test does not give us the exact truth about the polio affection, but it gives us a good impression of how much polio affection there is. You can see on the slide that the manual muscle test only detects rather big decreases in strength, but we are therefore aware that there can be polio in a muscle, even if it seems strong in the test.

Grade

0	No muscle contraction	0%
1	Palpable contraction	< 5%
2	Gravity eliminated	5 – 10 %
3	Against gravity	10 –20 %
4	Moderate / good	40 %
5	Maximum resistance	> 60 %

We use the manual muscle test as a guideline for how the patient should exercise or which kind of bandages could be useful. During testing we can also see and feel if there are fasciculations during the test, which tell us that the muscle can be overused. Sometimes we can compare a recent test with a test taken some years earlier and in that way we can follow the development of the decrease in muscle strength. I should maybe mention that we do not take EMG measurements regularly in Denmark. We have very good journals of the patients polio history from their initial hospitalization and we find that the muscle test is enough in most cases.

To be able to tell if the treatment makes a difference we also use other tests. Not for everybody, but when it is relevant. I will mention these tests:

- 6 min walk test which is the distance walked in 6 minutes as fast as possible.
- Time used to walk 10 meters,
- Walking distance outdoor where the patient walk until he or she needs a break. We use this when applying for car or a parking sign.
- We also have balance and fitness tests.
- Timed Stands Test which measures the time necessary for getting in and out of a chair 10 times without using the arms.

After hearing the polio survivor's story and performing the tests we make an evaluation to decide whether the problems are caused by disuse, overuse or maybe something else.

As in the States Denmark also has a rising number of lifestyle related diseases. The Health Department in Denmark recommends that everybody should do at least moderate exercising for 30 minutes each day. The polio population is in high risk of getting life style related diseases, because they often have a lower activity level than the rest of the population. The well-known life-style related diseases are: Hypertension, diabetes, osteoporosis, cardio-vascular diseases and depression. So even though a person has polio, he has to maintain a certain level of activity if possible and he has to keep his weight down in order to avoid further complications to his condition. The two main ways of handling this is healthy diet and exercising.

So what are the exercising recommendations for polio survivors in Denmark?

When we examine the patient we consider what status the muscles have. Is the strength stable or unstable? As you can see our recommendations of exercising the patients depends on the strength level and if the muscles are stable or not. By stable I mean, that there have not been more decrease in strength

than could be explained by age. The last line in the slide represent the muscles that are so overused through daily activities, that they should not exercise more. But only very few patients cannot exercise at all. Most patients can benefit from exercising even in a very light way.

Polio status	Muscle strength	Exercise
Stable	Normal	No restrictions but be careful
Stable	Reduced	Moderate strength exercise
Unstable	Reduced	Non-fatiguing
Unstable	Very reduced	No resistance
Large atrophy	Very reduced	No exercise

Unless the muscles are very weak (below 3+) we normally recommend a training program for the polio survivor. We want to improve strength if possible, improve muscle endurance and cardio respiratory fitness. If the polio survivor is overweight we offer consultations with our dietician, so the exercise can be combined with a change in diet. Many studies show that exercise is beneficial to polio muscles as long as the patient exercises with non-fatiguing exercises.

The following slides are our recommendations to the Danish polio survivors. If you want to improve cardio respiratory fitness you have to do aerobic training such as leg- or arm bicycling, swimming or rowing.

The principles are that you should exercise at 65% of max heart rate or at Borg scale 12 – 14 “Somewhat hard”.

You should exercise at least for 10 to 30 minutes depending on the condition of the exercising muscles. Preferably you should exercise at least twice a week.

The Borg scale rate of perceived exertion:

- 6 No exertion at all
 - 7 Extremely light
 - 8
 - 9 Very light-(easy walking slowly at a comfortable pace)
 - 10
 - 11 Light
 - 12
 - 13 Somewhat hard (It is quite an effort; you feel tired but can continue)
 - 14
 - 15 Hard (heavy)
 - 16
 - 17 Very hard (very strenuous, and you are very fatigued)
 - 18
 - 19 Extremely hard (You cannot continue for long at this pace)
 - 20 Maximal exertion
-

If non-disabled people want to improve strength they should exercise at very close to their maximum capacity. This is not recommendable for polio survivors, so we recommend that you exercise at maximum 50% of max. capacity. In some cases strength will improve even though you train at this lower level. Train in intervals, for instance take 10 repetitions, move on to the next machine, take a round in the machines and then return later. If it is too difficult to go from machine to machine, you have to take breaks in stead. For endurance training you should exercise with low resistance and many repetitions.

