NINTH INTERNATIONAL CONFERENCE ON POST-POLIO HEALTH AND VENTILATOR-ASSISTED LIVING:

STRATEGIES FOR LIVING WELL

June 2-4, 2005 ■ Saint Louis, Missouri

PROGRAM FOR THURSDAY, JUNE 2, 2005

This book belongs to:

POST-POLIO HEALTH
INTERNATIONAL

Post-Polio Health International
Including International Ventilator Users Network

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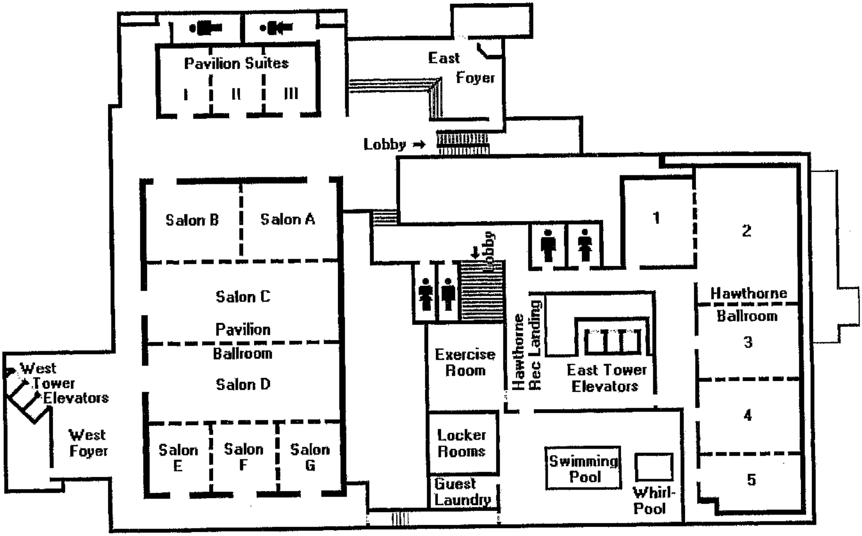

Details

Please wear your NAME BADGE; it is your "ticket" for the sessions.

The time schedule will be strictly adhered to because the sessions will be audio taped. TAPES are available on site. An order form is included in the conference bag. Personal recording (audio, video, etc.) of the sessions is prohibited.

EXHIBITS are located in Pavilion Suites I-II-III.

The Thursday, June 2, 2005, "MEET FOR HEALTHY TREATS" in the East Foyer is open to all full and Thursday registrants and those who purchased a ticket.

The Friday, June 3, and Saturday, June 4, MORNING BREAKFASTS are open to all full and daily registrants and will be available in the West Foyer and the East Foyer. Seating will be available in Salon D and the East Foyer.

MEAL TICKETS will be collected at the doors of Salon C & D. Meal tickets for the luncheons and Friday dinner are no longer available. All registrants are invited to the awards presentation and entertainment on Friday, June 3 at 7:30 pm in Salon C & D.

In case of an EMERGENCY, call the hotel operator "O" and request that they call "911" so they are alerted and can direct the emergency crew to you.

QUESTIONS from the audience will be submitted to the speaker/moderator in writing unless otherwise announced in the session.

Post-Polio Health International's mission is to enhance the lives and independence of polio survivors and home ventilator users through education, advocacy, research and networking.

Welcome to PHI's Ninth International Conference on Post-Polio Health and Ventilator-Assisted Living ...

On behalf of the Board of Directors and staff of Post-Polio Health International and the International Ventilator Users Network, we welcome you to Saint Louis and to this ninth unique symposium since 1981.

We gratefully acknowledge the expertise and commitment of our presenters, and thank them for their valuable abstracts, outlines, fact sheets and other materials enclosed in this book. If you wish to share this information, we respectfully ask that you acknowledge the presenters and their institutions and then add the following statement:

"This information was disseminated at Post-Polio Health International's Ninth International Conference on Post-Polio Health and Ventilator-Assisted Living, June 2-4, 2005."

We also would appreciate you informing PHI as well as the presenter that you are disseminating this material and where, so that we can track the ripple effect of the conference.

Audio tapes and CDs of the sessions will be available on site and also may be ordered after the conference from Network Communications (800-747-1426, 636-677-1912 fax, www.swiftsite.com/nettapes/PostPolio2005.html). Ordering information also will be available on www.post-polio.org and in future issues of *Post-Polio Health* and *Ventilator-Assisted Living.*

Personal recording (audio, video, etc.) of the sessions is prohibited.

This ninth symposium has been created and designed from the information needs, requests and suggestions of today's polio survivors and ventilator users. The purposes and outcomes expected are:

- To learn personal STRATEGIES FOR LIVING WELL
- To provide information and support to families and friends of polio survivors and ventilator users
- To exchange ideas with polio survivors and ventilator users
- To exchange ideas with health professionals
- To contribute to the worldwide activities supporting the improved health and independence of polio survivors and ventilator users
- To renew old acquaintances and make new friends

Our wish is that each and every one of you, whether consumer *or* health professional, or both, will return home with numerous strategies for living well and with a commitment to implementing them. We also sincerely hope that you leave with a continued commitment to supporting the work of PHI and IVUN. Your personal and professional contributions, both financially and in deed, are vital to us as we continue our much-needed efforts on behalf of polio survivors and ventilator users.

Audrey J. King
Conference Co-Chair
Audrey King

William Wischmeyer
Conference Co-Chair
William Wischmeyer

Joan L Headley
Executive Director
Joan L. Headley

Program for Thursday, June 2, 2005

9:00 am – 6:15 pm
Registration Desk
REGISTRATION

2:30 am – 5:30 pm; 8:30 pm – 9:30 pm
Pavilion Suites
EXHIBITS OPEN

11:30 am- 1:00 pm
Salon C and D
OPENING LUNCHEON *(ticket required)*
Post-Polio Health International Board President
Frederick Maynard, MD
U.P. Rehabilitation Medical Associates, Marquette, Michigan
Conference Co-Chairs
Audrey King
Toronto, Ontario, Canada
William Wischmeyer
Saint Louis, Missouri
William Siedhoff
Director of Human Services
Mayor's Office
Saint Louis, Missouri

1:30 pm – 2:45 pm
SESSION I (PLENARY)

Salon C and D
THE PAST, THE PRESENT, THE FUTURE
The Polio Vaccine Story
Christopher Rutty
Founder & President, Health Heritage Research Services, Toronto, Ontario, Canada
The Rotary Story
Ray Klinginsmith
Rotary International Foundation, Kirksville, Missouri
Ray Taylor
Polio Survivors & Associates, Pinehurst, North Carolina
The Unfinished Story
Daniel Wilson, PhD
Muhlenberg College, Allentown, Pennsylvania

2:45 pm – 3:15 pm
BREAK

3:15 pm – 4:30 pm
SESSION II OPTIONS

Salon B
ANESTHESIA PRECAUTIONS FOR PEOPLE WITH NEUROLOGIC CONDITIONS
Moderator: Lawrence Becker, PhD
Roanoke, Virginia
Selma Calmes, MD
Olive View-UCLA Medical Center, Sylmar, California

Salon C
INTEGRATIVE MEDICINE APPROACH TO POST-POLIO SYNDROME MANAGEMENT IN PRACTICE
William DeMayo, MD
Barbara Duryea, RN
John P. Murtha Neuroscience & Pain Institute,
Conemaugh Health System, Johnstown, Pennsylvania
Reactor: Sue Harris, LicAc
Whole Person Health, Canton, Massachusetts

Salon A
TRAVEL TIPS
Taking Cruises
Linda Priest, CTRS/L
Atlanta, Georgia
And, If You Use a Vent
Angela King, BS, RPFT, RRT-NPS
Pulmonetic Systems, Inc., Minneapolis, Minnesota

Salon E
EMOTIONAL EATING
My Story
Marge Torre
Bradenton, Florida
Robert Thayer
Clinton, Mississippi
What Is It and What to Do About It
Linda Bieniek, CEAP
La Grange, Illinois
Reactor: Stephanie Machell, PsyD
International Rehabilitation Center for Polio,
Framingham, Massachusetts

Salon F/G
DISABILITY INSURANCE: BUYING IT AND SECURING IT
Moderator: Saul Morse
Springfield, Illinois
Mark DeBofsky
Daley, DeBofsky and Bryant, Chicago, Illinois

Salon D
LEAVING A LEGACY
The Polio Oral History Project
Anna Rubin
International Rehabilitation Center for Polio,
Framingham, Massachusetts
Documenting Polio Stories:
Learn from the Canadian Experience
Sally Aitken
Polio Québec, Québec, Canada

4:30 pm – 6:15 pm
DINNER (On Your Own)

6:15 pm – 8:30 pm
TWILIGHT SESSION OPTIONS

6:15 pm – 8:30 pm
Pavilion Suites
THE LATEST IN VENTILATORY EQUIPMENT
Moderator: Larry Kohout
Edina, Minnesota
Representatives of ventilatory equipment manufacturers

6:15 pm – 8:30 pm
Salon A
SPIRITUAL HEALTH
Strategies for Living in Peace with Polio
Robert Ronald, SJ
Kuangchi Program Service, Taipei, Taiwan ROC
Songs for the Soul: Cries and Blessings
James Croegaert, BCC
Spiritual Services, Resurrection Medical Center, Chicago, Illinois

6:15 pm – 8:30 pm
Salon B
GETTING TO KNOW YOU & YOUR WORK: POST-POLIO SUPPORT GROUPS
Moderator: Beth Kowall, MS, OTR
Greenfield, Wisconsin
Support group representatives who are in attendance at the Conference

6:15 – 7:15 pm and repeated at 7:30 – 8:30 pm
Salon D
EXPERIENCE ACUPUNCTURE
Sue Harris, LicAc
Whole Person Health, Canton, Massachusetts

6:15 – 7:15 pm and repeated at 7:30 – 8:30 pm
Salon C
EXPERIENCE YOGA
David Riley, MD
Editor-in-Chief, *Explore: The Journal of Science and Healing,*
Santa Fe, New Mexico
Barbara Duryea, RN
John P. Murtha Neuroscience & Pain Institute,
Conemaugh Health System, Johnstown, Pennsylvania

6:15 – 7:15 pm and repeated at 7:30 – 8:30 pm
Salon G
EXPERIENCE REIKI
Stephanie Machell, PsyD
International Rehabilitation Center for Polio,
Framingham, Massachusetts

6:15 – 7:15 pm and repeated at 7:30 – 8:30 pm
Marriott Saint Louis Downtown Pool
EXPERIENCE WATSU
Kathleen Christ, LMT, NCMBT
Saint Louis Aquatic Healing Center, Saint Louis, Missouri

6:15 – 7:15 pm
Salon E
THERAPEUTIC USE OF MUSIC: EXPERIENCE MUSICAL ACUPUNCTURE AND MUSICAL BIOFEEDBACK
Janalea Hoffman, RMT, MA
Rhythmic Medicine, Olathe, Kansas

6:15 – 7:15 pm
Salon F
SERVICE DOGS FOR PEOPLE WITH NEUROMUSCULAR CONDITIONS AND THOSE WHO USE VENTS
Joanne Kocourek, RN, CCRC
with Annalies and Kristen
Worth, Illinois

7:30 – 8:30 pm
Salon E
THERAPEUTIC USES OF THE NATIVE AMERICAN CEDAR FLUTE
Janalea Hoffman, RMT, MA
Rhythmic Medicine, Olathe, Kansas

7:30 – 8:30 pm
Salon F
EXPERIENCE MYOFASCIAL RELEASE
Nancy Caverly, OTR/L
Mexico, Missouri

8:30 pm – 9:30 pm
East Foyer
MEET FOR HEALTHY TREATS

SESSION I

(Plenary)

1:30 pm – 2:45 pm

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THE PAST, THE PRESENT, THE FUTURE: The Polio Vaccine Story – A Canadian Perspective

Christopher J. Rutty, PhD
Medical Historian & Consultant
Health Heritage Research Services, Toronto, Canada

With 2005 marking the 50th anniversary of the Salk polio vaccine, the world is celebrating what many historians have described as a quintessentially "American story." This story revolves around Dr Jonas Salk's famous discovery of an inactivated, injectable polio vaccine (IPV) and the trial of the century of it that followed in 1954-55, orchestrated by the National Foundation for Infantile Paralysis, or U.S. March of Dimes. For Americans, the dramatic development and introduction of the Salk vaccine, particularly in the context of the cold war, reflected the superiority of American science, technology and ingenuity, and the power of individual courage and private philanthropy against the growing scourge of paralytic polio. The sudden tragedy of the "Cutter Incident" certainly undercut this heroic tale, although its drama pointed to how Americans could rise to the occasion and overcome this setback, albeit with a different type of vaccine, the Sabin oral, attenuated polio vaccine (OPV) by the early 1960s. Despite the rapid supplanting of IPV with OPV in the U.S., at least until the late 1990s, to most Americans it is Jonas Salk who is clearly remembered as the iconic hero who won the war against "The Crippler."

For most delegates to this international post-polio conference, the Salk vaccine story summarized above is well known, if not deeply ingrained in their personal and collective memories. However, based on more than 15 years of historical research utilizing extensive and hitherto untapped primary documentation related, in particular, to the original development and production of the Salk vaccine, this understanding of the polio vaccine story is considerably incomplete. Specifically, it discounts, if not completely ignores, the essential role played by Canadian science and technology in making a plentiful supply of the Salk vaccine possible and practical, and the Canadian political and public health role in demonstrating the clear safety and effectiveness of the Salk vaccine during and after the Cutter Incident.

This presentation chronicles the polio experience north of the 49th parallel – an experience often worse that in the U.S. – the Canadian political response to major polio epidemics, and especially the key role played by Connaught Medical Research Laboratories at the University of Toronto in making it possible for Jonas Salk to prepare an inactivated polio vaccine that would be safe to use in human children, and in enough quantities for an unprecedented mass field trial. A major Canadian role in the polio vaccine story did not end with the introduction of the Salk vaccine in 1955. It continued during the development, production and evaluation of the Sabin OPV in the early 1960s. Canada also played a leading role in supplying both types of polio vaccines to many countries around the world, a role that has continued to the present day in Canada's substantial financial support of the global polio eradication initiative.

Christopher J. Rutty, PhD
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THE PAST, THE PRESENT, THE FUTURE:
The Rotary Story

Ray Klinginsmith
Rotary International Foundation
Kirksville, Missouri

Ray Taylor
Polio Survivors & Associates
Pinehurst, North Carolina

FACT SHEET: POLIOPLUS

CONTACT: Vivian Fiore at (847) 866-3234 or fiorev@rotaryintl.org

Background

Rotary International was founded in 1905 in Chicago, Illinois USA, and is the world's first and one of the largest non-profit service organizations. It is comprised of 1.2 million members working in over 30,100 clubs in more than 160 countries. Rotary members initiate community projects that address many of today's most critical issues such as violence, AIDS, hunger, the environment and health care.

PolioPlus

In 1985, Rotary International created PolioPlus – a program to immunize all the world's children against polio by 2005 – Rotary's centennial. To date, the PolioPlus program has committed more than US$500 million to the protection of more than two billion children in 122 countries. These funds are providing much needed polio vaccine, operational support, medical personnel, laboratory equipment and educational materials for health workers and parents.

With its community-based network worldwide, Rotary is the volunteer arm of the global partnership dedicated to eradicating polio. Rotary volunteers assist in vaccine delivery, social mobilization and logistical help in cooperation with the national health ministries, the World Health Organization (WHO), UNICEF, and the U.S. Centers for Disease Control and Prevention.

PolioPlus is one of the most ambitious humanitarian undertakings made by a private entity ever. It will serve as a paradigm for private/public collaborations in the fight against disease well into the future.

Funding Challenge

In June 2003, Rotary announced that its members successfully raised approximately US$123 million in cash and commitments, surpassing the original campaign goal of US$80 million. The funds raised during this one-year campaign entitled, "Fulfilling our Promise: Eradicate Polio," are in addition to the US$500 million Rotary has contributed to polio eradication since 1985.

PolioPlus Partners Program

The PolioPlus Partners program, initiated in 1995, was created to provide Rotary members in polio-free countries the opportunity to work with members in endemic countries to support specific supplemental immunization activities involved in polio eradication. PolioPlus Partners provides the necessary tools to assist clubs and districts to educate members, communities, local media, and political representatives on Rotary's involvement in the initiative and the need for their support. Since 1995, PolioPlus Partners has contributed over US$ 33 million to a polio-free world.

PolioPlus Advocacy

Rotary's Polio Eradication Advocacy Task Force reaches out to governments worldwide to obtain vital financial and technical support. Since 1995, donor governments have contributed in excess of US$ 1.7

billion to polio eradication, due in part to Rotary's advocacy efforts. That amount, combined with direct funds from Rotary, is more than half the money needed for the entire global polio eradication program. Countries such as Australia, Austria, Belgium, Canada, Denmark, Finland, Germany, Ireland, Italy, Japan, Luxembourg, Netherlands, Norway, United Kingdom and United States of America are now major financial donors to this historic health initiative.

Rotary in Action

Besides raising funds, over one million men and women of Rotary have donated their time and personal resources to help immunize nearly 2 billion children during National Immunization Days throughout the world. Rotarians prepare and distribute different types of mass communication tools to get the message to people cut off from the mainstream by conflict, geography or poverty. Rotarians also recruit fellow volunteers, assist with transporting the vaccine, administer the vaccine to children and provide other logistical support.

- In **India** over 100,000 Rotary members and their families joined the Indian Government in January 2003 in immunizing over 165 million children in one day – signaling the largest public health event ever in the world.

- After extensive efforts to eradicate polio in **Cambodia**, health officials tracked the remaining pockets of polio to children living on the waterways, missed by the previously held NIDs. Rotary volunteers joined health officials in a boat-to-boat follow-up campaign to successfully reach this population and wipe out the virus.

- In **Nigeria**, 43 Rotary members from the United States joined Nigerian Rotary members to help vaccinate some 40 million children against polio in 2002. In addition, Nigerian Rotary members have been instrumental in educating Muslim and traditional leaders on the importance of protecting children from polio. In 2002, members met with Emir Alhaji Ado Bayero of Kano, one of Nigeria's most influential Muslim leaders. After the meeting, the Emir made an unprecedented endorsement by publicly administering the polio vaccine to more than 20 palace children.

- In 1996 and 1997, Rotarians in **Angola** led a campaign to solicit corporate jets, helicopters and vehicles to move the vaccine through Angola's land mine infested countryside. Additional volunteers mobilized by a single Rotary club helped the government reach 80 percent of its target population of children fewer than five years of age.

Lasting Legacy

The savings of polio eradication are potentially as high as US$ 1.5 billion per year – funds that could be used to address other public health priorities. The savings in human suffering will be immeasurable.

- Since 1979, the US has been recouping its entire contribution to smallpox eradication every 26 days.

PolioPlus – Rotary's gift to the children of the world.

ROTARY INTERNATIONAL
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THE PAST, THE PRESENT, THE FUTURE: The Unfinished Story

Daniel J. Wilson, PhD
Allentown, Pennsylvania

This presentation will focus on the polio survivors of the mid-century epidemics and their story. It will stress that the polio story did not end with the announcement on April 12, 1955, that the Salk Vaccine trial was a success and that eradicating polio in the United States was possible.

Whether they had polio before April 1955 or afterwards, and over 67,000 individuals had polio between 1955 and 1960, polio survivors still had lives to live. They had rehabilitation to finish, and families, school and work to return to. Most polio survivors would finish their education, find remunerative work, get married and have children. Most polio survivors held to the Polio Ethic: a strong will, determination, and hard work would bring success in rehabilitation as well as in other aspects of our lives.

Polio survivors can point to many successes in our individual lives as well as in the way polio survivors have contributed to American society in spite of, or perhaps because of, the impairments left by an insidious virus. There is, of course, Franklin D. Roosevelt, a role model for many polio survivors. But there are many others including Ed Roberts who opened up the University of California to students with disabilities and later helped start the Independent Living Movement. There was Justin Dart who helped secure passage of the Americans with Disabilities Act. Irving Zola would help create disability studies as a legitimate field of study. And ordinary men and women like yourselves went to work every day in spite of the pain and inconvenience, raised children from your wheelchairs, and through support groups and GINI / Post-Polio Health International came together to deal with post-polio syndrome.

That much is history, and as a historian of the polio experience I want to celebrate what we have achieved individually and collectively. But it is an unfinished story. There is much that needs to be done, that we can do, even as our bodies tire and fail us.

Here are some pieces of unfinished business that deserve our attention:

- Polio eradication: to the extent possible we need to work with the WHO and Rotary International to eradicate polio.
- Aging with a disability: we need to find creative ways to age gracefully with a disability that demands frequent adjustments both physically and psychologically
- Our spouses and life partners are also aging, developing disabilities of their own and less able to help us.
- The challenge of health care in the 21st century: finding knowledgeable physicians, negotiating insurance, Medicare or Medicaid; choosing between attendant care and institutional care

There are some larger social and political factors that will make our lives more difficult, at least in the short run.

The challenges of the current conservative political environment where it is unlikely that there will be any major expansion of SSDI, Medicare, or Medicaid.

The ADA is under assault in many courts, which are chipping away at our hard-won access.

Where these political issues affect us individually and collectively as polio survivors and as Americans with disabilities we need to become more politically active.

We need to make the case that it is both cheaper and healthier to help us stay independent in our own homes rather than forcing us into institutions.

We need to assert forcefully our right to access and equal treatment under the law. The ADA needs to be fully established and enforced, not limited.

Polio survivors have long been in the forefront of patient and disability advocacy — now is not the time to put away our pens, our word processors, our placards, and our bullhorns.

Polio survivors have long assumed we could do anything we put our minds and our crippled bodies to. In spite of diminished energies and increased impairments, I see no reason to change that and many reasons to keep pushing for our rights and needs.

Meeting here in St. Louis is an opportunity to get re-energized, to discover new ideas and strategies, to learn about new technologies that can help manage our disabilities. But when we leave St. Louis it must be with a determination to tackle the challenges that remain to the best of our still formidable abilities.

Daniel J. Wilson, PhD
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SESSION II OPTIONS

3:15 pm – 4:30 pm

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ANESTHESIA PRECAUTIONS FOR PEOPLE WITH NEUROLOGIC CONDITIONS

Selma Harrison Calmes, MD
Sylmar, California

The objectives of this session are to briefly review anesthesia care for common operations in polio patients, to review anesthesia safety in general in the United States today, to discuss how to increase the chances of getting the best anesthesia care available in your area and, finally, to answer questions on anesthesia practice and safety from the audience. The audience should leave the session understanding what particular issues need to be discussed with an anesthesiologist when surgery is anticipated, how to increase the chance of getting the best anesthesia care available in their geographic area, and how safe anesthesia is today, especially compared to the risk of hospitalization itself. Handouts of the slide presentation and a single page of recommendations related to anesthesia for post-polio patients will be available at the session.

CHOOSING AN ANESTHESIA PLAN: I'm often asked what anesthetic is best for post-polio patients. It just depends. It depends on <u>that</u> patient (with their particular health problems) having <u>that</u> operation (with its own risks and problems) at <u>that</u> point in time and by <u>that</u> particular surgeon (with his/her issues) and <u>that</u> particular anesthesiologist (with their own skills and issues). And, all these factors interact and interplay with each other.

Excellent anesthesia depends on understanding a patient's diseases (this is true for any patient, with any disease, not just post-polio patients) and how the diseases might affect anesthesia management. Also the planned operation must be considered because different operations have different anesthetic requirements, and not all operations can be done with a particular anesthetic technique. For example, it is difficult to do a laparoscopic (lap) cholecystectomy (removing the gall bladder through a laparoscope instrument) using regional anesthesia (a spinal or epidural anesthetic). The operation begins by injecting many liters of CO_2 gas into the abdomen, to grossly distend it so the surgeon can reach the needed organs. The distension is extremely uncomfortable for an awake patient, and also breathing is inadequate if the patient is breathing on their own. And, the distension can interfere with venous return to the heart, causing low blood pressure. Low blood pressure can also result from spinal or epidural anesthesia, so using these techniques in this setting is not helpful. All lap choles need to be done with general anesthesia, with controlled breathing. Other factors entering into the choice of an anesthesia plan include a surgeon's ability to operate under regional or local anesthesia and also anesthesiologists' particular skills.

POLIO CHANGES AND ANESTHESIA: What about the disease polio might be important in anesthesia management? Polio is an inflammatory disease of the nervous system. We typically think that it involved only the spinal cord, but numerous anatomic research studies document that all parts of the nervous system were affected, not just the spinal cord. This explains the wide-ranging issues that reveal themselves as post-polio patients age.

Starting at the brain, central neuronal changes may contribute to the common sensitivity to sedative medications, and can result in a long emergence from anesthesia. The poliovirus also affected the neuromuscular junctions (the connections between a nerve and its muscles), and this may be one cause of sensitivity to muscle relaxants. There is also a decrease in total muscle mass, and a standard dose of relaxants may be an overdose for a post-polio patient. Postop pain may be an issue; this is most likely due to inflammatory changes in the spinal cord, with resultant scarring. This could affect the transmission of the pain signals through the spinal cord. The inflammatory process of polio "spills over" to a spinal cord area where autonomic nerve fibers travel. The autonomic nervous system (the system that keeps your GI tract moving, keeps your heart beating at an appropriate rate and so on) can also be abnormal. This can cause gastro-esophageal reflux, tachyarrhythmias and sometimes, difficulty maintaining blood pressure under anesthesia. Because of respiratory muscle weakness, there can be respiratory inadequacy postoperatively. Laryngeal weakness, including cord paralysis, can also add upper airway obstruction, swallowing problems and aspiration. Body asymmetry due to muscle mass loss and scoliosis can be an issue. Osteopenic limbs and exposed peripheral nerves add further positioning problems.

Patients of particular concern are those using ventilators, even part-time, and those who were in iron lungs, even if they don't use ventilation presently. Preop pulmonary functions tests are the first step in anesthesia planning for them. Depending on the results of pulmonary function tests, the surgery and the type of anesthesia needed, it may be possible to continue to use the patient's ventilator intraoperatively. If not, the patient's ventilator can often be initiated after surgery, in recovery room. Postoperatively, there has to be careful consideration of any respiratory depression from narcotic pain medications and adequacy of the patient's ventilation. By careful planning, all polio patients should be able to have surgery without excessive risk.

WHAT KINDS OF ANESTHESIA ARE AVAILABLE? General anesthesia is not the only way!

GENERAL ANESTHESIA: The patient is completely asleep. Usually anesthesia begins with an intravenous injection (usually propofol or pentothal). With the help of a short-acting muscle relaxant, a breathing tube is often (but not always) placed in the trachea (windpipe) to insure that oxygen (O_2) can reach the patient's lungs. Then anesthesia continues with inhaled gases (often nitrous oxide and a vaporized liquid anesthetic such as sevoflurane) supplemented by injected narcotics, amnesic drugs and muscle relaxants if needed. At the end of the case, any residual muscle relaxant effect is reversed with drugs, the inhaled gases are stopped and the patient breathes 100% O_2. The breathing tube is removed when the patient can breathe on their own. In some cases it is left in, to allow assisted ventilation if needed.

REGIONAL ANESTHESIA: This means that only the part of the body being operated on is numb. The patient can be awake or asleep (using injected drugs) during surgery. An anesthesia provider should always be present to monitor you, to detect any possible problems early on, and to induce general anesthesia if the block is not satisfactory. The usual types of regional anesthesia follow:

1. **SPINAL:** A small amount of local anesthesia is injected into the subarachnoid space, around the spinal cord. (See diagram of spinal cord.) The procedure is like a lumbar puncture. The lower half of the body is numb; higher levels can result from higher doses. Prostate, bladder and rectal surgery are often done with spinal anesthesia. It usually gives good solid pain relief unless the abdomen is open. and the surgeon pulls on the bowel.

2. **EPIDURAL:** Instead of putting local anesthesia in the fluid-filled space around the spinal cord, a larger amount (and perhaps some narcotics) is placed in a potential space, the epidural space, in the lower back (occasionally higher). (See diagram of spinal cord.) The anesthetic drug migrates across several levels of tissue to reach the spinal cord itself. The advantage to this is that a small plastic catheter can be placed in the epidural space and used for additional anesthesia and additional pain-relieving drugs in the postop period. Physiologically, this is safer than spinal; the block is of slow onset. It is a little less predictable than a spinal. It is used for the same operations as spinal and also for vascular operations on the legs.

3. **BLOCKS OF THE ARM:** The nerves to the arm can be approached from above (supraclavicular block) or below (infraclavicular) the clavicle and through the axilla (axillary block), usually giving good relief for most arm and shoulder surgery. An IV block of the arm (also called a Bier block after the German surgeon who first did it; occasionally used for the leg in unusual situations) is an easy block in which the venous structure of the arm are emptied and then filled with a dilute local anesthesia solution. Although seemingly easy and safe, there have been deaths when this is done in emergency rooms or plastic surgeons' offices. Because these blocks require a larger volume of local anesthetic, there is a risk of local anesthetic toxicity. This can be prevented by careful placement and calculation of the maximum dose for that patient.)

Nerves to the hand and lower forearm can be easily blocked at the elbow and wrist.

4. **BLOCKS OF THE EYE:** A retro-bulbar (behind the eye) block is the standard regional anesthetic for eye surgery. In most parts of the country, the surgeon places this rather than an anesthesiologist. An anesthesia provider is still present, to detect any complications of the block, to give any needed sedation and to induce general anesthesia if needed.

5. **BLOCKS OF LOWER EXTREMITY:** The nerves to the leg can be relatively easily blocked in the inguinal area.

MONITORED ANESTHESIA CARE (MAC): The surgeon injects local anesthesia at the site of surgery; anesthesia staff is present to sedate and monitor the patient and to induce general anesthesia if needed. Not all operations can be done with MAC; it is best with superficial, simple surgeries such as carpal tunnel release. The surgeon's skills contribute greatly to the success of MAC.

In summary, we have numerous ways to approach pain relief during surgery!

ANESTHESIA SAFETY: There has historically been a great fear of anesthesia in the polio community, because of patient reports of problems allegedly due to anesthesia management, especially related to muscle relaxants. Although there are issues for post-polio patients having anesthesia, the general level of fear of anesthesia in the polio community is probably excessive, and there are many other, much higher incidence problems that can harm polio patients when hospitalized.

Anesthesia today is very safe! Over the last three decades, the number of deaths attributed to anesthesia dropped from 1 in 10,000 cases to 1 in 250,000 cases. This is a remarkable achievement, especially considering that 40 million anesthetics are now administered each year in the U.S. Our professional organization, the American Society of Anesthesiologists (ASA, 100 years old this year), led the way to greatly improved patient safety, and our organization serves as the national and international example for other specialties wanting to improve patient safety. We're proud of that! The ASA's safety achievements have been recognized by the prestigious Institute of Medicine's 1999 report, *To Err is Human*, the only specialty to be mentioned as improving patient safety. This report documented that an estimated 44,000 to 98,000 patients die each year from hospital safety issues.

Also at the national level, the American Medical Association (AMA) recognized our specialty's leadership when they patterned their patient safety institute, the National Patient Safety Foundation (established in 1996), after our Anesthesia Patient Safety Foundation (APSF). The APSF was created in 1985, to raise awareness of patient safety issues. The APSF publishes a quarterly newsletter, funds research on safety issues, presents educational sessions and exhibits at the annual ASA meeting and maintains a web site. In 1986, the ASA adopted monitoring standards for the first time. These list monitors, such as EKG, temperature and so on, that must be in use for each anesthetized patient. This was the first expected standard of care for our specialty.

In the mid-1970s, anesthesiologists began to analyze malpractice cases that had "closed," (settled) to try to identify what clinical practices might be associated with malpractice claims, so these could be improved. This became an official ASA project, the "Closed Claims Study" in 1985. Volunteer reviewers do a standard analysis of settled claims at 35 malpractice insurance companies. Currently, 6,448 claims are in the database. Trends are analyzed, results summarized, and then these analyses are published in the anesthesia literature.

Some extremely important results have come out of these analyses. Two of these papers are among the 50 most cited scientific papers in the anesthesia literature. The first report, published in 1990 *(Caplan RA, Posner KL, Ward RJ, Cheney FW. Adverse respiratory events in anesthesia: A closed claims analysis. Anesthesiology 1990: 72; 828-833),* showed that airway (breathing) problems were the most common cause of a closed claim. As a result, major efforts to anticipate airway problems and to devise alternate approaches to usual airway management began, have been very successful and continue to this day. Each annual meeting has many sessions on the latest in airway management. This is just one example of how our specialty works to improve patient safety.

Finally, advances in technology such as in monitoring, anesthesia machines and airway devices made critically important contributions to improved patient safety. To illustrate this, we will see a video of a monitor of neuromuscular transmission. This monitors the effect of muscle relaxants, one of the areas of fear for polio patients. This standard monitor allows muscle relaxants to be used safely in all patients.

Hopefully, this section makes it clear how committed the specialty of anesthesiology is to improving patient safety and what significant progress has been made in decreasing harmful anesthesia incidents. Post-polio patients who will be hospitalized for surgery have a much greater chance of dying or being harmed during hospitalization from *other* medical errors, such as getting an incorrect drug, rather than their anesthesia. At the current rate, 160 patients would be predicated to die from an anesthesia accident each year, compared to 44,000 to 98,000 from other hospital errors. Clearly, hospitalization itself should become the worry, and there could be a decrease in concern about anesthesia.

GETTING THE BEST ANESTHESIA: This is a difficult issue. The first step is an adequate evaluation by your usual polio physician, the surgeon and a pulmonologist. After group evaluation of your situation and a decision about exactly what surgery will be done, the hospital to be used can be chosen. In most areas of the country, you can have several choices of hospitals. An academic hospital with an affiliated rehab hospital would the ideal. In general, academic centers tend to have the best anesthesia departments. If your hospital is not an academic center, you might ask how many of the anesthesiologists are Board-certified and also is the hospital JCAHO accredited (you can check this yourself on the JCAHO web site). The surgeon may know of a particular anesthesiologist who might have experience in this area or at least listen to patients' concerns. A preop evaluation would be done and an anesthesia plan, with a backup plan in place, made. You are welcome to use my handout when you visit the anesthesiologist. And, don't forget the operation! It's best to go to an institution that specializes in whatever surgery you are to have.

There is a significant shortage of anesthesiologists today, and many are seriously over-worked. That might result in another anesthesiologist replacing one that you've talked with, at the last minute. (Usually this would be because the first anesthesiologist has been up all night, on call.) That may not be preventable and, hopefully, communication between the two will take place. Through the entire operative process, I urge polio patients to make clear what their expectations for care are and to not be satisfied until you get what you need. This can be wearing, and hopefully a companion can carry out some of this for you. Today, all American health care organizations are under enormous stress, and this tends to show in the patient care area; it helps to be a "squeaky wheel."

Selma Harrison Calmes, MD
Olive View-UCLA Medical Center, Sylmar, California

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INTEGRATIVE MEDICINE APPROACH TO POST-POLIO SYNDROME MANAGEMENT IN PRACTICE

William DeMayo, MD
Barbara Duryea, RN
Johnstown, Pennsylvania

Objectives:

1) Define integrative medicine
2) Review strategies for integrating evidenced-based complementary and alternative therapies into the clinical management of post-polio syndrome
3) Identify safe and effective self-help strategies for living a healthy life with chronic condition

Overview:

The March of Dimes Post-Polio Syndrome Best Practice Guidelines identifies strategies for symptom management. The symptom management strategies contain common themes:

- Education/self management approaches
- Exploring treatment options beyond conventional medicine

- to include complementary therapies
- Expanding the treatment focus to include mind, body, and spirit.
- These themes are also reflective of the unifying threads of complementary and
- alternative medicine:
- Individual responsibility for living a healthy life
- Connection between, mind, body and spirit
- Balance in life and lifestyle.

Effective clinical assessment and treatment of post-polio syndrome must be based on mutual goal setting between healthcare consumer and practitioner. Consumer empowerment supports the ability to effectively self-manage the work of dealing with a chronic condition, continuing daily life activities, and handling the emotions brought about by a chronic condition. Effective self-managers may benefit from therapies from alternative medical systems, body-based methods, biological based treatments, mind-body interventions and energy therapies.

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TRAVEL TIPS: Taking Cruises

Linda Priest, CTRS/L
Atlanta, Georgia

Taking a “Polio” Cruise on the High Seas

This session will emphasize the importance of recreation/re-creation in the lives of persons with chronic disabilities such as polio. Although the speaker has a degree in therapeutic recreation, it has not necessarily made it easier to come to terms with diminishing physical capabilities and diminishing recreation/vacation options. Come and hear one polio survivor’s experience in finding the perfect way to vacation while using a motorized wheelchair.

Ideas will be offered on how to select the most accessible cruise liners, prepare and pack for the trip, what to expect in terms of physical access on board and on shore, and how the Americans with Disabilities Act (ADA) impacts access to both domestic and foreign owned cruise lines. There will be a PowerPoint presentation showing physical access features to all amenities on board including hydraulic lifts to the pool and to the hot tub, accessible cabins and an accessible port excursion. There will be a discussion regarding how a cruise can be a cost effective vacation and why a cruise is the ideal choice for people who have had polio.

Consider the following:

- Early boarding is offered to people who are mobility impaired and assistance is provided when needed!
- You have to unpack only once!
- You are whisked away to exotic destinations without having to get in and out of your car!
- Accessing the pool or hot tub is made safe and easy with hydraulic lifts!

- There are automatic doors in most areas throughout the ship including your own cabin!
- Designated cabins have ADA compliant grab bars, raised toilet seats, lever handles, roll-in showers, hand-held showerheads, a five-foot turning radius and many other access features!
- Daily activities are non-stop and include such offerings as fitness & Yoga classes, day spa treatments, swimming, shopping, card games, bingo, free movies, art auctions, wine tasting.
- Educational opportunities such as cooking demonstrations, ice carving, digital camera demonstrations, and napkin folding classes are available.
- While all activities and classes on board are at your fingertips, so is your cabin where you can retreat at any time of the day or night for a nap.
- There is food available 24/7 with an array of choices that makes it possible to eat as healthy (or unhealthy) as you like.
- Free food and free room service are available any time of day so you can enjoy breakfast on your private balcony, a midnight snack or perhaps coffee when you wake from your afternoon nap.
- At night there is a wide range of activities to enjoy including theatrical performances, karaoke, dancing and musical entertainment from big band extravaganzas to an intimate piano bar gathering.
- All types of oxygen are permitted onboard and special diets including low sodium, low cholesterol, low fat and vegetarian meals can be provided.

Although experiencing ports of call can be challenging, we will discuss how to problem solve and select tours that will best meet your needs. Additional information will include airport transportation, parking at the pier and special equipment that is available onboard. So, whether you prefer sunbathing by the pool deck with a Margarita in your hand, gambling the night away in the casino, shopping till you drop at interesting boutiques or having a massage in the day spa ... there is something for you onboard a luxury ocean liner. Come join us and discuss the possibilities.

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TRAVEL TIPS:
And, If You Use a Vent

Angela King, BS, RPFT, RRT-NPS
Minneapolis, Minnesota

1. A Brief Overview of Physiological Effects of Air Travel
    a. The Cabin Environment:
        i. Air Pressure
            1. Normals
            2. At altitude
        ii. Air Quality
        iii. Humidity
    b. Effects on Respiratory Patients

2. In-Flight Oxygen
3. In-Flight Ventilation
4. Responses from various airlines regarding their policies on allowing mechanical ventilation during flight

Reference

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EMOTIONAL EATING:
My Story

Marge Torre
Bradenton, Florida

It is not true that you have to exercise to lose weight. In trying so many different diets, you really begin to feel like the true definition of a yo-yo. The important thing is to keep trying until you find the diet that really works for you. The real secret of dieting is not only to lose the weight, but more importantly, to keep the weight off.

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EMOTIONAL EATING:
My Story

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EMOTIONAL EATING:
"What Is Emotional Eating?" "What Can We Do About It?"

Linda Bieniek, CEAP
La Grange, Illinois

"Emotional Eating" is the use of food to dull the pain underlying an important emotional need.

Some people use alcohol, drugs, sex, money, gambling, work, and even TV, to avoid and numb their feelings. Overeating, binging, and compulsive eating are ways of using food for similar purposes. Regardless of which behavior we *feel a compulsion to* turn to, we need to explore these sensitive subjects with compassion and curiosity. Criticism or shame will only contribute to a cycle that leads to emotional eating. Instead, this paper offers several strategies and resources for beginning to explore the underlying needs of emotional eating in creative and fruitful ways.

Lightening Our Loads!

Most of us realize that emotional eating can add distress to any existing chronic health conditions. However, sometimes we need evidence of how our bodies are affected before we reach out for the support we need to take action. For example, gaining weight from emotional eating may ...

- Add pressure to our diaphragm, interfering with our breathing
- Limit our mobility and/or functioning
- Increase pressure to our joints, causing pain and wearing them out
- Place more stress on our heart, resulting in shortness of breath
- Create or exacerbate sleeping problems, such as sleep apnea
- Decrease our energy levels, possibly contributing to depression

What Can We Do About It?

"The only way out of the feelings, is through them."

Our bodies hold our physical, emotional, psychological, spiritual, and sexual wounds. Emotional eating is one of the ways that our wounded parts express their need for our help. We need open minds and kind hearts to support us in exploring our feelings. Each step requires patience and a deep appreciation of our needs for safety, support, and hope.

Pay attention to our body's sensations. We can learn from our bodies. Listening to our hungry feelings can lead us to insights. The *feeling of a compulsion* to eat is one way that our bodies may gain our attention. Expressing gratitude for our body and its messages is important. Appreciation encourages truthful revelations of our real needs. For example, using a Gestalt approach, we could ask our "inner wisdom": "What is my body trying to tell me?" Possible responses may include: "Notice Me!" or "Don't keep pushing me." We can gain clarity by continuing to dialogue with our body. For example, we could then ask: "What do you want me to notice?"

Author Geneen Roth has said: *"You can take any avenue into your heart and soul. Just start with the physical. The physical is a reflection of the deepest part of yourself..."* In her book, *Feeding the Hungry Heart* she provides an example of dialoguing with our problems on pages 44-48.

Learn skills that create safety and support before searching for an understanding of emotional eating and solutions. Internal and external safety, often described as a sense of security or trust, is of foremost importance before exploring our behaviors and feelings. For this reason, we need to learn skills for "pacing" our explorations and for "staying grounded" in reality. They will contribute to digesting new insights without "feeling overwhelmed" – a common trigger that can result in emotional eating.

Being "grounded" means being focused in reality rather than distracted by thoughts, fears, or activities. One way we can get grounded is to press our feet flat on the ground, if we are able. Otherwise, we can visualize our bodies connected to the earth in an appealing way (e.g., by gardening, sitting under a tree). Taking a few deep breaths will add to our ability to connect with our body's sensations or to our intuition. Imagining having a choir of supporters surround us – good, affirming, trustworthy people – will contribute to a sense of safety. Deep breathing, stretching, visualizing, expressing positive intentions, and using forms of the Expressive Therapies and/or Energy Therapies are options for calming anxiety and connecting with our body. A Treatment Approach Options chart is at www.post-polio.org/ipn/ppn18-4A.html.

Identify one external trigger at a time to gain insights. Since emotional eating typically is an unconscious reaction rooted in good intentions (e.g., protection, comfort, connection), we need to apply our curiosity and play private detective to uncover what truly causes us to overeat, binge or eat compulsively. In this context, a "trigger" is as an external event or sensory experience that produces a feeling, sensation, thought, behavior, or memory which can set off the cycle of compulsivity. Typically, the trigger sequence outlined below can occur in split seconds:

- We see, hear, smell, taste, feel, think, or experience something;
- We unconsciously or consciously are reminded of something – an experience, a feeling, trauma, loss, person, disappointment, etc.;
- We experience reactions: a body sensation such as discomfort; a thought such as "Oh, not that!"; or a feeling such as fear.
- We turn to food to avoid or control our feelings.

For example, upon hearing a certain song, "Jim" thought about of a past relationship that left him heartbroken. Instead of allowing his grief over his unresolved hurt to surface, he ate ice cream and cake and watched TV. Eating comfort food and watching TV were his ways of dissociating from his feelings.

We may identify our own "triggers" by noticing our eating patterns and then asking ourselves "What happened just before I overate?" and "What did I notice, hear, smell, think, taste, and/or feel in my body before I binged on cookies?" If we continue backtracking with these questions, we may discover a series of triggers that contributed to a particular emotional eating pattern.

Most importantly, we need to remember that our responses to our emotional needs are rooted in "good intentions." Before moving into the next section about the "Parts" approach, clarifying some distinctions may help. "Triggers" are external – what happens outside of us – whereas "Parts" are internal characteristics of our Core Self. We each have a variety of "Parts" of our personalities": a kind part, an angry part, a competent part, a communicative part, a quiet part, etc. When a "trigger" stirs up an internal reaction – often unconsciously – that reaction may stem from an old unresolved feeling or experience that we can identify as a "Part" of us. This simple description introduces us to a model that has proven very effective with individuals who have struggled to change their emotional eating patterns.

Consider the "Parts" approach to identify and respond to our emotional needs. The "Parts" approach" is one option for pursuing the next level of self-exploration and uncovering feelings that are closer to our hearts. Several versions of this approach exist. In the Internal Family Systems model, known as IFS, each aspect of our personalities and our behaviors may represent a "Part." Identifying the positive intentions and benefits of an "Emotional Eating Part" can provide us with valuable insights. These clues, in turn, enable us to find an affirming response to our feelings or beliefs instead of choosing to pursue the feeling of a compulsion to eat.

Our "emotional needs" are "Parts" of our Core Self. "Protective Parts" may use food to suppress or to substitute for emotional needs such as security/safety, nourishment, or affection. For example, the "lonely part" of us may turn to eating, but really needs human contact. In another situation, a "Part" that hungers for more food, may actually long for a purpose in life – signs of spiritual undernourishment. The following personality issues include examples of individuals' "emotional needs" or 'Parts."

An individual who DESIRES intimacy and sexuality, and also FEARS these needs may eat when ...