If you as a polio survivor experience signs of overuse: Excessive fatigue after exercising, excessive pain after training or fasciculations.; You have to exercise with less resistance (maybe even ½ the load) or decrease the number of repetitions. You can also decrease the frequency of exercising or exercise in a different way. But maybe exercising is not the best solution for you. For some polio survivors daily activities are enough training or even overuse, so you have to think of energy management, bandaging and technical aids. Even though the polio survivors in our clinic are not exercising heavy strengthening exercises, many of them feel that they get stronger and are able to cope with the tasks of daily living in a better way. They all say that when they pause with the training in the summer, they feel they become weaker and less rigid.

You can exercise in many different ways. I.e. Fitness center, swimming, gymnastics, fysio Pilates, home exercising, handicap sports, horseback riding etc. The most important thing is to find something that motivates you. Something you enjoy doing otherwise it will be too much hard work and you may fail to exercise enough. Another good advice is to find a training partner. When you have an appointment with somebody you are not so tempted to skip training. Combine the social aspect with exercising. But I will also advise you to have a therapist who is familiar with polio issues to help you find the right level of training.

If you don't have the possibility of exercising at a polio clinic nearby or if you don't feel that at a fitness center is right for you, you can exercise at home. I will just show a few ways of exercising at home. First of all you can have a physical therapist make you a home exercising program especially made for you.

Therabands can be very useful in exercising at home. They can be bought in different resistance levels. I will recommend the white or the yellow ones for polio survivors, unless you have every strong muscles some where in your body. Therabands can be bought on www.amazon.com and you can find all kinds of exercises at www.thera-bandacademy.com/exercises.

Remember to use the polio training principles:

- Low resistance,
- Exercise in intervals,
- Take brakes,
- Avoid excessive pain and fatigue

Nordic walking or bicycling can be a good alternative to exercising in-door

In our clinic we have a fitness center, swimming pool and offer group gymnastics. We have several kinds of groups: Relaxing, genuine training, weight reduction groups and we even have special groups for muslim women both in the pool and in the gym. Many of our patients continue to exercise at the clinic after the initial treatment, so they can maintain the fitness level they achieved in the beginning.

The benefits of exercising are multiple: Some polio survivors improve their strength; others maintain their strength level and some are diminishing the polio related loss of strength. Some polio survivors improve their functional capacity and balance. Exercising gives you the possibility of getting control over your weight and exercising reduces hypertension, risk of heart disease, risk of diabetes, depression, improved sense of well being.

We have just published a study of 50 polio survivors who received a multidisciplinary intervention with emphasis on physical therapy at our clinic and a few of the results were these:

6-min. Walk test **10,6% improvement** (a test where you walk as far as you can I 6 minutes

Timed Stands Test **12,9% improvement** (a test which measures the time necessary for getting in and out of a chair without using the arms 10 times)

“Vitality” from SF-36 **7% improvement** (a dimension in a quality of life questionnaire)

“Physical fatigue” MFI-20 **10% improvement** (a dimension in a fatigue questionnaire)

Most of the patients in this study exercised and 12 of them got new devices for walking.

So it does make good sense to exercise and to accept the right aids for walking and changes in life style.

Thank you for your attention.

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Exercise and Activity: How Much and What? Let's Get Practical

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Complementary and Alternative Medicine (CAM): What You Don't Know Can Hurt You

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Decisions about your health care are important—including decisions about whether to use complementary and alternative medicine (CAM). The National Center for Complementary and Alternative Medicine (NCCAM) has developed this fact sheet to assist you in your decisionmaking about CAM. It includes frequently asked questions, issues to consider, and a list of sources for further information. To find out more about topics and resources mentioned in this fact sheet, see “For More Information.”