- craving support, connections with others, or a sense of belonging
- desiring a certain person's love or attention yet reluctant to reach out

A person with unrealistic expectations may eat when ...

- becoming disillusioned about the future
- lacking acceptance of his/her limitations

A person that seeks independence yet NEEDS and WANTS people to depend on may eat when ...

- needing help, yet resenting when people don't offer their assistance
- remembering being excluded from social activities as a child

REFERENCES and RESOURCES

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Stone H and Stone S. (1989). *Embracing Our Selves: The Voice Dialogue Manual.* Nataraj L., Elisabeth. (1987). *Listen to the Hunger: Why We Overeat.* New York, NY: Harper Row.

Sonder, B. (1993). *Eating Disorders: When Food Turns Against You.* NY, NY: Franklin Watts.

Explore resources and treatment approaches that teach us nourishing ways of responding to our bodies, beliefs, emotions, and experiences. The good news is that therapeutic approaches and resources in the 21st century are far more effective than ever before. Emotional eating is a complex, multi-dimensional subject. Seeking assistance is a courageous step in breaking its cycle. Most importantly, we need to work with a professional who has vast experience, an enormous range of skills, and deep sensitivity to how our past experiences may affect our responses in therapy. When we develop a safe, trusting relationship with a competent professional we can make significant progress.

The following lists identify books, treatment options, and professionals. These can help us create shifts in our minds, bodies, emotions, and behaviors. My hope is that each of us will learn what we truly hunger for and will find the inner strength and support to embrace our deepest emotional needs.

The Best of Health!

ADDITONAL REFERENCES and RESOURCES

Geneen Roth's workshops and books, especially: *Breaking Free from Compulsive Eating (p. 142-146); Feeding the Hungry Heart (p.44-48); When Food Is Love (p.23-25; 200-201), and her Guidelines.* www.geneenroth.com 408.685.8601. (Not Therapy)

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Finney, L. (1995). *Reach for joy: How to find the right therapist and therapy for you.* Freedom, California: The Crossing Press.

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Olkin, R: (1999). *What psychotherapists should know about disability.* NY, NY: Guilford Press.

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SARK. (2005) *Make Your Creative Dreams Real: A Plan for Procrastinators, Perfectionists, Busy People, and People Who Would Rather Sleep All Day.* New York, NY: Simon and Schuster.

Whitfield, C. (1993). *Boundaries and Relationships: Knowing, Protecting and Enjoying the Self.* Deerfield Beach, FL: Health Communications, Inc.

Zukav, G. (2001). *The Heart of the Soul: Emotional Awareness.* NY, NY: Simon and Schuster.

TREATMENT APPROACHES and PROFESSIONALS

Bieniek, L. (2003) Treatment Approach Options. *Polio Network News*, 19(1). 9-11. www.post-polio.org/ipn/ppn18-4A.html

Internal Family Systems Model: Center for Self Leadership, P.C., P.O. Box 3969, Oak Park, IL 60303 (708) 383-2659 IFSCSL@aol.com, www.selfleadership.org: workshops, training programs, conferences, books, tapes/CDs, practitioners.

www.schoolforliving.org Judy Steele, MTP, Dynamind Practitioner, Tapas Acupressure Technique (TAT), NLP (Neuro-Linguistic Programming). judy.steele@earthlink.net 612.5903139.

Trauma Recovery and Eating Disorder Programs: www.riveroakshospital.com/newsite/programs.htm Dan Glaser, BCSW, Director. 800.366.1740.

www.castlewoodtc.com Castlewood Treatment Center. 636.386.6611. Mark Schwartz, Sc.D., Lori Galperin, LCSW, St. Louis, MO. 1.888.822.8938.

www.mccallumplace.com McCallum on the Park. 1-800.828.8158. Practitioner Referrals.

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DISABILITY INSURANCE: BUYING IT AND SECURING IT

Mark D. DeBofsky
Chicago, Illinois

I. Types of Disability Insurance
    A. Social Security
        1. State Disability
    B. Private Disability Income (DI)
    C. Long-term Disability (and short-term)
        1. ERISA
        2. ERISA Exemptions

II. Making a Claim – Pitfalls
    A. What's Different Than Before?
    B. Under the care of a physician
    C. Objective Evidence
    D. ERISA Problems
        1. Arbitrary and capricious
        2. Scope of court review
        3. No jury
        4. No damages

III. Working with Your Doctor

   - A. Restrictions and limitations
   - B. Records and reports

IV. Post-Polio Issues
   - A. Recent cases/rulings
      1. *Abram v. Cargill,* 395 F.3d 882 (8th Cir. 1/24/2005)
      2. *Wuollet v. Short-Term Disability Plan of RSKCo.,* 2005 U.S.Dist.LEXIS 3272 (D.Minn. 3/3/2005)
      3. *DiPietro v. Prudential Insurance Company of America,* 2004 U.S.Dist.LEXIS 5004 (N.D.Ill. 3/26/2004)
      4. Social Security Ruling SSR 03-1p;
         Titles II and XVI: Development and Evaluation of Disability Claims Involving Postpolio Sequelae, 68 FR 39611 (7/2/03)

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LEAVING A LEGACY:
The Polio Oral History Project

Anna Rubin
Framingham, Massachusetts

Polio — Voices Heard, Lessons Learned

The Polio Oral History Project is a treasure trove of oral histories from polio patients, doctors, nurses and therapists who worked in the polio wards, school teachers whose classrooms were touched by polio, mothers who "marched" with the March of Dimes, researchers and scientists involved in vaccine development and those working on worldwide polio eradication today.

We have collected and continue collecting stories that weave a rich tale, one which tells of the crisis of the epidemics, the extreme efforts parents went to in order to try to protect their children from the polio virus, the horrors of the acute illness, and the loneliness, isolation, pleasures and difficulties of hospitalization.

We have interviewed many mothers involved with the March of Dimes. Their stories tell of women from all walks of life pulling together in the huge effort to solve the “problem of polio” – a problem that threatened the wellbeing of an entire nation. The door-to-door efforts of these women created a phenomenal fundraising machine, which led to the creation of labs, research and ultimately the polio vaccine.

Also heard are tales of the often long and laborious road to recovery, the reactions of neighbors, schoolmates and family members and the community to those who survived polio, and the gradual acceptance and sometimes growing anger about new limitations caused by polio and, later, by post-polio syndrome.

We have recorded stories of the blatant discrimination disabled people encountered. Polio survivors can be heard talking about how the discrimination they experienced affected their lives, and how it lead to activism and the creation of the Americans with Disabilities Act (ADA). We have captured poignant stories of limited access to schools, workplaces, and even people's own homes, as well as the innovative solutions people employed to overcome these problems.

The project follows polio survivors through to their lives at present – a point at which many are facing new hurdles due to post-polio syndrome. We have recorded testimony about the new losses, feelings, and adjustments post-polio syndrome heralds. Lastly, the project looks at the status of polio in the world today, the eradication work still ongoing, and the fight to eliminate the threat of polio for future generations.

I am delighted to be bringing the Polio Oral History Project to the Ninth International Conference on Post-Polio Health and Ventilator-Assisted Living: *Strategies for Living Well*. I will be presenting an audio-visual presentation weaving together selected oral histories with photographs and clips of the polio epidemics, as well as some of our collected artifacts. In my presentation, I will touch upon a variety of topics including healthcare, disabilities, social activism, the 1940s and 1950s, and the psychological benefits of oral history. I look forward to seeing you at the session.

Anna Rubin, Project Manager and Principal Interviewer for the Polio Oral History Project
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508-872-2200, ext. 241, agrubin@partners.org, www.polioclinic.org (click on "History")

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LEAVING A LEGACY:
Documenting Polio Stories – Learn from the Canadian Experience

Sally Aitken
Québec, Canada

The second half of this session will take you through the serendipitous process which resulted first in a book in French (*Histoire de la Polio au Québec*) followed by one in English (*Walking Fingers: The story of polio and those who lived with it*). For each book I had 2 colleagues. Altogether we must have conducted about 200 interviews which we taped and wrote up. The purpose was not to tell our own story, but through the story as told by countless other polios, to compile a broad spectrum of experience and examples that just might strike an important cord in future readers. Polio for most of us was a battle and when the worst was over, we got on with our lives, putting "those years" behind us. These interviews were a long overdue opportunity to recall a past that for most had been silently stored in memory for years. Some people remembered little, others remembered so much that I'm sure they will be writing their own books. In retrospect, putting the material together was interesting and fun. Getting it from our computers into a marketable form was a challenge, but never did we doubt that it was going to happen. There will be time for questions and the sharing of ideas.

How to obtain copies of the books
Copies of both books will be available at the workshop. Or you can order "*Walking Fingers*" by e-mailing Vehicule Press (Vp@vehicluepress.com) or writing to them at:
Box 125, Place du Parc Station, Montreal, Quebec H2X 4A3, Canada
or by going to your bookstore and asking for "*Walking Fingers: The story of polio and those who lived with it*", edited by SallyAitken, Helen D'Orazio and Stewart Valin.

You can even find it on www.amazon.ca. For *Histoire de la Polio au Quebec* which was self-published, you can contact Polio Quebec at 3500 boul. Décarie, suite 263, Montréal, Qc, H4A 3j5
(514) 489-1143, 1-877-POLIOQC (1-877-765-4672)
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TWILIGHT SESSION OPTIONS

6:15 pm – 8:30 pm

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THE LATEST IN VENTILATORY EQUIPMENT

Moderator: Larry Kohout
Edina, Minnesota
Representatives of ventilatory equipment manufacturers

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SPIRITUAL HEALTH: Strategies for Living in Peace with Polio

Robert Ronald, S.J.
Taipei, Taiwan ROC

1. TWO ENEMIES to peace with polio:
   - PHYSICAL: Functional losses, pain, limitations, fatigue, restricted A.D.L.
   - NON-PHYSICAL: Frustration, discontent, fear, sadness, anger, low self-esteem.

2. PHYSICAL WAR: To counter the physical effects, using tactics of the doctors, therapists, dieticians, and other experts.

3. NON-PHYSICAL WAR: To counter non-physical effects, by mental tactics of attitudes, beliefs, convictions, determination.

4. PEACE:
(a) Freedom from noise, anxiety.
(b) Freedom from war or ending of war.

5. PEACE WITH POLIO:
(a) Freedom from anxiety while struggling with polio.
or
(b) Freedom because of nothing more to fear.
Finding ways to maintain inner peace in spite of war with the physical effects.

6. INNER PEACE: State of mind, emotional stability, calmness, contentment, and realization of self-worth.

7. STRATEGY ONE: Keep your hand on the helm, doing what you can.

8. WHAT ARE YOU? A drifting cloud? A dead piece of driftwood? Or a ship at sea with rudder and motor power?

9. BEING CAPTAIN of your ship does not make you captain of the waves. But how you handle the ship alters its passage through the storm. The best way to die is to go on living as well as you can.

10. STRATEGY TWO: Make peace with your limitations. Just as peace with others only comes when both parties finally accept their differences and agree to live with them, so: Peace with limitations only comes when you acknowledge them, adjust to what you cannot change, and improve what you can.

11. FOCUSING ON LOSSES brings mourning, anger, unrest, despair. Limitations are only seen as terrible calamities.

12. FOCUSING ON WHAT REMAINS gives hope, keeps you active. Limitations become just inconveniences to live with.

13. ACCEPTING DISABILITY should mean refusing to be defined by your limitations, determining not to let them stand in your way, and reaffirming life and commitment to living as fully as possible.

14. LIVING IN PEACE WITH POLIO is countering the regret for what you lost with gratitude for having had it. And eagerness to find new things to be grateful for in facing the challenges your limitations present.

15. STRATEGY THREE: Make peace with your God. Don't abandon faith in the spiritual or belief in the value of life.
It is impossible to face the difficulties of life with dignity and constancy without a strong philosophy of life, a rule of conduct, or a valued purpose of some kind.

16. FOR THOSE WHO BELIEVE IN GOD life has a value that is independent of health, strength, or status. And life has destiny beyond the vicissitudes of the present.

17. THE ONLY THING GOD ASKS is for us to do our best with what we have, in whatever circumstances we find ourselves.

18. WHY ME, LORD? WHY NOT ME? Am I so special, that I should be immune to the diseases and accidents that befall the rest of mankind? Or that God should remove from me every inconvenience or danger?

19. GOD DOES NOT QUARANTEE that the "good" will not suffer! Only that good will eventually come out of suffering. .
God doesn't mind when we get angry with Him. It shows we still believe. He is still there to help and comfort us.

20. MY MOTHER'S ADVICE:
When everything goes wrong:
(a) Count to 10 before you speak.
(b) Quietly assess the situation before you act.
(c) Pray. Not telling God what to do, just mentioning your need, then sitting back and waiting to be surprised. God's idea of what's best for us is often quite different from ours.
(d) Then get up and keep going.

21. STRATEGY FOUR: Don't abandon faith in yourself. Make peace with yourself.
The value of your life is not measured by how many pounds you can lift or things you can buy, or the power you have over others, or by your successes or failures, and doesn't depend on what others think of you.

22. ONLY ONE STANDARD COUNTS:
How true you are to yourself; how closely you adhere to principles of right and wrong; how hard you try to do what you should; how well you make amends for offenses; how well you treat enemies as well as friends; how much you resist inclinations to give up, to hate, to harm, or to take what is not yours.

23. BUT DOGGONE IT! We violate our peace due to our anger, greed, and weakness. Make peace with your guilt. Don't deny it. Accept the consequences. Make amends. The memory will remain but peace will return.

24. WHEN YOU LOOK IN A MIRROR don't see only your flaws or only your polio. You have flaws, but you are not the flaws. See yourself as a diamond. A diamond covered with dirt does not shine. A diamond in the dark does not sparkle. An uncut diamond is a worthless rock to the untrained eye. But it is still a diamond. You are a diamond in disguise. If others don't see that, it's their mistake, not yours. The value of a package is measured by its contents not by the wrappings. Don't look so hard at what you admire in others that you fail to see what there is to admire in your self.

25. SOME PEOPLE DON'T LIKE THEMSELVES. They wish that they were someone else, or somewhere else, or stronger, or had more brains, or more money or more success. So anxious about what they wish they had, they fail to enjoy what they do have.

26. THE HAPPIEST PERSON I KNOW is mentally retarded and can do very little, but he knows how to enjoy every moment without any envy or regret. He grew up in a family that loves and respects him, so he respects himself. He is at peace with himself.

27. THE UNHAPPIEST PERSON I KNOW is also mentally retarded and can do a lot. But she grew up in a family that was ashamed of her and rejected her for being defective. So she despises herself. To be unhappy with herself is all she ever learned.

28. STRATEGY FIVE: stay at peace with others. It's hard to be at peace with someone who refuses to be at peace with you.
Everyone wants peace on his/her own terms. You have to find some common ground that is good for both of you and big enough to be shared.
But sometimes, however, peace with yourself requires standing up for what is right even if it means fighting.

29. PEACE is finding a way to agree with someone who doesn't agree with you; a kind word to someone unkind to you; shaking hands with those you'd rather sock.

30. PEACE is being kind when others aren't; holding on even when others let go; not dominating over those weaker than you, but bending down to raise them up.

31. ONLY YOU CAN CREATE YOUR PEACE, by doing the right thing, at the right time, making the most of whatever happens.

32. THE PROBLEM IS we often won't know what the right thing is. And there isn't time to wait for tomorrow's hindsight. We just have to do the best we can.
Peace is not making the right decisions. It is making the decisions we think are right.
Peace is making the best of the decisions we do make even when they turn out wrong.

33. PEACE is taking time to sit back and enjoy what is happening about you. Not waiting for your ship to come in, but going out to find it.
Peace is enjoying the grass on your side of the fence. Not having the whole pie, but being content with the piece you have.
Peace is meant to be shared. True peace radiates. There is a glow about a person who is at peace with himself. It shines even in the darkness of failure or rejection.

34. THESE ARE MY STRATEGIES. WHAT ARE YOURS? LET'S SHARE.

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SPIRITUAL HEALTH:
Songs for the Soul – Cries and Blessings

Jim Croegaert, BCC
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Having worked in ministry, as well as music, for some years, I transitioned into hospital chaplaincy in 1997-8, receiving my certification from the Association of Professional Chaplains in 2000. It was a long way from my childhood in Peoria, where my older sister and younger brother and sister, shared living in the same white frame house all our time at home; of the polio disease that singled me out at age three and left its mark, separating me from my family for extended periods then and numerous times thereafter; of a hard-working dad who was an electrician by day and by night worked on repairing these new contraptions called televisions; of a mom who, though trained as a teacher, worked to make our home a home, until her life was taken by cancer when I was not yet 13.

At an early age, I discovered music as an important means of expression, and one that came naturally to me. I began writing songs as a high school student, signed my first songwriting contract at age 20 (my dad had to co-sign), and continued to write for many years through lots of changes. I have recorded a number of "albums" (as we used to call them!) and also had a number of songs recorded by other artists. One of my songs, "Was It a Morning Like This," became the title song for a Grammy Award-winning album by Sandi Patti.

The search for meaning has long been intertwined with my writing, and the reality that we live in a universe that is spiritual to the core, so to speak, is to me abundantly evident, and born out repeatedly in my life as a chaplain. It seems natural that my faith, or at times my struggle for faith, should find expression in my songs. It has also been clear that what I have to say has been significantly shaped by some of the defining experiences of my life, notably my polio and its consequences (though my physical ones are less than for many others) as well as my mother's death when I was young. But in the long run these experiences, while challenging, have been illuminating, and given me ways of seeing and knowing, of laughing and loving, that could never have been mine otherwise.

My lovely wife of (let's see now) 35 years will also join me on some songs, radically improving the visual part of my presentation.

WHY DO WE HUNGER FOR BEAUTY

Words & Music
Jim Croegaert

Dark are the branches reaching for light
High is the path of the hawk in its flight
Turning and gliding, greeting the night
Why do we hunger for beauty so bright?
Why do we hunger for beauty?

Moon hanging lonely there in the sky
Looking so holy, a host held up high
Off in the distance, train going by
Why does it move us, cause us to sigh?
Why do we hunger for beauty?

Frost on the window, never the same
So many patterns fit in the frame
Captured in motion, frozen in flame
And in the patterns, is there a Name?
Why do we hunger for beauty?
Why do we hunger for beauty?

LOOKING BACK (Excerpt)

Jim Croegaert

I'm afraid of saying more than I know
Even when I tell you I'm ready to go
Looking back through a long corridor
Cream tile walls and a grey marble floor
And the cart is moving...moving...moving
Through the metal swinging doors

They'd always tell you, It'll be all right
I remember one time someone in white
Put a hand o'er my eyes to shield me from the glare
Talked about a small town and people she knew there
Till the room was turning...turning...turning
No coming up for air

(Refrain)
But if I had been awake, would I have seen the knives
Flashing beneath those searching eyes
Yet even those searching eyes didn't see everything
Like the movement of the angel's wing

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GETTING TO KNOW YOU AND YOUR WORK: POST-POLIO SUPPORT GROUPS

Beth Kowall, MS, OTR, Greenfield, Wisconsin
Joan L. Headley, MS, Saint Louis, Missouri

Representatives of support group/organizations in attendance at the conference will be asked to briefly (about 7 minutes) present the following:

Introduction of themselves.
Explanation of the mission/goals of their group.
Describe *what has worked well* with their group.
Describe *what has helped maintain* their group.
And, name one major challenge facing the group. The challenges will be addressed on Saturday, June 4, Session III (1:30 pm-2:45 pm).

Support Groups

Excerpt from *Handbook on the Late Effects of Poliomyelitis for Physicians and Survivors*© edited by Frederick M. Maynard, MD and Joan L Headley, MS. (Revised 1999, ISBN 0-931301-04-1 pbk)

The goal of a support group is to empower its members with the tools necessary to make adjustments needed to continue a life of dignity and independence. Contrary to the image sometimes portrayed in the popular media, healthy support groups are not "pity-parties" and do not promote the idea that "misery loves company."

During the original illness, many polio survivors were hospitalized for extended periods of time and established an esprit de corps. After successful rehabilitation, the same survivors lived active, integrated lives. Many of today's successful support groups have rekindled this sense of belonging to a unique group. Also contributing their perspective to support groups, however with some hesitation or even resistance, are individuals who never were a part of a group based on having polio or a disability.

Support group(s) ...

- Share a common health concern.
- Govern themselves and their agenda with success dependent on each member's feelings of ownership.
- May use professionals as resource persons but not as leaders.
- Provide non-judgmental emotional support.
- Gather and share accurate and specialized information.
- Have membership that is fluid; newcomers are helped by veterans and become veterans who may outgrow the need for a group.
- Have a cause and actively promote that cause. Increase public awareness and knowledge by sharing their unique and relevant information.
- Charge small or no dues for involvement and typically struggle to survive (Laurie & Headley, 1999).
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Support groups provide a forum for people to learn from each other about how to enhance the quality of their lives (Koop, 1992). Historically, support groups related to a common health condition developed to help people resolve problems with bureaucracies. For this reason, groups are encouraged to operate with minimal structures and rules. Spending excessive time on organizational details detracts from the primary goals of providing personal support and advocating for systems' change.

Successful support groups promote "personal empowerment to overcome personal adversity" (Koop, 1992) by encouraging members to become active, assertive managers of their health care, challenging attitudes of helplessness, hopelessness, and victimization. Successful groups create a confidential environment for people to share their feelings safely. Healthy groups balance a time for "me," a time for "us," and time for "you" (Koop, 1992).

Communication is vital in a support group. Members should be encouraged to own their ideas and reactions by using "I" statements, such as "I think ..., I feel ..., I suggest ..." Participants should avoid speaking for the group without consultation, generalizing by stating, "all polio survivors ...," or telling others what to do, such as "you should ..."

Equally important is listening to whoever is speaking by not interrupting or engaging in cross-talk (Ziegler, 1996). Sometimes distressed members digress on tangents and tell detailed stories rather than staying focused on the topic. To minimize these situations, groups should develop ground rules for the meeting time and recognize the limits of the group's role by encouraging persons who experience continuous or intense distress to seek professional assistance.

Effective leadership is also vital. Many groups function successfully with co-leaders or a committed core team.

Effective leaders:
- Acknowledge members' ideas and seek suggestions and feedback.
- Consult with the group about major decisions and respect the group's consensus.
- Request assistance from members.
- Refer to the group as "our" not "my."
- Maintain an atmosphere of respect and order.
- Arrange for reputable, skilled speakers to present topics of interest.
- Obtain and offer names of ethical, knowledgeable professionals and service providers.
- Model self-acceptance and responsibility for their own health and well-being.
- Ensure that individuals who want to speak have an opportunity.
- Respond to the expression of emotion, tension, and conflict openly and with sympathy.
- Offer feedback but avoid authoritative directives by using "I suggest ..." statements, and intervene competently when appropriate.

Survivors join a support group for different reasons, voluntarily attend events, and leave the group when they choose.

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EXPERIENCE ACUPUNCTURE

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EXPERIENCE YOGA

David Riley, MD
Barbara J. Duryea, MSN, RN, CPHQ
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This one-hour overview requires no previous experience with yoga or meditation and will be able to be done while sitting comfortably in your chair.

In 2003 Conemaugh Health System conducted research on an innovative approach to the management of post-polio syndrome made possible by an award from the Uniformed Services University (USU) of the Health Sciences. It was based on the work done by the Stanford University Chronic Disease Self Management study and included an exercise program based on Hatha yoga and a meditation program called Mindfulness-Based Stress Reduction. The results of this research are being used to develop an education program for patients with post polio syndrome and to create an ongoing data collection project documenting the results.

Most patients with PPS suffer from weakness, fatigue, and pain. Most medical research evaluating drug treatments for PPS (e.g., Prednisone, Amantadine, Pyridostegmine, and Anticholinesterases) have been disappointing. However, it has been shown that milder, less extreme forms of exercise may improve muscular strength and fatigue, leading some experts to suggest that the most viable treatment presently available involves reassurance and non-fatiguing exercise.

Our project involved 23 individuals with PPS. All participated in a 5 day retreat in Johnstown, PA followed by 12 weeks of home practice with a home study DVD specifically developed for this research project. All of the participants were asked a series of questions about how they were doing at three time periods during the research project; the first day of retreat, the last day of retreat and twelve weeks after the project was started. The PPS patients as a group noticed significant improvement over the course of the project in pain, fatigue, and weakness and as individuals, many felt that this program had been a transformation for them in their relationship to PPS.

These results showed significant improvement in a patient population where not much hope as been offered and where the lack of deterioration is often viewed as success. Not only did these individuals improve, but also at the end of 12 weeks they were actively involved in self-care.

In this session we will give you a taste of their experience beginning with an overview of self-management and living a healthy life with PPS and how our program helped empower individuals. We will then guide you through an overview of an adapted approach to Hatha yoga and finish with an exercise in Mindfulness-Based Stress reduction.

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EXPERIENCE REIKI

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What is Reiki?

Reiki (Ray-Key) is a word made up of two Japanese words (Rei and Ki) that translate as Universal Life Energy. Reiki energy is a positive healing energy that is present in everyone and everything throughout the universe. Everyone can utilize it for healing, though receiving the Reiki attunements allows one to utilize it in a more focused and powerful manner.

According to Einstein and quantum physics, matter and energy are interchangeable. All living beings, and all that is, can be seen as "denser" energy. When illness or disease is present, this energy is disrupted in various ways. The disruption of energy may even precede the onset of symptoms, and is therefore seen as the "fundamental" level at which treatment would be needed to produce full healing. Reiki and other energy treatments operate at this level to heal and rebalance the energy field.

Though the energetic level is viewed in energy medicine as more fundamental, Reiki is not a stand-alone treatment. It should be viewed as an adjunct to other medical and/or psychological treatment. When used as such, it can accelerate healing and the effectiveness of other treatment modalities.

Reiki is an "intelligent" energy. It goes where it is needed, whether that part of the body is treated directly or not. The recipient "draws" the energy that the body needs, and only that amount. Because it may not be clear to either practitioner or recipient what the greatest need is, it can be difficult to fully predict the outcome of a Reiki treatment.

During a Reiki treatment, the person being treated remains clothed (Reiki energy can penetrate a thick plaster cast). He or she sits or lies down on a massage table. The practitioner places his or her hands on or above the recipient's body in a series of hand positions. Areas needing more treatment may be focused on instead of or in addition to the standard treatment. Both practitioner and recipient can speak during the treatment.

The person receiving Reiki may experience heat, tingling, or even sometimes sensations like electrical shocks during treatment. Some individuals see colors or have "psychic" experiences. Most people experience a sense of relaxation and well-being that may persist after the treatment ends. Some experience pain relief that ranges from mild to significant. Research has found that Reiki treatments can accelerate wound and bone healing, recovery from surgery, and remission from depression and anxiety. It can also facilitate and accelerate healing from psychological trauma. It is helpful for all medical and psychological conditions, and is only contraindicated for those experiencing psychosis (NOTE: Insulin-dependent diabetics who experience Reiki should test carefully prior to using insulin, as Reiki can change dosage needed).

When Reiki is used for chronic (vs acute) problems, the recipient may experience an intensification of current symptoms or revivification of old ones. This is a healing crisis. While it doesn't happen to everyone, it is quite common. Other signs of a healing crisis may be increased output of bodily fluids and excreta (which may also have a stronger odor than usual), nausea and other "vague flu-like symptoms," fatigue, restlessness, more vivid dreams, and thoughts and memories of past unresolved events. These symptoms should pass in 24-48 hours. Supportive measures include drinking plenty of water and resting. Rescue Remedy (available at any health food store) can help if the discomfort is extreme.

Anyone can become a Reiki practitioner. Many healthcare professionals have taken Reiki training. Many excellent practitioners have no other training, but you may prefer to see someone who practices another modality as well. Many massage therapists have Reiki training, as do nurses and an increasing number of mental health professionals. There are even physicians who have taken Reiki training. While the highest level of Reiki training is Master Teacher, practitioners at other levels are quite competent to provide hands-on treatments (though not to teach).

Reiki is quite easy to learn. Level one classes are available just about everywhere, take 1-2 days to complete, and generally cost $150. Even children can learn Reiki. An advantage to taking Reiki training is that you will be able to self-treat. Many people take Reiki simply for this reason, and/or to treat family, friends, pets, and plants. You can interview a Master Teacher to see if you are comfortable with his or her approach, and possibly experience a treatment with him or her prior to taking a class.

The groundedness you need to fly as high as you can

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EXPERIENCE WATSU

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Watsu: A Place to Start When You Are Physically Unable to Exercise

For people who are bedridden or in a wheelchair, exercise is a luxury that they can only dream about. Of course, movement is essential; it is life, it is health. Once regular and systemic movement becomes impossible, our entire quality of life begins to shift. So, is there an alternative to the state of "the spirit is willing, the body is weak"?

In my practice as a massage therapist, both on land and in water, I have discovered some gentle yet powerful moves that can be applied to individuals who can no longer exercise their own bodies. Like all good practices, the regularity and constancy is just as important as the actual modality that is chosen. Since the people that I see come in wheelchairs or on walkers, more coordination is involved because they also need a driver, someone to help lift, dress, etc. and sometimes actually someone to participate in each session with us. I fully appreciate how much more difficult it is to arrange for everyone and everything.

Due to all of these constraints, it is a tribute to my clients and their sheer will to make it happen, that I do see and have the privilege of working and learning with so many. Over the years, week after week, working with these fragile bodies has taught me so much about what is possible.

Aquatic therapy seems to be the best place to begin. The factors of water: buoyancy, hydrostatic pressure, resistance and sensory stimulation combined with warm water not only feels incredibly good, but makes the exercise of stretching and movement actually fun and enjoyable. How can something this fun be really good for you too?!? Having the client looking forward to the session and wholeheartedly participating is satisfying to the entire crew.

Watsu is a warm water (95 degrees) shiatsu massage that the client simply receives, no exertion is necessary and no lactic acid is produced. As the therapist, I am stretching, folding, rocking, cradling, pulling and twisting the client. Profound relaxation, rebalancing and a deep meditative state are the result. For anyone experiencing orthopedic or neurological problems, it can have amazing results. I see one young women (18) who is in a coma, another is an 83-year old man with Parkinson's, and another is a 33-year old man with brain injury. For individuals not so severely handicapped, Watsu can greatly assist them in returning more quickly to a healthier state and beginning their own exercise program. Again, I would recommend aquatic exercises, preferably AiChi (T'ai Chi) in the water. People with arthritis, fibromyalgia, hip or knee replacement or recovering from an injury find both of these modalities to have extremely rehabilitative effects.

Initially, the body feels tired and hungry, but after a few sessions, the body adjusts and begins to feel more energy and vitality. Health and balance have started to return. The effort is definitely worth it.

"It was said in Egypt, water is given to the soul as compensation for taking a bodily form. In water our bodies find the freedom the soul has lost."

Harold Dull

Accessing Holy, Sacred Realms While in an Aquatic Environment

Many of you have heard of Watsu, Wassertanzen and AiChi by now. These modalities have been available in St. Louis for over 6 years. Some coverage on TV, radio and magazines has brought some awareness of what these funny words mean.

Since I am the primary practitioner of this type of aquatic therapy and have given over 5,000 Watsus, and taught nearly 1,000 AiChi classes, I want to share with you some perspectives from these intense experiences.

Energy moves in our bodies at 100 times more powerfully in water than on land, i.e., an electric shock on land versus the same shock in water. It is our body's high electromagnetic conductivity in the water that makes all the difference. Interestingly, we also do not feel or sense pain as much in the water, and thanks to buoyancy and viscosity, we are able to move in ways that are literally impossible on land. These properties and more are what make aquatic therapy unique and an extremely powerful healing modality.

The temperature of the water is critical in achieving various results. In Watsu, a warm water shiatsu massage, skin temperature water is the most desired and beneficial, around 95 degrees. A comforting and deep state of relaxation is felt in all the muscle groups, as the body literally melts into the water. The client is then lifted and held by the practitioner while, very slowly, very gently, various stretches, yoga and tai chi moves, really a dance of movements, are commenced on the body. The eyes are closed and the ears are in the water and gradually this hypnotic state of being begins to release the body and mind in ways that are unspeakable, beyond words and thoughts. This profoundly altered state of being does not last for just a few moments, but for an extended period of time. Clients have commented that they escaped for awhile, but the truth is, they returned home to who they really are. And the more you receive the work, the deeper and more profoundly you move into this state of being for a longer time. It feels so heavenly, so unearthly, so peaceful and beautiful that all questions, concerns, and daily commitments and responsibilities simply are gone, erased, like they never existed. You are restored and feel better than you have in years and years. You have entered the state of silence with the degree of a master meditator, though you may know nothing of meditation or accessing this deeply altered state. It can be addictive, on the other hand, you feel more ready and willing to participate in your life and in your world than ever before. There's a renewed sense of courage and understanding, inner strength and peacefulness that fills the entire body and mind. The less you can talk about it, the more I know that you have received it.

Physically, some interesting aspects are noticeable immediately. Since I'm also a massage therapist and do land-based work, when I'm working on a body on the table, the body feels about its correct age. Either it is in good tone or not, but nonetheless, it 'feels' about the appropriate age. In the water, everything 'feels' much differently. The body returns to a child-like state of freshness, mobility, fluidity, and accessibility. It is truly amazing. The body, our divine child 'feels' truly lovely and ever so peaceful.

Watsu: Warm Water Shiatsu Massage

WATSU is a warm water shiatsu massage that is experienced more like a dancing meditation than a type of bodywork. The tremendous amounts of energy that are moved and released clearly makes Watsu a powerful form of bodywork, but the feeling that one has is mystical, very gentle, peaceful and healing.

Freeing the spine in a weightless environment is the cornerstone of a Watsu session. The therapist supports the client in 95°F water while gently rocking and stretching the back and limbs. Acupressure (Shiatsu) points are stimulated and muscles are massaged while the body is in a gentle motion. The body can then unwind to a profound degree easily and naturally and subtle healing energies, which are usually restricted, are allowed to circulate.

Movement and stillness are interwoven in harmony with the breath. This, combined with the feeling of weightlessness, warmth and the support of the water, induces a deep state of relaxation of body and mind. During Watsu, physical and mental tension, fear, muscle spasms, and joint restrictions dissolve. Clients find they have more flexibility and awareness.

Since all life began in the ocean and we are 70%, to 80% water, returning to an environment that closely resembles our conception and birth is healing to the deepest parts of our being. The key to the inner journey is allowing the mind to rest in a place of preconceptual thought and prelanguage. Watsu ever so gently assists the body and the mind in that delicate and beautiful process. It's a spiritual dance that calls forth healing in every cell of the body.

Energy moves 100 times more efficiently in water than on land. Working the energy centers of the body in the water is easier and more powerful than traditional bodywork. For people who are ill or deconditioned, Watsu is a soothing yet potent form of exercise that the body simply receives without exertion. No lactic acid is produced and the body grows stronger without tension. After several sessions, the client is usually ready to begin some simple stretching and movement on land, while continuing most of the exercising and strength building in an aquatic environment for a quicker and more stable healing.

In addition, in water our lower *Tan Tien* (about 2" below the navel and 2" deep) moves up to our middle *Tan Tien* or Heart Chakra to lend more strength to the opening of our Heart Chakra. Sometimes, Watsu is referred to as "Embracing and Opening the Heart."

During a Watsu session, the eyes are closed and the ears are in the water, so outside stimulation is minimized and the neocortex or higher rational brain, relaxes. A sense of space and time disappears, and if the body feels safe, the primitive brain, which directly or indirectly produces all the hormones in the body, is free to rebalance and repair. While the body is tense or experiencing various levels of distress, the neocortex is ever vigilant and on duty. Gently persuading the neocortex to relax and take a break is not usually an easy task. However, the warm water, flowing movements and support of the practitioner does facilitate very deep states of relaxation and rejuvenation of all the systems.

Land massage affects the various muscles of the body, but Watsu affects all the systems of the body, especially the inner organs. When the inner organs are massaged and relaxed, they release toxins which may feel like gas or bloating. Large quantities of fresh water are needed for the next 24 hours to facilitate the toxins flushing away. Immediately, the workload of the systems is easier and healing of the body can accelerate.

In spiritual terms, it has been likened to baptism or an initiation to the return of wholeness. One important feature of Watsu is the final movement or closure with the integration of mind and heart energies. To be balance, in harmony and fully integrated with body, mind, heart and spirit is the essence of inner peace and wholeness.

Watsu treatments are recommended for the following conditions: chronic pain, arthritis, neuromuscular disorders, chronic headaches, chronic fatigue, hyperactivity, autism, sleep disorders, anxiety disorders, cerebral palsy, multiple sclerosis, spinal cord injuries, polio, Rhett's syndrome, fibromyalgia, abuse issues, depression, addictions, Parkinson's disease and other diseases.

Aquatic Therapy: The Wonders of Water

Water is a miracle and a joy to experience and the long-term effects continue on the land, but generally, a person suffers a debilitating injury or illness before discovering the rehabilitative effects of water. Especially important in a good program are warm water, gentle movements and soothing music.

Outcomes of aquatic therapy include improved balance, coordination and motor skills (excellent for fall prevention), increased chest expansion and cardio-respiratory activity, increased weight bearing abilities, improved muscular endurance and strength, and decreased pain.

Therapy in the water works because of buoyancy, hydrostatic pressure, resistance and sensory stimulation. Water decreases joint compression and force reactions and therefore lessens arthritic, back, chronic pain or pain caused by surgery or injury . Water diminishes the effect of gravity. When submerged to shoulder depth, our bodies experience a 90 percent apparent weight loss. Clients move without joint stress and increase flexibility because buoyancy assists movement.

Movement is also less painful because of hydrostatic pressure, which tends to decrease edema and increase circulation to deep muscle groups. Hydrostatic pressure also assists in stabilizing unstable joints. Water supports the body and eliminates the need for walking aids.

Hydrostatic pressure on the chest wall stimulates chest expansion and deeper ventilation, which increases cardio-respiratory activity. With sedentary patients, there is a gradual decline in vital capacity. Movement in the water can improve it.

Muscular strength and tone will improve from working against the variable water resistance. The more force used against the water, the more "weight" the water carries. Moving through the water resistance requires co-contraction of the abdominal and back muscles, teaching central stabilization. Balance, proprioception and coordination can all be improved.

Water can have a positive effect on osteoporosis and bone density. It was once thought that heavy impact was necessary to maintain youthful bone density. It is now understood that working against resistance is what is required.

Sensory stimulation of the water increases kinesthetic awareness of body parts and also promotes greater relaxation. Water temperature is important and should be 87 F to 92 F for best results.

The socializing aspect is significant as well and clients enjoy meeting others and moving in a pain-reduced environment. Some of the clients' comment: "It's rejuvenating!" "It's addictive!" "My back no longer hurts." "Rapid recovery from knee surgery." "Aquatic therapy before and after surgery -- what a difference!" "Our hair and make-up don't get wet." "We like moving at our own pace." "The music is soothing." "For all ages, male or female, it's a great mix."

The program that is suggested by the Arthritis and Fibromyalgia Foundations are walking, gentle stretching, muscle and strength endurance, and relaxation.

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THERAPEUTIC USE OF MUSIC: EXPERIENCE MUSICAL ACUPUNCTURE AND MUSICAL BIOFEEDBACK

Janalea Hoffman, RMT, MA
Olathe, Kansas

PRACTICAL MUSICAL SOLUTIONS

I. INTRODUCTION
  A. Overview of Therapeutic Music
  B. The Sound Environment
    1. How sound affects our Immune System
    2. How the sound environment fits in your wellness program

II. BODY AWARENESS
  A. Entrainment – Our bodies are constantly synchronizing with external rhythms.
  B. Musical Biofeedback
    1. Music is a point of reference to help slow down the body.
    2. Awareness of internal body rhythms is essential.
  C. The relationship of body rhythms to musical rhythms.
  D. How music can lower your blood pressure and heart rate

III. Experiential Segment.
  A. Synchronize body rhythms with musical rhythms.
    1. Experience 60 beats a minute music.
    2. Experience 50 beats a minute music.
  B. How to use music with heart arrhythmia's.
  C. Ideal state is to slow down the body physiologically while the mind stays alert – alpha and theta states.
  D. Experience Musical Acupuncture
    1. Music and pain relief
    2. How sound moves energy in the body

IV. DISCUSSION, QUESTION/ANSWER, AND CLOSING

Janalea Hoffman, RMT, MA
Rhythmic Medicine, Olathe, Kansas

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SERVICE DOGS FOR PEOPLE WITH NEUROMUSCULAR CONDITIONS AND THOSE WHO USE VENTS

Joanne Kocourek, RN, CCRC with Annalies Kocourek and Kristen Kocourek
Worth, Illinois

SERVICE DOG TASKS

Service dogs generally receive six months to a year of schooling on tasks, obedience and public access manners. Most dogs placed by non-profits since the 1970s have been trained to assist people who have a wide variety of mobility impairments. Some teams have mastered up to fifty tasks, enjoying the challenge of such an advanced education. The list of tasks in this section are a broad sampling of what has been developed over the past quarter century to address daily living needs and safety issues.

RETRIEVE BASED TASKS

- Bring portable phone to any room in house
- Bring in groceries – up to ten canvas bags. Fetch a beverage. Fetch food bowl(s)
- Pick up dropped items like coins, keys etc., in any location
- Bring clothes, shoes, or slippers laid out to assist with dressing
- Unload towels, other items from dryer
- Retrieve purse from hall, desk, dresser or back of van
- Fetch basket with medication and/or beverage from cupboard
- Use target stick to retrieve an indicated item off shelves in stores retrieve one pair of shoes from the closet
- Drag Cane from its customary location to another room or pick up and return cane if falls
- Drag walker back to partner

CARRYING BASED TASKS (non retrieval)

- Move bucket from one location to another. Lug a basket of items around the house
- Transport items downstairs or upstairs to a specific location
- Send the dog to obtain food or other item from a caregiver and return with it.
- Pay for purchases at high counters
- Transfer merchandise in bag from a clerk to a wheelchair user's lap
- Carry mail or newspaper into the house

DEPOSIT BASED TASKS

- Put trash, junk mail, plastic into a wastebasket or garbage can or recycling bin
- Assist partner to load clothing into top loading washing machine
- Put silverware, non-breakable dishes, plastic glasses, dirty food bowls in sink
- Deliver items to "closet". Deposit dog toys into designated container
- Put prescription bag, mail, other items on counter top

TUG BASED TASKS

- Open refrigerator, cupboard doors or drawers with attached strap. Open interior doors via a strap.
- Answer doorbell and open front door with strap attached to lever handle
- Shut restroom door that opens outward via a leash tied to doorknob. Shut interior home, office doors
- Assist to remove shoes, slippers, sandals, socks, slacks, sweater, coat
- Drag laundry basket through house with a strap. Drag bedding to the washing machine
- Pull a drapery cord to open or close drapes

NOSE NUDGE BASED TASKS

- Cupboard door or drawers – nudge shut, Dryer door – hard nudge, Stove drawer – push it shut
- Dishwasher door - put muzzle under open door, flip to shut
- Refrigerator & freezer door – close with nudge
- Call 911 on K-9 rescue phone – push the button

- Operate button or push plate on electric commercial doors. Turn on light switches
- Turn on metal based lamps with touch-lamp device installed – nudge base
- Assist wheelchair user to regain sitting position if slumped over
- Help put paralyzed arm back onto the armrest of wheelchair
- Return paralyzed foot to the foot board of a wheelchair if it is dislodged

PAWING BASED TASKS (some dogs prefer it to nose nudge)

- Cupboard door, dryer door – shut it with one paw. Refrigerator & freezer door – one forepaw or both
- Call 911 on K-9 rescue phone – hit button with one paw
- Operate light switch on wall – jump up, paw the switch. Depress floor pedal device to turn on appliance(s)
- Jump up to paw elevator button or operate push plate on electric commercial doors
- Close heavy front door, other doors – jump up, use both forepaws

BRACING BASED TASKS (no harness)

- Transfer assistance from wheelchair to bed, toilet, bathtub or van seat – hold Stand Stay position, then brace on command, enabling partner to keep their balance during transfer
- Assist to walk step-by-step, brace between each step, from wheelchair to nearby seat
- Position self and brace to help partner catch balance Prevent fall by bracing on command if the partner needs help recovering balance.
- Steady partner getting in or out of the bathtub
- Assist partner to turn over in bed; have appropriate backup plan
- Pull up partner with a strap [tug of war style] from floor to feet on command

HARNESS BASED TASKS – Mobility Assistance

- Assist moving wheelchair on flat [partner holds onto harness pull strap] avoiding obstacles
- Work cooperatively with partner to get the wheelchair up a curb cut or mild incline
- Haul open heavy door, holding it ajar using six-foot lead attached to back of harness
- Tow ambulatory partner up inclines [harness with rigid handle or pull strap may be used]
- Brace on command to prevent ambulatory partner from stumbling [rigid handle]
- Help ambulatory partner to climb stairs, pulling then bracing on each step
- Pull partner out of aisle seat on plane, then brace until partner catches balance
- Transport textbooks, business supplies or other in a wagon or collapsible cart
- Backpacking – customary weight limit is 15% of the dog's total body weight

MEDICAL ASSISTANCE TASKS (Sample)

- Bark for help on command
- Find the caregiver on command, lead back to location of disabled partner
- Put forepaws in lap of wheelchair user, hold that upright position so wheelchair user can access medication or cell phone or other items in the backpack
- Wake up partner if smoke alarm goes off, assist to nearest exit
- Operate push button device to call 911; let emergency personnel into home and lead to partner's location
- Fetch insulin kit, respiratory assist device or medication from customary place during a medical crisis
- Lie down on partner's chest to produce a cough, enabling patient to breath, when suction machine and/or care-giver unavailable

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THERAPEUTIC USES OF THE NATIVE AMERICAN CEDAR FLUTE

Janalea Hoffman, RMT, MA
Olathe, Kansas

DESCRIPTION

In this workshop you will learn simple techniques for playing the cedar flute, Native American style. It is one of the easiest instruments to play because you do not need to read music to be successful. The class is based on the Native 5-note scale which is very easy to learn. This is an excellent instrument because you can be easily rewarded. Traditional musical instruments require a lot of persistence and practice before you are rewarded. The cedar flute (5-note scale) helps individuals experience success very quickly with a beautiful mellow sound. In this workshop you will have hands-on experience with a cedar flute and see how quickly you can achieve musical success. You do not need any prior musical knowledge to enjoy and fully benefit from this workshop (Each participant will have a plastic tube in the flute, for sanitary purposes).