Key Points

- Take charge of your health by being an informed consumer. Find out what scientific studies have been done on the safety and effectiveness of the CAM treatment in which you are interested.
- Decisions about medical care and treatment should be made in consultation with a health care provider and based on the condition and needs of each person. Discuss information on CAM with your health care provider before making any decisions about treatment or care.
- Tell your health care providers about any complementary and alternative practices you use. Give them a full picture of what you do to manage your health. This will help ensure coordinated and safe care.
- If you use a CAM therapy provided by a practitioner, such as acupuncture, choose the practitioner with care. Check with your insurer to see if the services will be covered. (To learn more about selecting a CAM practitioner, see our fact sheet, “Selecting a CAM Practitioner.”)

1. What is CAM?

CAM is a group of diverse medical and health care systems, practices, and products that are not presently considered to be part of conventional medicine. Complementary medicine is used together with conventional medicine, and alternative medicine is used in place of conventional medicine. Conventional medicine is medicine as practiced by holders of M.D. (medical doctor) or D.O. (doctor of osteopathy) degrees and by their allied health professionals, such as physical therapists, psychologists, and registered nurses. Some health care providers practice both CAM and conventional medicine.

The list of what is considered to be CAM changes continually, as those therapies that are proven to be safe and effective become adopted into conventional health care and as new approaches to health care emerge. For more about these terms, see the NCCAM fact sheet “What Is CAM?”

2. How can I get reliable information about a CAM therapy?

It is important to learn what scientific studies have discovered about the therapy in which you are interested. It is not a good idea to use a CAM therapy simply because of something you have seen in an advertisement or on a Web site or because someone has told you that it worked for them. (See sidebar for some tips on evaluating the information you see on a Web site.)

Understanding a treatment's risks, potential benefits, and scientific evidence is critical to your health and safety. Scientific research on many CAM therapies is relatively new, so this kind of information may not

be available for every therapy. However, many studies on CAM treatments are under way, including those that NCCAM supports, and our knowledge and understanding of CAM is increasing all the time. Here are some ways to find scientifically based information:

- Talk to your health care practitioner(s). Tell them about the therapy you are considering and ask any questions you may have about safety, effectiveness, or interactions with medications (prescription or non-prescription). They may know about the therapy and be able to advise you on its safety and use. If your practitioner cannot answer your questions, he may be able to refer you to someone who can. Your practitioner may also be able to help you interpret the results of scientific articles you have found.
- Use the Internet to search medical libraries and databases for information. One database called CAM on PubMed, developed by NCCAM and the National Library of Medicine, gives citations or abstracts (brief summaries) of the results of scientific studies on CAM. In some cases, it provides links to publishers' Web sites where you may be able to view or obtain the full articles. The articles cited in CAM on PubMed are peer-reviewed—that is, other scientists in the same field have reviewed the article, the data, and the conclusions, and judged them to be accurate and important to the field. Another database, International Bibliographic Information on Dietary Supplements, is useful for searching the scientific literature on dietary supplements.
- If you do not have access to the Internet, contact the NCCAM Clearinghouse. The staff is available to discuss your needs with you and assist you in searching the peer-reviewed medical and scientific literature.
- Visit your local library or a medical library to see if there are books or publications that contain scientific articles discussing CAM in general or the treatment in which you are interested. Thousands of articles on health issues and CAM are published in books and scientific journals every year. A reference librarian can help you search for those on the therapy that interests you.

Questions to ask when evaluating Web site information:

- Who runs the site? Is it Government, a university, or a reputable medical or health-related association? Is it sponsored by a manufacturer of products, drugs, etc.? It should be easy to identify the sponsor.
- What is the purpose of the site? Is it to educate the public or to sell a product? The purpose should be clearly stated.
- What is the basis of the information? Is it based on scientific evidence with clear references? Advice and opinions should be clearly set apart from the science.
- How current is the information? Is it reviewed and updated frequently?

For more tips on evaluating information on the Web, read NCCAM's "10 Things To Know About Evaluating Medical Resources on the Web."