THERAPEUTIC ASPECTS OF NATIVE STYLE CEDAR FLUTE PLAYING:

1. Motor skills – helps improve fine motor skills due to the repetitive fingering required. The beautiful sound that you get early on is motivating to keep the fingers going. The player is rewarded for their finger exercise due to the beautiful organic sound.

2. Increases Body Awareness – Due to the tactile element of this instrument – having to cover the holes completely to get a good sound – the player increases tactile awareness. Playing also increases awareness of breathing and depth of the breath.

3. Improves Self-Esteem – The fact that you don't need to know how to read music to play this instrument, helps to facilitate a sense of accomplishment very quickly. Most musical instruments require a lot of patience and persistence before you are rewarded with a nice sound. The quick reward of the cedar flute helps give individuals a sense of accomplishment.

4. Improves Breathing – The gentle breath required to get a nice sound helps encourage deeper breathing. This technique is good for individuals with asthma or other respiratory challenges who would normally not be able to play a wind instrument.

5. Excellent Outlet for Emotions – Every person needs an outlet for emotions, but especially anyone with a physical disability who experiences more than the usual frustrations. Music is a great emotional outlet, but to be able to express emotions through the breath on this instrument is very therapeutic. Many feelings can come through the flute that words could never express.

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EXPERIENCE MYOFASCIAL RELEASE

Nancy Caverly, OTR/L
Mexico, Missouri

MYOFASCIAL FREEDOM

Myofascial Release is a very effective hands-on technique that provides sustained pressure into myofascial restrictions to eliminate pain and restore motion. The theory of Myofascial Release requires an understanding of the fascial system (or connective tissue). The fascia is a specialized system of the body that has an appearance similar to a spider's web or a sweater. Fascia is very densely woven, covering and interpenetrating every muscle, bone, nerve, artery and vein as well as all of our internal organs including the heart, lungs, brain and spinal cord. The most interesting aspect of the fascial system is that it is not just a system of separate coverings. It is actually one structure that exists from head to foot without interruption. In this way you can begin to see that each part of the entire body is connected to every other part by the fascia, like the yarn in a sweater.

Fascia also plays an important role in the support of our bodies, since it surrounds and attaches to all structures. These structures would not be able to provide the stability without the constant pull of the fascial system. In fact, our bones can be thought of as tent poles, which cannot support the structure without the constant support of the guide wires (or fascia) to keep an adequate amount of tension to allow the tent (or body) to remain upright with proper equilibrium. In the normal healthy state, the fascia is relaxed and wavy in configuration. It has the ability to stretch and move without restriction. When we experience physical trauma or inflammation, however, the fascia loses its pliability. It becomes tight, restricted and a source of tension to the rest of the body. Trauma, such as a fall, whiplash, surgery or just habitual poor posture over time has a cumulative effect. The changes they cause in the fascial system influence the skeletal framework for our posture. The fascia can exert excessive pressure (more than 2,000 pounds per square inch) producing pain or restriction of motion. They effect our flexibility and are a determining factor in our ability to withstand stress and strain. The use of Myofascial` Release allows us to look at each person as a unique individual. One-on-one therapy sessions are hands-on treatments during which therapists use a multitude of Myofascial Release techniques and movement therapy. Independence through the enhancement of strength, flexibility and postural and movement awareness is encouraged.

For individuals who have paraplegia (paralysis of the trunk and legs) or paraparesis (weakness of trunk and legs), myofascial release is an important component of long-term care. Management of the body at and below the level of paralysis, paresis, generally includes neuromuscular reeducation, skin and joint protection, functional range of motion, and instruction in self-management of the legs in activities of daily living. There is a tendency to de-emphasize soft tissue management in areas at or below the level of paralysis. However, to do so is to risk decreasing the optimum function of the entire body.

An analogy can be drawn to wearing tights that have one leg twisted when you pull them over the feet and legs. A half twist in the foot creates significant torque by the time the material has been stretched over the thighs to the waist. The waist and thigh position can be readjusted; however, optimum comfort and ease of motion are not achieved until the twist in lower portion of the tights is corrected. Similarly, lower extremity and lower trunk myofascial restrictions, whether secondary to polio, spinal cord injury, multiple sclerosis, cerebral vascular accident, spina bifida, or some orthopedic surgeries have to be addressed to maximize comfort and ease of motion in the entire body. Such restrictions can add tension throughout the trunk and even into the neck, head and upper extremities. It is as if the twisted tights were part of a body suit. Individuals with this fascial tension an benefit by having their "body suit" periodically assess for myofascial restrictions and treated accordingly.

The hands of the therapist using myofascial release techniques are the change agents for the myofascial osseus system. With gentle pressure with both hands, the heat and piezoelectric effect produce change in the fascial system. Slow, sustained traction or compressions using the bony structure as levers can effect change, also. Patience and a heightened sense of awareness of subtle change are necessary for the therapist to practice. The body corrects itself, and the movement into the restriction and gradual release is controlled by the individual, not the therapist. Therefore, myofascial release is a safe treatment when performed by a competent therapist who has had training in the technique.

Another aspect of myofascial release is called myofascial unwinding. This occurs when, as noted above, there is created a flow of the body's bioenergy. his flow triggers the mind/body complex into spontaneous motion. The spontaneous therapeutic motion allows the body to assume positions in space that represent positions of past traumas. These positions of trauma represent one's subconscious fear, negative memories and/or pain that have created holding or bracing patterns which have impeded progress in the traditional therapeutic approach. It is these positions in space and the re-experiencing of this main memory which is never injurious, that take the threat out of the system and a the mind/body complex to let go of these holding or bracing patterns so that healing can commence. There must be the component of trust between therapist and client for the cleansing effect of myofascial unwinding to take place. An individual can learn unwinding, thus becoming his/her own therapist.

In the video, Myofascial Freedom, John Barnes PT, the founder and master teacher of Myofascial Release, discusses the components of the system and provides four techniques for self-therapy. The figures illustrate the positions for each technique.

Adapt the positions as needed if unable to maintain due to disability.

1. Lower Leg Stretch – Gastrocnemius and soleus muscles
Place one foot about two feet in front of the other; hold onto top of sturdy chair or table. Bend the knee of the foot in front, keeping the rear foot flat on the floor. Straighten up after lunge, repeat nine more times. Change front foot and repeat 10 times.

2. Thigh-Hamstring muscles
Lie down on bed or floor, on back. Flex (bend) both legs, placing feet on the surface. Put foot of one leg on the thigh of the other leg. Lift "other leg" off surface while pushing down with foot on thigh. Do this movement ten times, then change positions of both feet. Repeat movement ten times again.

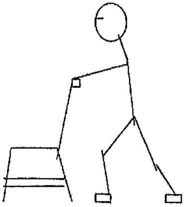
3. Arm and Shoulder
Using a bath towel, hold one end with right hand. Place towel over right shoulder and grasp with left hand behind chest. Pull with both hands ten times. Change positions with left hand and place towel over left shoulder, grasping behind chest with right hand. Repeat movement ten times.

4. Head and Neck
Hold bath towel ends in each hand, raising arms so that towel is just below the base of the skull on neck. Pull on both ends at the same time while gently pushing head back on towel. Relax. Repeat the movement nine times

Maintaining flexibility is important to the polio survivor, as the body parts – muscles and fascia of arms and legs in particular – will contract causing pain and pressure on weight bearing bones. Understanding the purpose and actions of the myofascial system allows the polio survivor to assist in having good posture and pain free movement.

Information for this presentation was compiled from articles by John T. Barnes PT from 1997 to 2004. To find out more about the Myofascial Release Seminars go to www.fascial.org or call 1-800-FASCIAL. The Myofascial Release Treatment Centers are located in Paoli, PA, and Sedona, AZ. Seminars are open to therapists, physicians and lay people.

Positions for Flexibility-Strengthening Exercises:



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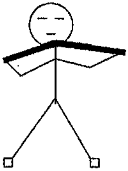

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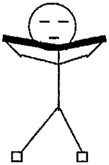

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THE RESEARCH FUND

The one million survivors of poliomyelitis in the United States, and the 12 million worldwide, know there are consequences of living and aging with a disability. They also know that funding for research into their problems is limited.

Post-Polio Health International (formerly Gazette International Networking Institute) established The Research Fund (formerly The GINI Research Fund) in 1995 dedicated to "seeking scientific information leading to eventual amelioration of the consequences of poliomyelitis and/or neuromuscular respiratory diseases."

Q: What research will PHI support?
A: The grants will help support researchers, scientists, and clinicians worldwide to investigate the cause(s), treatment, and management of post-poliomyelitis and neuromuscular respiratory disease.

As it approves grants, PHI will foster new innovative research – both basic science and clinical – that will result in improved quality of life for people with disabilities, as well as support valid ongoing research.

Q: How will funding decisions be made?
A: A panel made up of peers and people with disabilities will review all grant applications that meet established requirements for respiratory research or post-poliomyelitis research. This panel's recommendations will be reviewed by the PHI's Board of Directors, who will make the final funding decisions.

Q: How can contributions be made?
A: Post-Polio Health International is a not-for-profit 501(c)(3); Federal ID No. 34-0961952. Tax-deductible contributions can be made online (www.post-polio.org) or sent to Post-Polio Health International (PHI), 4207 Lindell Boulevard, #110, Saint Louis, Missouri 63108-2915 USA

Checks should be made payable to "Post-Polio Health International" (US dollars only). PHI also accepts VISA, MasterCard, and Discover.

The Research Fund now with a corpus of $420,000 awarded its first grant from the interest in the fall of 2000.

THE FIRST AWARD (2001)
Ventilator Users' Perspectives on the Important Elements of Health-Related Quality of Life

THE SECOND AWARD (2003)
Women with Polio: Menopause, Late Effects, Life Satisfaction and Emotional Distress

THE THIRD AWARD (2005)
Timing of Noninvasive Ventilation: Does earlier use result in prolonged survival?

Visit www.post-polio.org/resrch.html to read the reports.

POST-POLIO HEALTH INTERNATIONAL

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Note Cards Available!

Post-Polio Health International remembers the survivors of polio...

To commemorate the 50th anniversary of the development of the Salk vaccine, Post-Polio Health International chose to honor those for whom the vaccine was too late. Since its inception in 1958, the organization has focused its resources and efforts on improving the health and independence of polio survivors and ventilator users and is committed to continuing this practice.

Artist Deborah Goodwin and polio survivor Mickie McGraw teamed up to create a visual reminder that millions of polio survivors are citizens of the world community who are in need of information, advocacy and research. (The artwork is in shades of blue and yellow with green accents.)

> *The nautilus shell represents an external stillness and static mobility. Contained and protected within is a rich and active life force that radiates outward from the central creation point of its spiral to reach beyond the limits of its boundaries.*
>
> *The butterfly depicts the ephemeral, unique beauty of each life that begins encased within a cocoon and emerges in its time, transformed, to color the world and give wings to the future.*
>
> *Together they celebrate our human potential to transcend limitations. They commemorate the 50th anniversary of the development of the Salk polio vaccine, which forever changed our lives and our future.*

To help PHI remind the world of this anniversary, and to support our work, order your set of 10 note cards for $13.50 (s&h included).

Send the form below to PHI, 4207 Lindell Blvd. #110, Saint Louis, MO 63108 (314-534-5070 fax) or order online at www.post-polio.org/order-card.html.

Please send _____ sets of the 50th Anniversary Commemorative Note Cards.

For larger orders or international orders, please contact 314-534-0475 or info@post-polio.org.

TOTAL AMOUNT FOR ORDER: $ ____________

QUANTITY	PRICE
1 set	$13.50 per set, s&h included
2-4 sets	$11 per set, plus total s&h of $2.50
5-10 sets	$11 per set, plus total s&h of $5.00

Payment Options:

☐ I am paying by credit card. (PHI accepts VISA, MasterCard and Discover.)

☐ I am sending my check made payable to "Post-Polio Health International" (US dollars only)

☐ Please send an invoice.

PHI Member ID No. (if known) ____________

Name ____________

Affiliation ____________

Address ____________

City ____________

State/Province ____________

Zip/Postal Code ____________

Country ____________

Phone (include area/country code) ____________

email ____________

Complete if using a credit card ...

☐ Visa

☐ MasterCard

☐ Discover

Card No. ____________

Exp. Date ____________

Authentication No. (on back of card) ____________

Name on Card ____________

Signature ____________

NINTH INTERNATIONAL CONFERENCE ON POST-POLIO HEALTH AND VENTILATOR-ASSISTED LIVING:

STRATEGIES FOR LIVING WELL

June 2-4, 2005 ■ Saint Louis, Missouri

PROGRAM FOR FRIDAY, JUNE 3, 2005

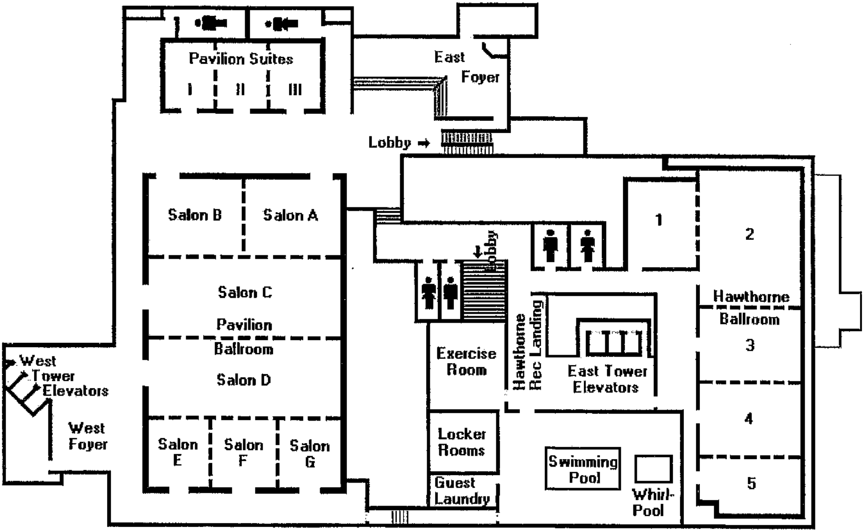
This book belongs to:

____

POST-POLIO HEALTH INTERNATIONAL

POST-POLIO HEALTH INTERNATIONAL
INCLUDING INTERNATIONAL VENTILATOR USERS NETWORK

4207 LINDELL BOULEVARD, #110
SAINT LOUIS, MISSOURI 63108-2915 USA
314-534-0475, 314-534-5070 FAX
INFO@POST-POLIO.ORG, WWW.POST-POLIO.ORG



Details

Please wear your NAME BADGE; it is your "ticket" for the sessions.

The time schedule will be strictly adhered to because the sessions will be audio taped. TAPES are available on site. An order form is included in the conference bag. Personal recording (audio, video, etc.) of the sessions is prohibited.

EXHIBITS are located in Pavilion Suites I-II-III.

The Thursday, June 2, 2005, "MEET FOR HEALTHY TREATS" in the East Foyer is open to all full and Thursday registrants and those who purchased a ticket.

The Friday, June 3, and Saturday, June 4, MORNING BREAKFASTS are open to all full and daily registrants and will be available in the West Foyer and the East Foyer. Seating will be available in Salon D and the East Foyer.

MEAL TICKETS will be collected at the doors of Salon C & D. Meal tickets for the luncheons and Friday dinner are no longer available. All registrants are invited to the awards presentation and entertainment on Friday, June 3 at 7:30 pm in Salon C & D.

In case of an EMERGENCY, call the hotel operator "O" and request that they call "911" so they are alerted and can direct the emergency crew to you.

QUESTIONS from the audience will be submitted to the speaker/moderator in writing unless otherwise announced in the session.

Post-Polio Health International's mission is to enhance the lives and independence of polio survivors and home ventilator users through education, advocacy, research and networking.

Welcome to PHI's Ninth International Conference on Post-Polio Health and Ventilator-Assisted Living ...

On behalf of the Board of Directors and staff of Post-Polio Health International and the International Ventilator Users Network, we welcome you to Saint Louis and to this ninth unique symposium since 1981.

We gratefully acknowledge the expertise and commitment of our presenters, and thank them for their valuable abstracts, outlines, fact sheets and other materials enclosed in this book. If you wish to share this information, we respectfully ask that you acknowledge the presenters and their institutions and then add the following statement:
"This information was disseminated at Post-Polio Health International's Ninth International Conference on Post-Polio Health and Ventilator-Assisted Living, June 2-4, 2005."

We also would appreciate you informing PHI as well as the presenter that you are disseminating this material and where, so that we can track the ripple effect of the conference.

Audio tapes and CDs of the sessions will be available on site and also may be ordered after the conference from Network Communications (800-747-1426, 636-677-1912 fax, www.swiftsite.com/nettapes/PostPolio2005.html). Ordering information also will be available on www.post-polio.org and in future issues of *Post-Polio Health* and *Ventilator-Assisted Living.*

Personal recording (audio, video, etc.) of the sessions is prohibited.

This ninth symposium has been created and designed from the information needs, requests and suggestions of today's polio survivors and ventilator users. The purposes and outcomes expected are:

- To learn personal STRATEGIES FOR LIVING WELL
- To provide information and support to families and friends of polio survivors and ventilator users
- To exchange ideas with polio survivors and ventilator users
- To exchange ideas with health professionals
- To contribute to the worldwide activities supporting the improved health and independence of polio survivors and ventilator users
- To renew old acquaintances and make new friends

Our wish is that each and every one of you, whether consumer *or* health professional, or both, will return home with numerous strategies for living well and with a commitment to implementing them. We also sincerely hope that you leave with a continued commitment to supporting the work of PHI and IVUN. Your personal and professional contributions, both financially and in deed, are vital to us as we continue our much-needed efforts on behalf of polio survivors and ventilator users.

Audrey J. King
Conference Co-Chair
Audrey King

William Wischmeyer
Conference Co-Chair
William Wischmeyer

Joan L. Headley
Executive Director
Joan L. Headley

Program for Friday, June 3, 2005

8:00 am – 1:30 pm
Registration Desk
REGISTRATION

8:15 am – 9:00 am
East and West Foyers
CONTINENTAL BREAKFAST

8:30 am – 3:30 pm
Pavilion Suites
EXHIBITS OPEN

9:00 am – 10:15 am
SESSION I OPTIONS

Salon C
ASSISTANCE FROM ALLIED HEALTH PROFESSIONALS
Falling: Fear, Risks, and Practical Strategies
Kristine Legters, PT, DScm NCS
Gannon University, Erie, Pennsylvania
What OTs and PTs Can (and Can't) Do for Polio Survivors
Laura Ryan, OTR/L
Kristeen Muldoon, MSPT
International Rehabilitation Center for Polio, Framingham, Massachusetts

Salon E
COMPUTERS AND THE INTERNET
What a Computer Can Do for You
Cheeri Davide Ong, MSEd
Information Specialist, NCPAD, Chicago, Illinois
NCPAD Website: A Friend to Polio Survivors
Sunny Roller, MA
University of Michigan, Ann Arbor, Michigan

Salon D
PLANNING AHEAD TO STAY IN YOUR HOME WHEN GETTING OLDER
Moderator: Beth Kowall, MS, OTR
Greenfield, Wisconsin
Stephanie Malench, MSW, LCSW
Full Living Services, Saint Louis, Missouri

Salon A
WHAT ABOUT NUTRACEUTICALS?
Moderator: Beverly Brannan
House Springs, Missouri
Charles Dumont, MD
Associate Director, Integrative Medicine,
Loyola University Health Systems, Maywood, Illinois

Salon F/G
INTIMACY AND SEXUALITY: MIND, BODY, AND HEART CONNECTIONS
Linda Bieniek, CEAP
La Grange, Illinois
Hannah Hedrick, PhD
Mountain View, Hawaii

Salon B
CLARIFYING CHOICES
Moderator: Lawrence Becker, PhD
Roanoke, Virginia
Non-Invasive Ventilation for a Tracheostomized Polio-Patient without Intubation Tube
Grethe Nyholm, RN
Birgitte Brandt Lassen, RN
Respiratory Centre East, Copenhagen, Denmark
Lotte Mortensen, RN
Institution for Respiratory Care Patients, Copenhagen, Denmark
The Right Ventilation at the Right Time
Diana Guth, RRT
Home Respiratory Care, Los Angeles, California
Betsy Thomason, RRT
Millennium Respiratory Services, Whippany, New Jersey
Angela King, BS, RPFT, RRT-NPS
Pulmonetic Systems, Inc., Minneapolis, Minnesota

10:15 am – 10:45 am
BREAK

10:45 am – 12:00 noon
SESSION II OPTIONS

Salon C
ANALYZING YOUR GAIT: THE ROLES OF EXERCISE, BRACING OR SURGERY
Mary Ann Keenan. MD
Orthopaedic Surgery, University of Pennsylvania, Philadelphia, Pennsylvania
Alberto Esquenazi, MD
Gait & Motion Analysis Lab, Moss Rehabilitation Hospital, Philadelphia, Pennsylvania

Salon D

RESEARCH I: WHAT IS BEING DONE? WHAT NEEDS TO BE DONE?

Moderator: Lauro Halstead, MD
National Rehabilitation Hospital, Washington, DC

Results of a NHIS Survey: How Info Might Prompt New Research and Care

Nancy Myers, PhD, RN, CPHQ
Northeastern Ohio Universities College of Medicine, Rootstown, Ohio

Update on Growth Factors Used in Mouse Model

Burk Jubelt, MD
Department of Neurology, SUNY Upstate Medical University, Syracuse, New York

Update on Modafinil Study

Olavo Vasconcelos, Jr., MD
Physician Research Coordinator, Uniformed Services University, Bethesda, Maryland

Salon A

UPDATE FROM MEDICARE

Moderator: Jean Csaposs
New Jersey Polio Network, Martinsville, New Jersey

Prescription Drug Cards

Bill Hunot
Social Security Administration, Saint Louis, Missouri

Payment for Durable Medical Equipment and Staying in Your Home: What Medicare Can Do for You

Diana Brady
CLAIM, Columbia, Missouri

Salon F/G

TRAUMA TREATMENT: WHAT IS IT AND WHAT ARE THE BENEFITS

Stephanie Machell, PsyD
International Rehabilitation Center for Polio, Framingham, Massachusetts

Salon B

CAN WE TALK ABOUT IT? BEING PREPARED FOR MEDICAL CRISES, ADVANCE DIRECTIVES, LIVING WILLS

Moderator: Lawrence Becker, PhD
Roanoke, Virginia
Allen Goldberg, MD, FRACP
Chicago, Illinois
Kristi Kirschner, MD
Rehabilitation Institute of Chicago, Chicago, Illinois

Salon E

EATING BETTER FOR BETTER HEALTH WITH YOUR FAMILY AND FRIENDS

Jann and John Hartman
Baltimore, Maryland

12:15 pm – 1:15 pm
Salon C and D
LUNCHEON *(ticket required)*

1:30 pm – 2:45 pm

SESSION III OPTIONS

Salon C

SOLUTIONS FOR OVERUSE AND DISUSE WEAKNESS

Moderator: Glee Helms, RN, NP
Novato, California
Frans Nollet, MD, PhD
Rehabilitation Medicine
University of Amsterdam, Netherlands
Tracie Harrison, PhD, RN, MSN, FNP
University of Texas, Austin, Texas

Salon B

ANALYZING YOUR SLEEP

Moderator: Bill Stothers
San Diego, California

Is It Apnea, Hypoventilation ... or Both ... or Something Else?

Augusta Alba, MD
Rehabilitation Medicine
Coler Goldwater Speciality Hospital and Nursing Facility, Roosevelt Island, New York
Oscar Schwartz, MD, FCCP, FAASM
Advantage Pulmonary & Sleep Medicine
Saint Louis, Missouri

Sleep Hygiene

William DeMayo, MD
John P. Murtha Neuroscience & Pain Institute, Conemaugh Health System, Johnstown, Pennsylvania

Salon D

SPINAL BRACING & NEW TECHNOLOGY IN LOWER EXTREMITY ORTHOTICS

Mark Taylor, MLS, CPO
University of Michigan, Ann Arbor, Michigan
Reactor: Alberto Esquenazi, MD
Gait & Motion Analysis Lab, Moss Rehabilitation Hospital, Philadelphia, Pennsylvania

Salon F/G

SUMMARIES OF SELECT THERAPIES: YOGA, WATSU, REIKI, MYOFASCIAL RELEASE

David Riley, MD
Editor-in-Chief, *Explore: The Journal of Science and Healing,* Santa Fe, New Mexico
Barbara Duryea, RN
John P. Murtha Neuroscience & Pain Institute, Conemaugh Health System, Johnstown, Pennsylvania
Kathleen Christ, LMT, NCMBT
Saint Louis Aquatic Healing Center, Saint Louis, Missouri
Stephanie Machell, PsyD
International Rehabilitation Center for Polio, Framingham, Massachusetts
Nancy Caverly, OTR/L
Bland, Missouri

Salon A

EXPLORING STRATEGIES: QIGONG AND ACUPUNCTURE

Charles Dumont, MD
Associate Director, Integrative Medicine, Loyola University Health Systems, Maywood, Illinois

Sue Harris, LicAc
Whole Person Health, Canton, Massachusetts

Salon E

PHI'S WEBSITE: WHAT IT CAN DO FOR YOU AND WHAT YOU CAN DO FOR IT

Sheryl Rudy
Webmaster, Post-Polio Health International, Saint Louis, Missouri

2:45 pm – 3:15 pm
BREAK

3:15 pm – 4:30 pm

SESSION IV OPTIONS

Salon D

PAIN AND POLIO: PITFALLS, MYTHS AND REALITIES

Moderator: Selma Calmes, MD
Olive View-UCLA Medical Center, Sylmar, California

Julian Lo, MD, FRCPC
Physical Medicine & Rehabilitation, West Park Healthcare Centre, Toronto, Canada

Salon F/G

FINDING TECHNOLOGY TO MAINTAIN INDEPENDENCE

David Gray, PhD
Program in Occupational Therapy, Washington University School of Medicine, Saint Louis, Missouri

Laura Ryan, OTR/L

Kristeen Muldoon, MSPT
International Rehabilitation Center for Polio, Framingham, Massachusetts

Salon C

HOW SELF ASSESSMENT CAN HELP YOU IN OBTAINING BETTER CARE FROM HEALTH PROFESSIONALS

Mary Kinane, BA, PGCE

Hilary Hallam

Denise Carlyle, BA, MA, PhD, LRAM
Lincolnshire Post-Polio Network, Lincolnshire, United Kingdom

Reactor: Carol Vandenakker, MD
Physical Medicine & Rehabilitation, University of California Davis Medical Center

Salon E

PHI SECOND RESEARCH AWARD: WOMEN WITH POLIO AND THE MENOPAUSE STUDY-PRACTICAL ADVICE BEHIND THE DATA

Claire Kalpakjian, PhD

Sunny Roller, MA
University of Michigan, Ann Arbor, Michigan

Salon B

MAINTAINING PULMONARY HEALTH

Monitoring and Preventing: What You Can Do

Diana Guth, RRT
Home Respiratory Care, Los Angeles, California

Betsy Thomason, RRT
Millennium Respiratory Services, Whippany, New Jersey

The Importance of Cough

Augusta Alba, MD
Rehabilitation Medicine (retired)
Coler Goldwater Specialty Hospital and Nursing Facility, Roosevelt Island, New York

Salon A

PEDORTHIC SOLUTIONS

Improving Balance and Stamina via Pedorthic Solutions

Edith James, C.Ped.
Comfort Shoe Specialists, Saint Louis, Missouri

Pedorthic Management of Post-Polio Using Baby Steps

Dennis Janisse, C.Ped.
National Pedorthic Services, Inc., Milwaukee, Wisconsin

6:30 – 9:00 pm
POST-POLIO HEALTH INTERNATIONAL AND INTERNATIONAL VENTILATOR USERS NETWORK'S AWARDS DINNER & ENTERTAINMENT
Sponsored by Respironics, Inc.
(www.respironics.com)

6:00 – 6:20 pm: Cash Bar in East Foyer
6:20 – 7:30 pm: Cash Bar and Dinner *(ticket required)* in Salon C and D
7:30 – 8:00 pm: Presentation of Awards (open to all registered participants)
8:00 – 9:00 pm: Entertainment (open to all registered participants)

Join us for an evening of celebration, great food and good fun as we take a break from our "work" to acknowledge the contributions of those who have supported the mission of PHI and IVUN with extraordinary service in education, advocacy, networking and research.

Featuring performers from *everydaycircus*, this evening's entertainment will come to us direct from Saint Louis' unique City Museum (www.citymuseum.org).

SESSION I OPTIONS

9:00 am – 10:15 am

◆

ASSISTANCE FROM ALLIED HEALTH PROFESSIONALS: Falling – Fear, Risks and Practical Strategies

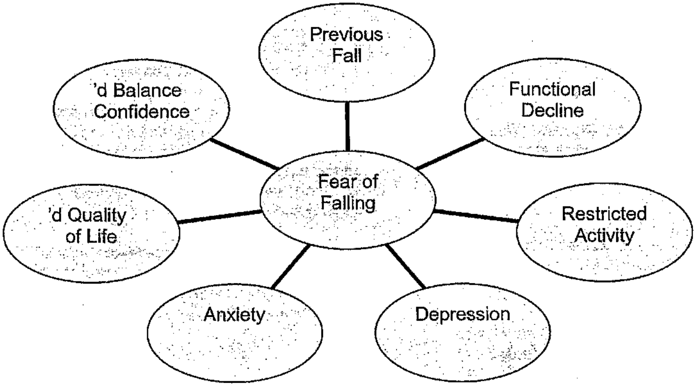
Kristine Legters, PT, DSc, NCS
Erie, Pennsylvania

What are YOUR risk factors for falling?

- Confused mental state ☐
- Visual impairment ☐
- *Decreased leg strength ☐
- Use of assistive device ☐
- Environmental hazards ☐
- Urinary incontinence ☐
- Dizziness ☐
- Decreased leg coordination ☐
- Low activity level ☐
- Use of psychotropic meds ☐
- *Balance difficulties ☐
- Decreased sensation in feet ☐
- Use of multiple medications ☐
- Alcohol consumption ☐
- BP s when standing ☐
- Cardiac medications ☐
- Abnormal walking pattern ☐
- Depression ☐

* Risk factors of falling that have been investigated in those with Post-Polio Syndrome

Fear of Falling (FOF) in Older Adults – How is it different in those with PPS?



The factors that contribute to FOF in older adults are multi-factorial. The prevalence of FOF in those with PPS *far exceeds* that of the community dwelling older adult. Those with PPS report FOF when they are *tired*, when they are *outside* and when they are *weak*. *Falls* in those with PPS are most frequent while *walking*, when *outside* and often involve an *environmental hazard*.

Strategies to Reduce Your Risk of Falling and FOF

Determine your risk for falls – Knowledge is power! Make *CHANGES* to your identified risk areas ....there are many factors that are *within your control* to change.

Assess your home environment – improve lighting, get rid of clutter, use nightlights, use handrails, non-skid surface on steps or reflective marking on steps, store frequently used items within easy reach, grab bars in the bathroom, shower seat, NO throw rugs or electrical cords in your path, proper height of beds and chairs, clear outdoor walkways, repair uneven walkways, use cordless phones

Assess yourself – feet and toes pain-free, shoe-wear that fits and is flat, low, wide heel with non-skid soles, clothing that doesn't drag, no sock feet for walking, annual hearing and visual evaluation, discuss your medications with your physician especially if you are on more than 4 medications or if they make you dizzy or lightheaded; attention to unstable/low BP; reduce frequent trips to the bathroom in the middle of the night

Know yourself and your PPS – know and pay attention to your body's signals – pain, fatigue, time of day, level of activity for that day or the day before – only do "risky" tasks at times when you are at your best

Be as active as you can be (given your PPS) – if you can exercise your feet and legs, do so. They are the key to good balance!

Take your time – you need to move at speeds that are consistent with your energy and ability! Rushing to the phone is not worth a fall!

Pay attention to changes in your health – don't assume that every change is a result of PPS. Discuss these changes with your physician!

Seek expertise and education – there are (likely) professionals in your area that can assist you with appropriate exercises to improve your balance, proper fitting of orthotics and assistive devices, a home assessment for your improved safety, how to get up from a fall, new adaptive equipment for the home and additional information on preventing falls within the home; TALK about your FEAR of FALLING

Other things – consider a personal alarm, hip protectors

References:

Legters K, Verbus N, Kitchen S, Tomecsko J, Urban N. Fear of falling, balance confidence and health related quality of life in individuals with post polio syndrome. *Physiotherapy Theory and Practice* (anticipated press release June 2006)

Hill KD, Stinson AT. A pilot study of falls, fear of falling, activity levels and fall preventions actions in older people with polio. *Aging Clinical and Experimental Research.* 2004;16:126-131.

Lord SR, Allen GM, Williams P, Gandevia SC. Risk of falling: Predictors based on reduced strength in persons previously affected by polio. *Archives of Physical Medicine and Rehabilitation.* 2002;83:757-763.

Silver JK, Aiello DD. Polio survivors: Falls and subsequent injuries. *American Journal of Physical Medicine and Rehabilitation.* 2002;81:567-570.

Kristine Legters, PT, DSc, NCS
Gannon University
Erie, Pennsylvania
Legters001@gannon.edu, 814-871-5641

◆

ASSISTANCE FROM ALLIED HEALTH PROFESSIONALS:
What OTs and PTs Can (and Can't) Do for Polio Survivors

Kristeen Muldoon, MSPT
Laura Ryan, OTR/L
Framingham, Massachusetts

Rehabilitation of PPS

- Full medical evaluation by physiatrist to r/o causes of new weakness and identify other neurological, orthopedic or medical causes
- Occupational and Physical Therapy Evaluation
- Brace Clinic
- Wheelchair/Scooter Clinic
- Speech Therapy
- Psychological Support
- Nutritional Support

Medical Work-up

- Blood work (CPK, TSH, Anemia)
- MRI
- Sleep Study
- EMG/NCS
- PFT

Treatment of PPS

- Management of weakness of upper and lower limbs
- Determine appropriate strengthening of upper and lower limbs
- Improve mobility
- Improve safety awareness
- Decrease pain/manage pain
- Evaluate appropriate assistive devices and equipment
- Management of pain

Physical Therapy and PPS

- Evaluate LE, trunk and neck status
- Evaluate assistive devices
- Evaluate bracing needs
- Evaluate wheelchair/scooter needs
- Evaluate pain
- Evaluate gait
- Evaluate sleep habits

What Physical Therapy can do for the Polio Survivor

- Gait training with appropriate assistive device
- Appropriate trunk and LE bracing
- LE strength and ROM exercises (non-fatiguing)
- Appropriate cardiovascular program
- Pain management
- Prescribe appropriate wheelchair or scooter
- Sleep hygiene
- Management of cold intolerance

Case Study

Occupational Therapy and PPS

- Evaluate past/current functional status, roles and occupations
- Evaluate UE status including muscle and nerve damage
- Evaluate level of understanding of PPS
- Evaluate pain
- Evaluate psychosocial skills

What Occupational Therapy Can Do For the Polio Survivor

- Lifestyle Modification/Home Modification
- Joint/Nerve Protection Techniques
- Falls Prevention
- Appropriate UE Exercises/cardiovascular exercise

Occupational Therapy for PPS

- Orthoses for upper extremity
- Driving Adaptations
- Ergonomic Assessment/Assistive Technology
- Coping and Adaptation

Case Study

References

Burger H, Marinecek C: The influence of post-polio syndrome on independence and life satisfaction. Disabil Rehabil 22:318-322, 2000

Halstead LS: *Managing Post-Polio: A Guide to Living Well with Post-Polio Syndrome.* Washington, DC, NRH Press, 1998

Jubelt B, Agre JC: Characteristic and management of post polio syndrome. *JAMA* 284:412-414, 2000.

Silver JK, Aiello DD: Postpolio syndrome. In Frontera WR, Silver JK (eds): *Essentials of Physical Medicine and Rehabilitation.* Philadelphia, Hanley & Belfus, 2001, pp678-686

Silver JK, Aiello DD: What internists need to know about postpolio syndrome. *Cleveland Clinical J Med* 69:704-712, 2001

Silver JK, Gawne AC: *Postpolio Syndrome.* Philadelphia, Hanley & Belfus, 2004

Kristeen Muldoon, MSPT
Laura Ryan, OTR/L
International Rehabilitation Center for Polio
Framingham, Massachusetts
www.polioclinic.org

◆◆

COMPUTERS AND THE INTERNET:
The NCPAD Website: A Friend to Polio Survivors

Sunny Roller, MA
Cheeri Ong, MSEd

What Is the Internet?

Also known as the "Net"
A current-day public and global computer network or "information super-highway"
Commonly supports services such as email, the World Wide Web, file transfer, and Internet Relay Chat

Net Speak:
A Glossary of Internet Terms

Browser – this is the program on your computer that enables you to access the Internet. The most well known are Microsoft's Internet Explorer (IE) and Netscape (NS).

Directory – sites such as Yahoo or the Open Directory that compile a subjective guide to Web sites according to category.

Domain name – the means of locating an entity on the Internet. For example, the domain name for this site is www.ncpad.org.

ISP - An Internet Service Provider is a business which provides connectivity to the Internet. It provides you with the ability to send and receive Internet e-mail, browse the World Wide Web and download files from Internet servers.

Search engines - sites such as Google or Altavista that use "robots" to scour the Internet. They then index the content of Web sites and enable visitors to find them via keywords.

URL - Uniform Resource Locators. In simple terms this is your site's address, the name or numbers that appear in the address window of your browser. For example, the URL for the home page of NCPAD is: http://www.ncpad.org

Resources on the Net

E-Mail
Mailing Lists
Newsgroups
The Worldwide Web

E-MAIL: *You've Got Mail!*

A method of composing, sending, and receiving messages over electronic communication systems.
Most e-mail systems today use the Internet, and e-mail is one of the most popular uses of the Internet
Each user has a distinct address: *yourname@ISP.com*
For example: janedoe@yahoo.com

Mailing Lists & Listservs

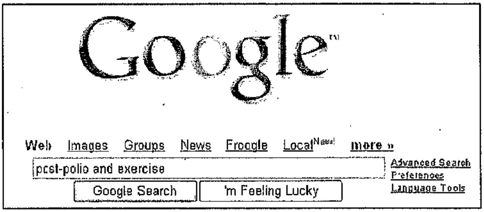
A mailing list is a collection of names and addresses used by an individual or an organization to send material to multiple recipients. The term is often extended to include the people subscribed to such a list, so the group of subscribers are referred to as "the mailing list", "listserv" or simply "the list".
Mailing List for Individuals with Post-Polio Syndrome:
Post-Polio-Med@maelstrom.stjohns.edu
Website address: http://skally.net/ppmed/

The World Wide Web: Surfing the Net
Web sites are designated by an address called a Uniform Resource Locator (URL)
Governmental Web sites: URL -<u>http://www.whitehouse.gov/</u>
Educational Web sites: URL - <u>www.uic.edu</u>
Organizational Web Sites: URL - <u>www.ncpad.org</u>
Commercial Web sites: URL - <u>www.amazon.com</u>

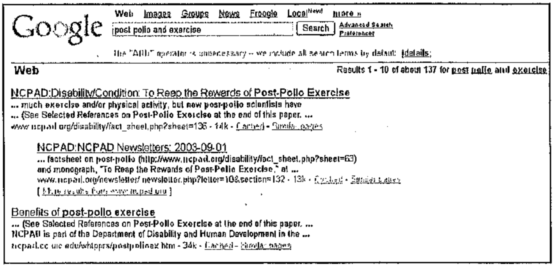
Searching for Information:

Search Engines & Directories
Computer programs/ WebPages that assist users in locating information on the Web. Some of the most popular include **Google**,Yahoo, Altavista, HotBot, Excite, and Infoseek.

Sample Google Search Result



post-polio and exercise



post polio and exercise

The "AND" operator is unnecessary -- we include all search terms by default. [details]

Web Results 1 - 10 of about 137 for post polio and exercise

NCPAD:Disability/Condition: To Reap the Rewards of Post-Polio Exercise
... much exercise and/or physical activity, but now post-polio scientists have
... (See Selected References on Post-Polio Exercise at the end of this paper. ...
www.ncpad.org/disability/fact_sheet.php?sheet=136 - 14k - Cached - Similar pages

NCPAD:NCPAD Newsletters: 2003-09-01
... factsheet on post-polio (http://www.ncpad.org/disability/fact_sheet.php?sheet=63)
and monograph, "To Reap the Rewards of Post-Polio Exercise," at ...
www.ncpad.org/newsletter/ newsletter.php?letter=10&section=132 - 13k - Cached - Similar pages
[More results from www.ncpad.org]

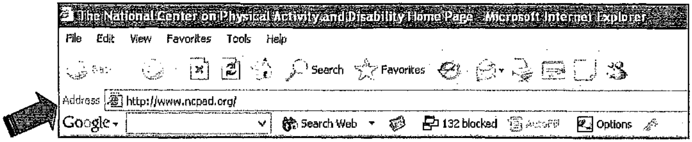
Benefits of post-polio exercise
... (See Selected References on Post-Polio Exercise at the end of this paper. ...
NCPAD is part of the Department of Disability and Human Development in the ...
ncpad.cc.uic.edu/whtpprs/postpolioex.htm - 34k - Cached - Similar pages

For Your Protection
DO NOT give out personal information or identification (address, telephone number) to any UNKNOWN or UNSECURE websites, listservs or e-mails.

The National Center on Physical Activity and Disability (NCPAD)
NCPAD's mission is to encourage and support people with disabilities who wish to increase their overall level of physical activity and fitness and participate in all types of physical activity.

What is NCPAD?
<u>A resource and information center</u> on physical activity and disability, with *thousands* of references on the subject.
<u>A health promotion center</u> encouraging and supporting healthy lifestyles for people with disabilities.
A <u>research and training center</u> promoting further research on the benefits of physical activity and guiding best practice in the field.

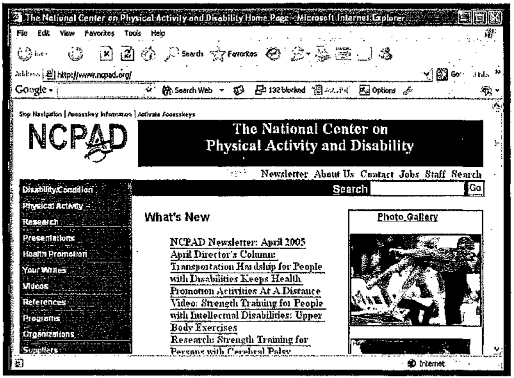
How to Get to NCPAD



Address http://www.ncpad.org/

Type www.ncpad.org on the Address bar

Welcome to NCPAD.org



Address http://www.ncpad.org/

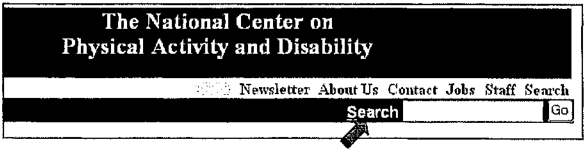
The National Center on Physical Activity and Disability

What's New

NCPAD Newsletter: April 2005
April Director's Column:
Transportation Hardship for People with Disabilities Keeps Health Promotion Activities At A Distance
Video: Strength Training for People with Intellectual Disabilities: Upper Body Exercises
Research: Strength Training for Persons with Cerebral Palsy

Where to Find Information

General Search Box – lets you search any page on the NCPAD web site that has the keywords that you type in mentioned.



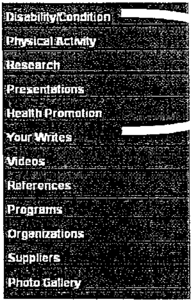
The National Center on Physical Activity and Disability

NCPAD Resources

FACT SHEETS providing brief, focused information summaries on:
Recreation and Leisure Activities
Exercise and Fitness Activities
Games and Sports
Specific Disabilities and Conditions
Information on how to make recreation and leisure environments accessible for people with disabilities.

The **NCPAD monograph** series of commissioned works providing detailed examination of important topic areas in disability and physical activity.

Searching for Factsheets and Other Online Articles



- Go to www.ncpad.org
- Refer to the RED COLUMN on the left side of the computer screen
- These are the different categories from which our online articles are organized

Exercise Examples:
Searching for Minute-Videoclips

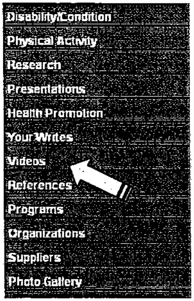
Go to www.ncpad.org

Refer to the RED COLUMN on the left side of the computer screen

Click on **Videos**

Select from the list of topics

Click on the picture or the available link to view the videoclip



Exercise Examples:
Searching for Minute-Videoclips

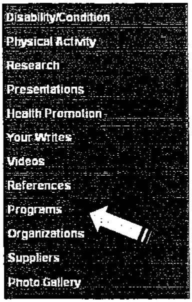
Exercise for People with Multiple Sclerosis - Series I
Exercise for People with Multiple Sclerosis - Series II
Exercise Program for Individuals with Spinal Cord Injuries: Paraplegia - Video & Quick Series Booklet
Golf
Making A Splash: Inclusion of People with Disabilities in Aquatic Venues
Seated Strengthening Exercises
Seated Stretching
Skiing
Sled Hockey
Strength Training Video for People with Intellectual Disabilities: Upper Body Exercises
Strength Training Video for People with Intellectual Disabilities: Warm-Up Stretching
Therapeutic Riding for Children with Disabilities
Water Skiing

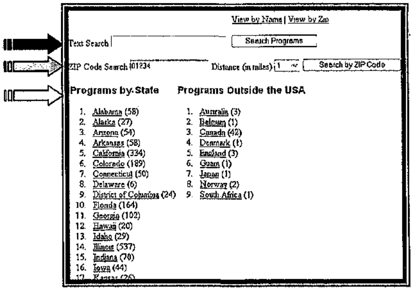
Searchable Databases

Facilities and programs offering recreation, leisure, and fitness activities for people with disabilities;
Manufacturers and vendors of adapted equipment for recreation, sport and leisure time activities;
Conferences and Meetings that feature information on physical activity and disability;
Citations for published and unpublished books, monographs, manuals, etc. on topics related to physical activity and disability.