3. Are CAM therapies safe?

Each treatment needs to be considered on its own. However, here are some issues to think about when considering a CAM therapy.

- Many consumers believe that “natural” means the same thing as “safe.” This is not necessarily true. For example, think of mushrooms that grow in the wild: some are safe to eat, while others are poisonous.
- Individuals respond differently to treatments. How a person might respond to a CAM treatment depends on many things, including the person’s state of health, how the treatment is used, or the person’s belief in the treatment.
- For a CAM product that is sold over the counter (without a prescription), such as a dietary supplement,¹ safety can also depend on a number of things:
 - o The components or ingredients that make up the product
 - o Where the components or ingredients come from
 - o The quality of the manufacturing process (for example, how well the manufacturer is able to avoid contamination).

The manufacturer of a dietary supplement is responsible for ensuring the safety and effectiveness of the product before it is sold. The U.S. Food and Drug Administration (FDA) cannot require testing of dietary supplements prior to marketing. However, while manufacturers are prohibited from selling dangerous products, the FDA can remove a product from the marketplace if the product is dangerous to the health of Americans. Furthermore, if in the labeling or marketing of a dietary supplement a claim is made that the product can diagnose, treat, cure, or prevent disease, such as “cures cancer,” the product is said to be an unapproved new drug and is, therefore, being sold illegally. Such claims must have scientific proof.

¹ “Dietary supplements” were defined by Congress in a law passed in 1994. A dietary supplement is a product (other than tobacco) taken by mouth that contains a “dietary ingredient” intended to supplement the diet. Dietary ingredients may include vitamins, minerals, herbs or other botanicals, amino acids, and substances such as enzymes, organ tissues, and metabolites. Under current law, dietary supplements are considered foods, not drugs.

- For CAM therapies that are administered by a practitioner, the training, skill, and experience of the practitioner affect safety. However, in spite of careful and skilled practice, all treatments—whether CAM or conventional—can have risks.

4. How can I determine whether statements made about the effectiveness of a CAM therapy are true?

Statements that manufacturers and providers of CAM therapies may make about the effectiveness of a therapy and its other benefits can sound reasonable and promising. However, they may or may not be backed up by scientific evidence. Before you begin using a CAM treatment, it is a good idea to ask the following questions:

- Is there scientific evidence (not just personal stories) to back up the statements? Ask the manufacturer or the practitioner for scientific articles or the results of studies. They should be willing to share this information, if it exists.

- Does the Federal Government have anything to report about the therapy?
 - o Visit the FDA online at www.fda.gov to see if there is any information available about the product or practice. Information specifically about dietary supplements can be found on FDA's Center for Food Safety and Applied Nutrition Web site at www.cfsan.fda.gov. Or visit the FDA's Web page on recalls and safety alerts at www.fda.gov/opacom/7alerts.html.
 - o Check with the Federal Trade Commission (FTC) at www.ftc.gov to see if there are any fraudulent claims or consumer alerts regarding the therapy. Visit the Diet, Health, and Fitness Consumer Information Web site at www.ftc.gov/bcp/menu-health.htm.
 - o Visit the NCCAM Web site, nccam.nih.gov, or call the NCCAM Clearinghouse to see if NCCAM has any information or scientific findings to report about the therapy.
- How does the provider or manufacturer describe the treatment? The FDA advises that certain types of language may sound impressive but actually disguise a lack of science. Be wary of terminology such as "innovation," "quick cure," "miracle cure," "exclusive product," "new discovery," or "magical discovery." Watch out for claims of a "secret formula." If a therapy were a cure for a disease, it would be widely reported and prescribed or recommended. Legitimate scientists want to share their knowledge so that their peers can review their data. Be suspicious of phrases like "suppressed by Government" or claims that the medical profession or research scientists have conspired to prevent a therapy from reaching the public. Finally, be wary of claims that something cures a wide range of unrelated diseases (for example, cancer, diabetes, and AIDS). No product can treat every disease and condition.