Finding Physical Activity and Recreation Programs In Your Area

Go to www.ncpad.org
Refer to the RED COLUMN on the left side of the computer screen
Click on **Programs**





ZIP Code Search 01234 Distance (in miles) 1

Programs by State

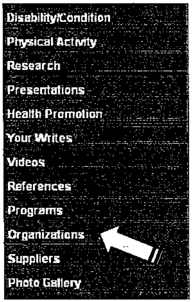
1. Alabama (58)
2. Alaska (27)
3. Arizona (54)
4. Arkansas (58)
5. California (334)
6. Colorado (189)
7. Connecticut (50)
8. Delaware (6)
9. District of Columbia (24)
10. Florida (164)
11. Georgia (102)
12. Hawaii (20)
13. Idaho (29)
14. Illinois (537)
15. Indiana (70)
16. Iowa (44)
17. Kansas (26)

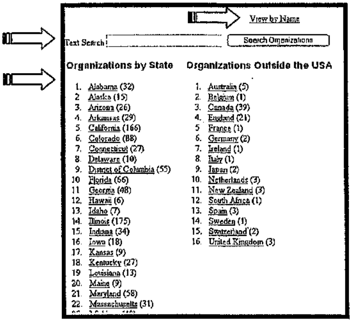
Programs Outside the USA

1. Australia (3)
2. Belgium (1)
3. Canada (42)
4. Denmark (1)
5. England (3)
6. Guam (1)
7. Japan (1)
8. Norway (2)
9. South Africa (1)

Finding Physical Activity and Recreation Organizations In Your Area

Go to www.ncpad.org
Refer to the RED COLUMN on the left side of the computer screen
Click on **Organizations**





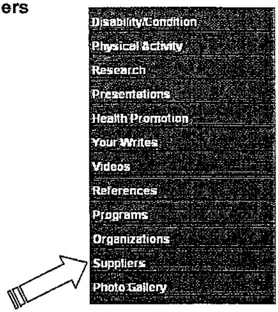
Organizations by State

1. Alabama (32)
2. Alaska (15)
3. Arizona (26)
4. Arkansas (29)
5. California (166)
6. Colorado (88)
7. Connecticut (27)
8. Delaware (10)
9. District of Columbia (55)
10. Florida (66)
11. Georgia (48)
12. Hawaii (6)
13. Idaho (7)
14. Illinois (175)
15. Indiana (34)
16. Iowa (18)
17. Kansas (9)
18. Kentucky (27)
19. Louisiana (13)
20. Maine (9)
21. Maryland (58)
22. Massachusetts (31)

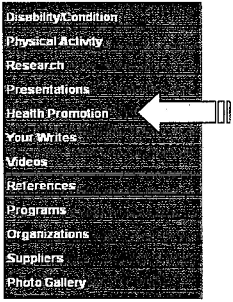
Organizations Outside the USA

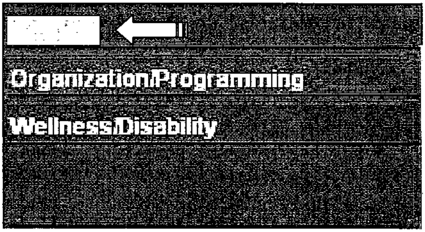
1. Australia (5)
2. Belgium (1)
3. Canada (39)
4. England (21)
5. France (1)
6. Germany (2)
7. Ireland (1)
8. Italy (1)
9. Japan (2)
10. Netherlands (3)
11. New Zealand (3)
12. South Africa (1)
13. Spain (3)
14. Sweden (1)
15. Switzerland (2)
16. United Kingdom (3)

Equipment & Equipment Vendors' Database
Go to www.ncpad.org
Refer to the RED COLUMN on the left side of the computer screen
Click on **Suppliers**



Nutrition Section
Go to www.ncpad.org
Refer to the RED COLUMN on the left side of the computer screen
Click on Health Promotion
Then click on Nutrition





Personalized Attention
Friendly, highly trained information specialists are available by a toll-free telephone, TTY, e-mail, or fax to provide personalized responses to your questions.
Toll-free phone: 1-800-900-8086
E-mail to: ncpad@uic.edu
Fax: 312-355-4058

Contribute to NCPAD
NCPAD encourages writers to contribute their experiences and expertise (on physical activity/ recreation/ exercise and disability/ chronic health conditions) to the NCPAD website.

For more information, please contact Cheeri Ong at
cheeri@uic.edu or 800-900-8086.

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PLANNING AHEAD TO STAY IN YOUR HOME WHEN GETTING OLDER:

Stephanie Malench, MSW, LCSW
Saint Louis, Missouri

Continuum of Care - Levels of Care for the Older or Disabled Adult, Including Community Resources

When someone can no longer live in their own home alone any longer, or just wishes to live closer to people his or her own age, and be part of a community, he or she and their family have many choices.

Although many people may initially think of a nursing home (now called skilled nursing facilities or nursing and rehabilitation centers) as the next step, there are many alternatives in the community which are less restrictive.

These choices include:
- Senior apartment buildings
- Retirement communities
- Assisted living facilities
- Residential care facilities

The above will be referred to in this presentation as group living environments when the reference is to more than one level.

The purpose of this presentation is to explain to you the differences so that if you ever have to make a decision about moving yourself or a loved one, you have the information to make a calm, rational decision.

Framework

As we go through the different types of facilities and what to look for at each level, you may raise your hand to share your experiences in visiting different types of facilities.

You may also feel free to ask questions at any time. (Would it be better to hand out cards to jot down questions?)

Activity (25 minutes + sharing time)

In groups of 2 or 3, make a list of what you consider to be the five most important qualities to look for in a group living environment.

Select a representative to share your list with the larger group.

Senior Apartment Buildings

Like apartment buildings for the general public, senior apartments can be individual buildings or a complex, low-rise or high-rise.

Senior apartments may also be part of a larger senior community, which includes one or more of the following:
- Assisted Living
- Residential Care
- Skilled Nursing

Facilities or campuses that contain more than one level of care are called continuing care communities or progressive care facilities.

Some senior apartment buildings have a sliding fee scale for those who are low-income.

Others may also take residents under the age of 65 who are disabled.

Retirement Communities

Similar to senior apartment buildings, with additional services for a fee.
Services vary, but usually include one or two meals, transportation, and activities.
Retirement communities may also be part of a larger community with assisted living, residential care or skilled nursing care.

Assisted Living Facilities

Apartment style accommodations for those needing minimal assistance with medications, bathing, and dressing.
Meals, laundry, and housekeeping are provided.

Residential Care Facilities

Licensed by the Missouri Department of Health and Senior Services to provide assistance with medications, bathing and dressing.
Resident must be able to find a pathway to safety and exit independently.

Shopping with the Five Senses

Now that you know the differences between different levels of care, here are some general guidelines when shopping for any type of new residence, from a senior apartment to a skilled nursing facility.

- Eye Scan
- During your tour of the potential group living environment, notice if the building or unit is clean, uncluttered, and in good repair.
- Is it wheelchair accessible (if needed)?
- Is staffing visible?
- Smell
- Are there any strong urine, disinfectant, or deodorizer smells?
- How does the building smell during meal times (if meals are provided)?
- Sound
- How frequently do call buttons go off?
- How does staff talk to each other?
- Is the intercom used frequently?
- Taste
- If a complementary meal is provided with the tour, did it taste homemade, or commercially mass produced?
- Touch
- Are there positive interactions between staff and residents, between staff, and between residents (i.e. hugs, pats on the back)?

IX. Questions/Comments

Helpful Websites

www.ssa.gov- Social Security

www.dhss.state.mo.us/Senior_Services- Guide for seniors to compare long-term care facilities. Includes information from state surveys

www.mcqc.com- Missouri Coalition for Quality of Care- Guide for seniors to compare long-term care facilities. Includes information from state surveys

www.memberofthefamily.net- nursing home watch list organized by state www.seniorsworldnetwork.us- Of particular usefulness are the headings Senior Advisors, U.S. Government Links, and Seniors Internet

www.NewLifestyles.com- Order directory of senior residences in select cities and other information

www.aoa.dhhs.gov- Administration on Aging website- resources for older adults and professionals

www.retirementhousingonline.com- information on different levels of senior living

www.nimh.nih.org- news, information, meeting and clinical trial information for all mental health issues, including depression, anxiety, and eating disorders

www.mid-eastaaa.org/bthrough.html- membership group of St. Louis area agencies and individuals interested in older adult issues; links to resources in St. Louis area and national on all issues related to older adults such as driving, home modifications, Medicaid, etc.

Contact Stephanie for a copy of the Home Safety Checklist and the Caregiver Checklist.

Stephanie Malench, MSW, LCSW
Full Living Services, St. Louis MO
(314) 952-7525
www.fulllivingservices.com

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WHAT ABOUT NUTRACEUTICALS?

R. Charles Dumont, MD
Maywood, Illinois

Nutraceuticals, a definition: "Foodstuff (taken orally) that is held to provide health or medical benefits in addition to its basic nutritional value." Many books and writings include other natural products (herbs, etc.) and natural product extracts in the category of nutraceuticals.

Vitamins and Supplements: Approach carefully

"Consumers are, in effect, volunteering for a vast largely unregulated experiment with substances that may be helpful, harmful or simply ineffective."
Jane Brody on the use of vitamins and supplements- *New York Times*, October 26, 1997

Belief system: Some medical disorders/symptoms may be a result or cause of vitamin, mineral or other nutritional deficiency
    Deficiency may be between conventional ranges of deficiency and toxicity
    There is unrecognized great variability in individual needs
    There is a recognized difference between "sufficient" and optimal doses
    In some instances "megadoses" of vitamins/minerals/supplements may be required.
A new and so one of the most unexplored and confusing area of medicine
We do not fully understand the chronic long term use of large doses of vitamins and supplements which may potentially be harmful if given in large doses, particularly over long periods of time, each supplement must be evaluated on its own merit.
Consider cumulative and interactive effect if several supplements are taken at once
Consider potential interactions with other endogenous vitamins/minerals, and medications
There may be potential benefit as well - in many instances we just don't know

Myths of Herbal Medicines: Herbal medicines are natural and therefore perfectly safe and better than synthetic medicines. All preparations are the same. Wild-crafted herbs are more natural and therefore better.

Facts of Herbal Medicines: Herbal medicines are pharmaceuticals; they may contain (often multiple) active agents and may have side effects/drug interactions. Herbal medicines are poorly regulated in this country – preparations can vary. Wild-crafted herbs can be potentially harmful (and not good for the ecology).

Chinese Medical Herbs: Chinese Medicine is not Western Medicine. Multiple are combined and balanced. Proper use requires the expertise of a trained practitioner.
Use (and diagnosis) is based on Chinese medicine pathophysiology.

Choosing Alternative Approaches Attitude:

- Zen mind
    - Non-judgmental
    - Open (empty) mind
    - Do not bring in pre-conceived concepts
- This is a diverse group of medical systems and therapeutic approaches
    - Each approach must be judged on its on merit
    - Consider each approach regarding:
        - Safety
        - Effectiveness
        - Cost (financial, time, life style change)
- (If needed) Find a trusted credentialed (CAM) practitioner
- Set goals
    - Trial: How much, how long
    - Outcome measures
- Safety is based on:
    - Clinical studies
    - Mechanism of the alternative approach
    - Dose and length of treatment
- Effectiveness is based on:
    - Clinical studies
        - No. and quality of studies
        - Mechanism of the alternative approach
        - Dose and length of treatment
    - Historical data
    - Antidotal data

Resources:

Blumenthal M. et. al. *Herbal Medicine: Expanded Commission E Monographs* Austin TX: American Botanical Council, 1999.
Blumenthal M. et. al. *The Complete German Commission E Monographs: Therapeutic Guide to Herbal Medications.* Austin TX: American Botanical Council, Boston: Integrative Medicine Communications, 1998.
Duke J. *The Green Pharmacy.* Emmaus, PA: Rodale Press, 1997.
Foster S and Tyler V. *Tyler's Honest Herbal* Binghamton, NY: Haworth Press, 1999.
Robbers J and Tyler V. *Tyler's Herbs of Choice: The Therapeutic Use of Phytomedicine*, Binghamton, NY: Haworth Press,1999.
Roberts A, et. al. *Nutraceuticals: The Complete Encyclopedia of Supplements, Herbs, Vitamins, and Healing Foods* New York, NY: Perigee, 2001.
Murray M. *Encyclopedia of Nutritional Supplements* Rocklin CA, 1996.
Ulbricht C and Basch E. *National Standard: Herb and Supplement Reference* St Louis, MO: Elsevier/Mosby, 2005.

R. Charles Dumont, MD
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INTIMACY AND SEXUALITY: MIND, BODY AND HEART CONNECTIONS

Linda Bieniek, CEAP, La Grange, Illinois
Hannah Hedrick, PhD, Mountain View, Hawaii

"What's Love Got To Do With It?"

Intimacy and sexuality are about "Emotional Connections" and LOVE: How we show love to our Selves and how do we express caring and "safe love" to others. "Safe love" includes being able to express our vulnerabilities and being compassionate about the vulnerabilities of others.

Mind, Body, and Heart Connections: Past to Present

- Our bodies carry our physical, emotional, psychological, sexual, medical, and spiritual wounds.
- We tend to repeat patterns related to our unresolved wounds from our past until we heal them. Hendrix, H. (1988). *Getting the Love You Want.*
- Acknowledging, accepting, and healing our wounds will enhance our capacity for intimacy and sexuality. Jung said it is the greatest legacy we can leave for our children, grandchildren, and loved ones.
- Behaviors that are harmful or hurtful (e.g., addictions, isolating) each have a positive intent (e.g., protection, comfort).
- When we WANT to resolve our feelings, moving INTO them and responding to our underlying emotional needs is the way OUT OF THEM.
- Facing our Selves with deep compassion, the curiosity of a benevolent private detective, and gentleness is crucial for healing any relationship – with our Selves or others.
- Seeking assistance from an ethical, enormously skilled, and vastly experienced professional who uses effective, holistic treatment approaches is extremely useful when we want to heal from our pasts.

Why Are Intimacy and Sexuality Important?

Because these experiences …

- Inspire and energize us.
- Bring the most joy, value, and meaning to our lives.
- Impact our health and healing.
- Offer us nourishing connections, community, and sacredness.

REFERENCES: Ornish, D. (1988) *Love and Survival.* Schwartz, R. (2001) *Introduction to the Internal Family Systems Model.* and (1995) *Internal Family Systems Therapy.* Viorst, J. (1986). "Lessons in Love" in *Necessary Losses.* Welwood, J. (1985) *Challenges of the Heart.*

What Is Blocking Our Connections?

Most barriers to intimacy stem from issues that are deeply rooted in **fear**. These barriers typically relate to our needs for safety and protection, acceptance, connections, self-esteem, comfort, validation, expression, and individuation. This means that problematic behaviors that pose intimacy barriers are based on positive intentions. Discovering our true emotional needs empowers us to take steps that will transform behaviors that previously, but no longer, serve useful purposes.

Some Background: Since the time we were infants, we learned ways to protect ourselves. We survived difficulties, even traumas. Our creative intelligence enabled us to adapt to situations that were out of our control. Now, however, many of our protective strategies no longer fulfill our present needs.

For example, a man grew up with a father who was addicted to alcohol, witnessed extreme emotional volatility. As a child, he learned that it was not safe to express feelings. As an adult, he continued having difficulties expressing and responding to feelings. Recognizing the effects of his childhood experiences will help this man resolve his feelings of fear and shame. When we work through feelings, we can free our ability to express our Selves. This process of exploration is not intended to blame people in our pasts, but rather to gain our ability to live more fully.

Also, until we resolve our underlying barriers to intimacy, we are likely to repeat relationship patterns and experience further disappointments and distress. Awareness and acceptance empowers us to pursue safe, private, and therapeutically effective approaches that can free our energy for relationships we long for.

Past Experiences Have Left Their Imprints ...

- Lacking healthy human attachments: support and validation of the developing Selves.
- Being separated from our caretaker during infancy or another critical stage of development.
- Lacking affirmation of our inner beauty and individuality.
- Experiencing or witnessing physical, emotional, psychological, sexual, medical, or spiritual abuse or exploitation; or physical, emotional, or medical neglect.
- Lacking healthy role models who expressed feelings in safe and nurturing ways.
- Experiencing family or cultural attitudes that perceived physical limitations or illnesses as shameful, non-sexual, or as devaluing a person's worth.

REFERENCES:

Hendrix, H. (1988) Getting the Love You Want. Glaser, D. "Barriers to Intimacy." Masters and Johnson Seminar. New Orleans, LA. L. Elisabeth. (1987) *Listen to the Hunger*. Harper Rowe. Lieberman, A. (1987). *The Psychology of Separation and Loss*. Jossey-Bass Publishers.

Nosek, M. A. et al. (2001) National Study of Women with Physical Disabilities: Final Report. *Sexuality and Disability*. 19 (1). Olkin, R. (1999) *What Psychotherapists Should Know About Disability*. The Guilford Press.

Self-Protective Responses Speak of Our Needs ...

- Fearing abandonment, exposure (humiliation, shame), overwhelming expectations.
- Fearing conflict and an inability to manage feelings.
- Perceiving our Selves as undesirable, unlovable, a burden or inadequate.
- Suppressing physical tension, unresolved feelings, desires.
- Feeling a compulsion to numb feelings. Using alcohol, work, eating, sex, gambling, medications, drugs, or care-taking to block physical and emotional pain. These behaviors limit our ability to respond compassionately to our real underlying needs. They also block sexual sensations of pleasure.
- Fearing physical and emotional needs and dependencies including obtaining medical treatment for existing health problems.
- **Lacking spiritual nourishment: a sense of belonging, purpose in life, perception of having others to depend on and to give and receive love.**

A Research-Based Example: Westbrook, M. (1996). Disability as a life course: Implications of early experiences for later coping. *Polio Network News*, 12(3), 3-6.

Polio survivor Mary Westbrook, Ph.D., discovered a pattern between polio survivors who reported difficulty **asking for help** and their early polio experiences. She found a correlation between speaking up for our needs and separations from our parents/caretakers during critical stages of development. For various reasons, these experiences resulted in a belief that asking for help is unsafe. Such a belief is a major barrier in healthy relationships. Interdependence includes an inability to ask for assistance and express our emotional needs. Westbrook's findings offer an example of a past experience's effect present day behaviors and relationships.

Avenues for Connecting With Our Selves

AWARENESS is a first step: How do we express ourselves? How can any of the ideas listed below fulfill our needs?

MIND

Beliefs, knowledge, desires, values, goals
Analytical abilities, problem-solving skills, tolerance for differences, adaptability, flexibility
Expressiveness, communication skills, inquisitiveness, imaginations, cleverness, and creativity

BODY

Sensations: comfort, discomfort, energy, tightness, calmness, centered, pain level
Senses: feel, touch, see, hear, smell, taste, movement, expression, awareness
Mobility, muscular strength, functioning and activity level, sexuality, sexual activities

Emotions, emotional needs, compassion, open-heartedness, trust, responsiveness, acceptance
Understanding, affection, closeness, intimacy, sexuality, vulnerabilities, sensitivities

"Imagine" – The Power of Beliefs

Our BELIEFS influence what and how we react to our Selves and others. In our own body-felt experiences, what do we notice when we meet a person? Is this person someone I can comfortably relate to on several levels? Is this person someone I can safely express my vulnerabilities to? (Demos)

Our beliefs also affect how we behave, problem-solve, and the choices we make. If we desire intimacy and closeness, exploring the roots of our "limiting beliefs" can free us from their constraints. We've already learned about the role of early experiences on how we respond to present day situations. Now we can explore what, if any beliefs, are limiting our ability to pursue or strengthen the depth of our intimacy.

1. Do you believe it is **possible** for you to have the depth of intimacy you desire?
2. Do you believe you are **capable** of developing and nurturing a mutually satisfying intimate relationship?
3. Do you believe you **deserve** the quality of relationship that you want?

Dilts, R., et al. (1990) *Beliefs: Pathways to Health & Well-Being.* Portland, OR: Metamorphous Press.

Strategies for Strengthening our Connections

WITH OUR BODY

Breathe deeply, slowly, and fully to relax, get centered, and gain energy.
Nurture our bodies, protect our health: Sufficient rest, nutrition, relaxation, pleasure; exercise safely for our specific conditions, and obtain medical treatment, as needed.
Seek healthy touch: Hugs, massages, and ethical, competent bodywork.
Soak up sensual beauty: Nature, the arts, music, aesthetically inspiring symbols.

WITH OUR MIND

Develop a realistic sense of Self: Capabilities, strengths, talents, limits, vulnerabilities, needs. How we can take care of yourselves and what we can need and can offer to others.
Invest in Self-Development: Learn cutting-edge strategies for creating positive results. Explore resources. Consult competent, ethical professionals. Develop our intuition.
Identify relationship goals for expressing intimacy and healthy sexuality.
Set boundaries, limits: In relationships, activity levels, aspirations, commitments.

WITH OUR HEART

Gain awareness of feelings and work through resentments, anger, fears, hurts.
Respond compassionately and creatively to physical limitations, personal vulnerabilities. Seek support, validation, insights, resources, and professional assistance, as needed.
Seek and develop relationships that are energizing and supportive. Limit time and involvement with people who are negative, critical, or closed-minded.
Express gratitude for "what is" and the people who support us.

Strategies for Negotiating Fulfilling Relationships

"The better the relationship, the more loving and sexual the connection will be."

The last section offered ideas for connecting with our Selves. This portion lays a foundation for enhancing sexual intimacy with a trusted partner. As we age, and develop physical limitations, we may need to express our love and affection differently than in our pasts. Health changes and losses of familiar and treasured ways of making love may trigger grief, fear, shame, or anger. Resolving such feelings is important for releasing tension in our bodies, limiting beliefs, and our creative energy. We can find ways of expressing our sexuality without diminishing our identities as sexual beings and growing distant from each other. When we **want** to strengthen loving sexual connections, we may find the following strategies useful.

Assume Responsibility for Our Selves

- Assert feelings, desires, requests and needs in safe, appropriate environments.
- Approach changes with compassion, optimism, and curiosity.
- Focus on developing our own skills, personalities, knowledge, and creativity.
- Respect and keep commitments. Dependability builds trust.
- Delegate the work of caretaking/personal assistance to another person, preferably someone who is hired, if that is affordable. If not, negotiate mutual needs.

Communicate and Listen with Empathy

- Communicate openly, non-defensively, honestly, directly, and sensitively.
- Verbalize the changes and new realities. Choose times and places that are safe.
- Eliminate all barriers to speaking up and hearing the truth.
- Break the cycle of blame and criticism. It creates negative energy.
- Negotiate conflicts by accommodating and compromising with each other.
- Invest in couples counseling and learn "fair fighting" skills.