5. Are there any risks to using CAM treatments?

Yes, there can be risks, as with any medical therapy. These risks depend upon the specific CAM treatment. The following are general suggestions to help you learn about or minimize the risks.

- Tell your health care providers about any complementary and alternative practices you use. Give them a full picture of what you do to manage your health. This will help ensure coordinated and safe care. For example, herbal or botanical products and other dietary supplements may interact with medications (prescription or non-prescription). They may also have negative, even dangerous, effects on their own. Research has shown that the herb St. John's wort, which is used by some people to treat depression, may cause certain drugs to become less effective. And kava, an herb that has been used for insomnia, stress, and anxiety, has been linked to liver damage.
- If you have more than one health care provider, let all of them know about the CAM and conventional therapies you are using. This will help each provider make sure that all aspects of your health care work together.
- Take charge of your health by being an informed consumer. Find out what the scientific evidence is about any treatment's safety and whether it works.
- If you decide to use a CAM treatment that would be given by a practitioner, choose the practitioner carefully to help minimize any possible risks.

6. Are CAM therapies tested to see if they work?

While some scientific evidence exists regarding the effectiveness of some CAM therapies, for most there are key questions that are yet to be answered through well-designed scientific studies—questions such as whether the therapies are safe, how they work, and whether they work for the diseases or medical conditions for which they are used.

NCCAM is the Federal Government's lead agency for scientific research on CAM. NCCAM supports research on CAM therapies to determine if they work, how they work, whether they are effective, and who might benefit most from the use of specific therapies.

7. I am interested in a CAM therapy that involves treatment from a practitioner. How do I go about selecting a practitioner?

Here are a few things to consider when selecting a practitioner. If you need more information, see our fact sheet "Selecting a CAM Practitioner."

- Ask your physician, other health professionals, or someone you believe to be knowledgeable regarding CAM whether they have recommendations.
- Contact a nearby hospital or a medical school and ask if they maintain a list of area CAM practitioners or could make a recommendation. Some regional medical centers may have a CAM center or CAM practitioners on staff.
- Contact a professional organization for the type of practitioner you are seeking. Often, professional organizations have standards of practice, provide referrals to practitioners, have publications explaining the therapy (or therapies) that their members provide, and may offer information on the type of training needed and whether practitioners of a therapy must be licensed or certified in your state. Professional organizations can be located by searching the Internet or directories in libraries (ask the librarian). One directory is the Directory of Information Resources Online (DIRLINE) compiled by the National Library of Medicine (dirline.nlm.nih.gov). It contains locations and descriptive information about a variety of health organizations, including CAM associations and organizations.
- Many states have regulatory agencies or licensing boards for certain types of practitioners. They may be able to provide you with information regarding practitioners in your area. Your state, county, or city health department may be able to refer you to such agencies or boards. Licensing, accreditation, and regulatory laws for CAM practices are becoming more common to help ensure that practitioners are competent and provide quality services.

8. Can I receive treatment or a referral to a practitioner from NCCAM?

NCCAM is the Federal Government's lead agency for scientific research on CAM. NCCAM does not provide CAM therapies or referrals to practitioners.

9. Can I participate in CAM research through a clinical trial?

NCCAM supports clinical trials (research studies in people) on CAM therapies. Clinical trials on CAM are taking place in many locations worldwide, and study participants are needed. To find out more about clinical trials in CAM, see the NCCAM fact sheet "About Clinical Trials and CAM." To find trials that are

recruiting participants, go to the Web site nccam.nih.gov/clinicaltrials. You can search this site by the type of therapy being studied or by disease or condition. If you do not have access to the Internet, contact the NCCAM Clearinghouse for information.

For More Information

NCCAM Clearinghouse

The NCCAM Clearinghouse provides information on CAM and NCCAM, including publications and searches of Federal databases of scientific and medical literature. The Clearinghouse does not provide medical advice, treatment recommendations, or referrals to practitioners.

Toll-free in the U.S.: 1-888-644-6226

TTY (for deaf and hard-of-hearing callers): 1-866-464-3615

NCCAM Web site: nccam.nih.gov

E-mail: info@nccam.nih.gov

Assisted Living Communities for Survivors

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