Extend Emotional Support

- Show interest in each other's feelings and thoughts. Accept differences.
- Express appreciation verbally and non-verbally.
- Affirm commitments and a willingness to work through relationship issues.
- Affirm each other's lovability, essence, strengths.
- Find ways of expressing affection, playfulness, and enjoyable physical contact.

Embrace Differences and Compatibilities

- Understand each other's needs and be willing to respond to them.
- Respect and support differences in interests, friendships, careers, etc.
- Create a unique "we" identity from shared experiences.
- Contribute to mutually shared goals and responsibilities.

Hendrick, G. and K. (2004) *Lasting Love: 5 Secrets of Growing a Vital, Conscious Relationship*. Klein, E. & Kroll, K. (1992) *Enabling Romance*. No Limits Pub. Schwartz, M. (2001) Intimacy Presentation.

Expressions of Our Sexuality

- *Sensuality:* awareness and expression of our body through our senses.
- *Intimacy*: our need and ability to experience emotional closeness with another human being—to give and receive support, nurturing, and trust.
- *Identity*: how we view ourselves as a sexual person; our interest in discovering who we are in terms of our sexuality, personality, and values.
- *Communication*: the ability to express our needs, desires, and boundaries; to understand other; and to clarify misunderstandings.
- *Sexual Esteem*: positive regard for and confidence in our capacity to experience our sexuality in satisfying and enjoyable ways.

Aspects of Sexuality contribute to our overall health when they are integrated and congruent--when what we do and say matches our values, identity, and sexual-esteem. Healthy touch can stimulate our circulation, self-esteem, mental alertness, and cardiovascular system. Studies show evidence that sexual activities can relax and energize us, enhancing longevity and our immune systems as well as reducing heart disease and pain levels. When sexual touching is caring and affectionate, it is more likely to be satisfying and fulfilling. And sexual expressions of deep love are often sacred experiences when we value spiritual connections. For more ideas: Bieniek, L. (2005) "Sexuality: What Works for Me" presentation at the Ninth International Post-Polio and Ventilator-Assisted Living. Holstein, L. (2001) *How To Have Magnificent SEX: 7 Dimensions of a Vital Sexual Connection.*

Breathing Energy, Love, and Sexuality

Schonhofer's research on individuals with Chronic Respiratory Failure (CRF) and the effects of using Non-Invasive Mechanical Ventilation (NMV) on their intercourse and masturbation patterns offers valuable findings.

Schonhofer B, et al. Sexuality in patients with noninvasive mechanical ventilation due to chronic respiratory failure. *Am JRespirCritCareMed.* 2001;164(9):1612-1617.

- Sexually active participants had a mean value of 5.4 episodes of intercourse per month; this is greater than in the general population without CRF of the same age. *These individuals may have sought NMV and considered it an asset for gaining the energy to continually being sexually active.*
- Two factors, PO2 at rest and exercise tolerance, resulted in reduced sexual activity. *The good news is that HMV may improve these factors for some individuals.*
- Four men used NMV during intercourse. *They illustrate the power of self-acceptance, creativity, and of choosing a relationship with an open-minded, accepting partner.*
- Individuals with partners were more sexually active while using NMV than single participants. *One of the many advantages of being in a good relationship.*
- To help in reaching climax, some participants adjusted their ventilator settings, using higher frequency and tidal volume during intercourse vs. their usual settings at rest.
  It is great to hear of such possibilities. At the same time, it is important for us to consult our health providers about the safety of such strategies and any other options for increasing our pleasure and satisfaction when making love!

Unconditional and Conditional Love

In closing, we can commend our Selves for our desire to learn more about intimacy and sexuality. Our interest in these subjects reflects our passions for living. Each day we make choices about nourishing our bodies, opening our minds to challenges, and opening our hearts to love. If these ideas have whetted your appetite, the books, treatment approaches, and professionals listed below may add to your desires for experiencing deeper meaning, joy, and fulfillment. John Welwood offers us poetic wisdom as we pursue the intimacy our hearts yearn for:

- Say **"YES"** to unconditional love for our Selves and our many different, and often conflicting, feelings, attitudes, and behaviors. Often referred to as "Parts" of our Selves, each has an underlying positive intention. In embracing the "YES" to unconditional love for our Selves, our challenges are to:
    - discover the underlying emotional needs of our diverse "Parts" of our Selves;
    - obtain kind, skillful assistance with deep experience in using strategies for transforming "Parts" that no longer serve useful purposes into sources of energy and fulfillment; and
    - seek ways of responding tenderly and courageously to our ongoing emotional needs as we experience health and lifestyle changes.

Welwood warns about confusing the meaning of unconditional love in saying:

- Don't put a conditional **"NO"** on the **"YES" of an open heart**. Welwood discourages us from closing down our open hearts towards a loved one because we feel hurt by or angry with the person.
- Don't impose a **"YES" of the heart** on the **"NO" of our personal needs for safety, integrity, and our highest values.** In other words, we can love a person unconditionally, and at the same time, we need to protect our Selves and our deepest values. We need boundaries to protect the safety and well-being of our Selves and our loved ones (e.g., situations such as an abusive relationship, setting limits with children).

Whatever health, relationship, or lifestyle changes we need to make, my hope is that these ideas will deepen our ability to enjoy expressing and receiving love through our bodies, minds, and hearts.

Welwood, J. (1985) "Unconditional Love" in *Challenge of the Heart.* For info on "Parts of our Selves" see Schwartz, R. (2001) Introduction to the Internal Family Systems Model and (1995) Internal Family Systems Therapy. Bieniek, L. (2005) "Emotional Eating" presentation at the Ninth International Conference on Post-Polio and Ventilator-Assisted Living. St. Louis, MO.

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Zukav, G. (2001). *The Heart of the Soul: Emotional Awareness.* NY, NY: Simon and Schuster.

TREATMENT APPROACHES, WORKSHOPS, TRAINING PROGRAMS, CONFERENCES, and PROFESSIONALS

Bieniek, L. (2003) Treatment Approach Options. *Polio Network News*, 19(1). 9-11.

Bieniek, L. (2005) Sexuality: What Works for Me and Emotional Eating presentations at the **Ninth International Conference on Post-Polio Health and Ventilator-Assisted Living.** St. Louis, MO.

Internal Family Systems Model: Center for Self Leadership, PC. P.O. Box 3969, Oak Park, IL 60303 (708) 383-2659. IFSCSL@aol.com, www.selfleadership.org. Richard Schwartz, PhD, Director.

Books, tapes, trainings, workshops, conferences, practitioners.

Relational Therapy and Sexual Trauma Programs:

New Orleans Institute http://www.riveroakshospital.com/newsite/programs.htm. Daniel Glaser, Director, 800.366.1740.

http://www.tworivershospital.com/services/mandj_general.htm

Energy Therapies: www.schoolforliving.org Judy Steele, MTP: Dynamind Practitioner, Tapas Acuppressure Technique (TAT), NLP (Neuro-Linguistic Programming), workshops, phone consultations. judy.steele@earthlink.net 612.590.3139. St. Louis Park, MN.

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CLARIFYING CHOICES:
Non-Invasive Ventilation for a Tracheostomized Post-Polio Patient without Intubation Tube

Grethe Nyholm, Head Nurse (RN) and Birgitte Brandt Lassen, RN
Lotte Mortensen, Matron (RN)
Copenhagen, Denmark

In this lecture we will describe the course of treatment for a 77-year-old male, who suffers from post-polio syndrome.

This patient is treated by Respiratory Care Centre East, which takes care of patients with chronic respiratory conditions in need of permanent ventilator treatment.

In addition the patient is connected to the Institution for Respiratory Care Patients, which is part nursing home part rehabilitation ward for patients of the same category.

The story is quite special, as this patient is tracheostomized, but does not use an intubation tube, only a small hole in the trachea, which is closed when the patient is ventilated with his Bi-PAP machine. The tracheostomy is only used for suction.

The case story describes the patient's course of treatment from the time of the Polio Epidemic, through the following social life, his post-polio syndrome debut and to the patient's life with non-invasive ventilation, tracheostomy and arrangement with personal helpers.

We will show pictures and video takes from the patient's everyday life in his home.

The lecture will be directed towards both ventilator users and professionals.

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CLARIFYING CHOICES:
The Right Ventilation at the Right Time

Diana Guth, RRT,
Home Respiratory Care, Los Angeles, California
Betsy Thomason, RRT,
Millennium Respiratory Services, Whippany, New Jersey
Angela King, BS, RPFT, RRT-NPS,
Pulmonetic Systems, Inc., Minneapolis, Minnesota

SESSION II OPTIONS

10:45 am – 12:00 noon

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ANALYZING YOUR GAIT: THE ROLES OF EXERCISE, BRACING OR SURGERY

Mary Ann Keenan, MD
Orthopaedic Surgery, University of Pennsylvania
Philadelphia, Pennsylvania

Alberto Esquenazi, MD
Gait and Motion Analysis Lab
Moss Rehabilitation Hospital
Philadelphia, Pennsylvania

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RESEARCH I: WHAT IS BEING DONE? WHAT NEEDS TO BE DONE?

Who Is More Likely to Report PPS? Results of the 94/95 NHIS

Nancy A. Myers, PhD
Rootstown, Ohio

Background: Since the 1980s, researchers have been working to quantify the number of polio survivors who are affected by Post Polio Syndrome (PPS), and to identify what factors may put some survivors at risk for disease. Relying primarily on convenience samples of polio survivors and/or PPS patients, estimates of the prevalence of PPS within the survivor community have ranged from 20% to more than 70%. Risk factors that have been identified in various studies have included gender, the extent of the survivor's original polio infection, and the polio survivor's personality (or Type A behaviors in survivors). Common drawbacks of these studies are that they have not included data that are representative of all polio survivors, and have generally only studied one risk factor at a time.

Methods: In 1994 and 1995, the National Health Interview Survey (NHIS), a national health survey that samples a representative group of the U.S. population on an annual basis, identified and asked questions of a national sample of polio survivors. Information was collected about survivors' polio infection, current health status, experience with PPS, and personality traits. These data were used to determine the national prevalence of PPS, and to analyze what factors are more likely to be reported by survivors with PPS. A multivariate model, which included physiological, social, and personality variables, was constructed and tested using logistic regression to determine differences between survivors who reported a diagnosis of PPS and those who did not.

Major Findings: In this nationally representative sample, while nearly 25% of survivors reported that they believed they suffered from PPS, only 11% had been diagnosed with PPS by a physician. In multivariate analyses, the following characteristics were found to increase the odds that a survivor would report a medical diagnosis of PPS: having more years of education, having contracted polio as an adult, having more than five muscle groups affected by polio, and having required hospitalization for polio. An increasing score on the NHIS Type A-like personality traits scale was associated with decreasing odds of reporting a diagnosis of PPS. Patient gender was not associated with diagnosis of PPS; there were not enough cases of non-white survivors diagnosed with PPS in order to draw conclusions about the relationship between race and diagnosis of PPS.

Implications for Future Research and Practice: While physiological features of survivors' original polio infections are associated with risk of PPS, there are other, non-physiological characteristics that warrant further research to ascertain their relationships with PPS. Race/ethnicity should be explored in future research models as well, in order to understand how the prevalence of and experience of PPS may differ between racial/ethnic groups. Finally, the theory that all polio survivors share a common, Type A personality that contributes to the development of PPS should be examined in larger samples of polio survivors in order to ascertain whether this relationship exists and in what contexts.

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RESEARCH I: WHAT IS BEING DONE? WHAT NEEDS TO BE DONE?
A Mouse Model of Post-Polio Syndrome

Burk Jubelt, MD, Stacie L. Ropka, Jeremy M. Shefner, Robert L. Schelper
Syracuse, New York

This project involves the development and characterization of a mouse model for Post-Polio Syndrome (PPS). An animal model may allow a determination of the cause(s) and therapeutic interventions for PPS. Patients with PPS develop new late weakness many years after their acute poliomyelitis. A similar picture is seen in this mouse model.

Mice were inoculated intracerebrally with $10^{11.0}$ TCD_{50} of the attenuated W-2 strain of type 2 human poliovirus (PV2/W-2). Surviving paralyzed mice were examined at 4, 8 and 12 months for the development of new weakness. Strength and new weakness were determined by using the MRC manual muscle testing scale. Mice developing new weakness, stable paretic mice and normal controls were euthanized at 12, 24 and 48 months post-infection for pathologic and virologic changes. Mice were perfused with formaldehyde for pathologic studies. Other mice were euthanized and spinal cords/brains removed for RT-PCR for viral RNA.

In the initial cohort of 65 inoculated mice, 49% (32 mice) died during the acute infection (1-15 days after inoculation), 9% (6 mice) survived without paralysis and 42% (27 mice) survived with paralysis. Of the 27 mice with residual paralysis, 10 died from anesthesia during EMG testing. At one year, of the 17 surviving paretic mice, 4 had flaccid paralysis without recover (25%), 7 were stable (41%) and 6 (35%) developed new late weakness. In second cohort of 78 mice, there were 36 survivors. Of those, 20 had residual weakness from the acute infection. At one year post-infection 3 had flaccid paralysis without recovery (15%), 7 were stable (35%) and 10 (50%) developed late weakness.

Electromyographic (EMG) testing at 4 and 12 months revealed chronic denervation as is seen in human poliomyelitis. Qualitative pathologic studies revealed neuronal degenerative changes without inflammation. Virologic studies (RT-PCR) at about 2 years after inoculation detected viral genes in only a small number of mice, 2 of 15.

Mice infected with human poliovirus PV2/W-2 develop acute paralytic disease. About one-third of surviving paretic mice developed new late weakness at one-year post infection. EMG findings were consistent with old poliomyelitis as is seen in humans. Pathologic studies reveal that motor neuron degeneration continued after recovery from the acute disease and no inflammation was seen. Rarely was any evidence of viral infection found in these late poliomyelitis survivors. This appears to be an excellent model to determine the cause and treatment of PPS.

Studies are presently underway to determine if growth factors, specifically glial cell line-derived neurotropic factor (GDNF) and insulin-like growth factor (IGF-1) will stop the late weakness. GDNF helps maintain the cell body while IGF-1 prevents terminal sprout dropout. Studies are underway to transport the genes of these growth factors to the motor nerve cells by insertion into a vector (adeno-associated virus) and injecting intramuscularly.

Supported by: Morris Family Foundation, Chaffiot Family Foundation and The Upstate Medical University Foundation Post-Polio Syndrome Research Fund.

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RESEARCH I: WHAT IS BEING DONE? WHAT NEEDS TO BE DONE?

Update on Modafinil Study

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Rockville, Maryland

Post-Polio Syndrome (PPS) Fatigue: The New Challenge 50 Years After the Salk Vaccine

Post-Polio Syndrome (PPS) is the term used to describe the reemergence of symptoms decades after recovery from acute poliomyelitis. Symptoms include increasing muscle weakness, pain, and atrophy, fatigue, breathing and swallowing difficulties, sleep disorders, and cold intolerance. After started, symptoms progress overtime and lead to gradual functional loss. Usually, by not always, PPS symptoms begin 15 or more years of stable function that follows recovery from paralytic polio.

Among the PPS symptoms, fatigue is the earliest and most disabling. Because of fatigue, many polio survivors are forced to leave work or lose the ability to live independently. The fatigue of PPS is not only debilitating, it affects the vast majority of polio survivor population. Estimates show that 79% to 89% of patients with PPS suffer from fatigue. A 1985 survey of 676 polio survivors showed that 91% of the sample experienced new or increased fatigue, with 41% claiming an interference of fatigue in performing work and 25% in self-care activities. A questionnaire completed by 276 Norwegian subjects with PPS showed that the prevalence of fatigue in PPS patients is significantly higher than in matched controls.

The cause of fatigue in PPS patients is only vaguely understood. It is thought that multiple domains of subjects' function are involved. In PPS patients, at least in part, fatigue is related to the gradual loss of individual nerve cells that make contact with other nerve cells (within the central nervous system), or with muscle fibers (within the peripheral nervous system). This results in subsequent loss of nerve transmission to these circuits. During the original polio infection, the poliovirus destroys nerve cells in the brain and spinal cord, particularly but not only, motor neurons. Among other things, this can result in loss of muscle function, including weakness or paralysis. However, to compensate for this loss, surviving neurons sprout out extra branches that are able to reestablish synapses (contacts), especially with orphaned muscle fibers that have lost their original nerve supply. Because of this process of reinnervation the individual is able to regain function. This is easily noticeable within the muscle system: body muscles are able to work again, sometimes as well as before. Ironically, these repaired circuits appear to wear down with aging. Some researchers have suggested that PPS develops because these extra sprouts cannot "hold" forever, but instead get weaker over time due to "over-use". Eventually, the sprouts degenerate, and function mediated by the neural contacts they have secured for years decline or disappears. This explains why recovered muscles gradually weaken and loose bulk when PPS settles in. An important lesson from the facts outlined above is that the fatigue faced by PPS patients is complex and involves multiple domains of function (emotional, intellectual, social, etc.), not simply the physical (muscular) dimension.

Unfortunately, except for supportive care, effective pharmacological therapies for the fatigue of PPS remain elusive. This problem remains as one of the most difficult new challenges faced by survivors of the last epidemics 50 years after the Salk vaccine.

Attempts at symptomatic management of other PPS symptoms have not met with much success either. In the past, several groups of researchers worked independently while investigating the origin of PPS and ways to reduce the burden of the incapacitating fatigue. About half a dozen clinical trials directed to reduce fatigue, the most common and disabling problem faced by patient, were done but arrived at negative results. Table 1 provides a short review of these trials.

Table 1: Summary on Previous Clinical Studies on Fatigue of PPS.

Agent	Rationale	Dosing	Length	N	Design	Result	Reference
Pyridostigmine	Defective neuromuscular transmission	60 mg x4 day	14 Weeks	62	Double-blind, placebo-controlled, randomized, single center	(-)	Horemans HL et al, 2003
Pyridostigmine	Defective neuromuscular transmission	60 mg x3 day	24 Weeks	126	Double-blind, placebo-controlled, randomized, multi center	(-)	Trojan DA et al, 1999
Bromocriptine	Decreased dopamine in basal ganglia	12.5 mg day	8 Weeks	5	Pilot single-blinded, crossover	(+)	Bruno RL et al, 1996
Prednisone	Chronic inflammatory reaction	80 mg day	24 Weeks	17	Double-blind, placebo-controlled randomized, single center	(-)	Disnmore S et al, 1995
Amantadine	Decreased dopa in basal ganglia, also effective in MS and PD	100 mg x2 day	6 Weeks	23	Double-blind, placebo-controlled randomized, single center	(-)	Stein DP et al, 1995
Pyridostigmine	Defective neuromuscular transmission	180 mg x3 day	4 Weeks	25	Open label	(+)	Trojan DA *et al*, 1995
hGH	Promote nerve growth	0.03 mg/kg x3 week	12 Weeks	6	Pilot Open label	(-)	Shetty KR *et al*, 1995

In year 2001 the PPS Program was funded. The PPS Program is sponsored by the Uniformed Services University (USUHS) and administered under the auspices of the Henry M. Jackson Foundation (HJF). The mission of the PPS Program is to advance knowledge on the cause and treatment of post-polio syndrome. To achieve this goal several independent studies are taking place, some in the form of clinical trials intended to test the effect of medications to reduce the symptom burden in PPS patients.

Currently, the PPS Program is enrolling volunteers to participate in a clinical trial on PPS fatigue. This study will test if a medication called modafinil (Provigil) can help reduce the fatigue of patients with post-polio syndrome. This research is being done because, despite intense work, there still is no effective treatment for PPS fatigue, the most debilitating problem in persons with PPS. The nature of PPS fatigue is poorly understood but a central element is likely. This is supported by the damage caused by the poliovirus to neurons is supra spinal areas of the central nervous system, particularly the basal ganglia and reticular formation. Drugs reducing fatigue in neurological conditions usually act by facilitating central catecholaminergic tone. The centrally-acting α-adrenergic agonist modafinil may help lower fatigue in PPS subjects. Modafinil has been used successfully to reduce fatigue in patients with other neurological disorders, including multiple sclerosis. Other studies in our program are directed to investigate different aspects of PPS. A second study (also actively enrolling) is looking at alterations in the brain and spinal cord of polio survivors that might help explain the development of PPS and the origin of PPS symptoms. This one is not a treatment trial. Instead, we are employing electrophysiology techniques and magnetic resonance to map possible residual abnormalities in the central nervous system induced by the polio virus during the original infection.

A third study is coming up soon. This one will examine if cognitive problems that are common is survivors with PPS, by measuring the brain ability to concentrate, sustain attention, register and memorize information, etc., with the use of traditional neuropsychological tests. These studies aim to advance knowledge in several different areas of PPS and hopefully, help us design and test therapeutic interventions that can be safely used to reduce disability in polio survivors. For more information, please contact our research nurse coordinator, Ms. Kay Kelley, at 301-295-0231.

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UPDATE FROM MEDICARE: Prescription Drug Cards

Bill Hunot
Social Security Administration
Saint Louis, Missouri

Payment for Durable Medical Equipment and Staying in Your Home: What Medicare Can Do for You

Diana Brady
CLAIM, Columbia, Missouri

TRAUMA TREATMENT: WHAT IS IT AND WHAT ARE THE BENEFITS

Stephanie T. Machell, PsyD
Somerville, Massachusetts

What is Trauma?

An experience is considered traumatic if it is:

1. Outside the normal range of experience, including events that would be atypical when experienced by an individual at that age/developmental stage
2. Involves a serious threat to physical, psychological, or spiritual well-being, including the possibility of death
3. Produced feelings of shock, horror, intense fear, and/or helplessness

Trauma can be caused through direct experience of such an event, or by witnessing or hearing about it.

An extensive discussion of the neurobiology of trauma can be found in some of the references at the end of this article. Simply stated, when the person experiences a traumatic event, neurotransmitters and hormones are released. These biochemical processes are intended to help the person survive trauma, and cause alterations in physiological and psychological functioning that would allow for escape or enhance the likelihood of survival. If the person has the opportunity to process what has happened and to allow time for recovery without further stressors occurring, there may be little or no effect from a traumatic experience.

However, if there is no time for processing, if others in the person's environment are unempathic, or if further trauma occurs, physiological and psychological processes may continue that set the stage for the development of trauma-related disorders.

What Was Traumatic About the Experience of Polio?

Many aspects of the polio experience are reported to have been traumatic by polio survivors. What one experiences as traumatic depends on many factors, including prior history of trauma, the age at which the event happened, social support, level of understanding of what is happening, ability to leave or act to change the situation, and physical/psychological condition at the time of the event.

Among the aspects of polio that survivors report as having been traumatic are being paralyzed, separation from parents and familiar surroundings, painful/intrusive medical procedures, lack of information about what was happening, abuse by medical professionals and others (including family), bullying, being viewed as different and ostracized, repeated hospitalizations for surgeries, and concerns about body integrity and functioning.

The stigma around polio created further problems for survivors. Rather than being given the time and space to process their feelings with family and supportive others, they were encouraged to act as if nothing had happened and to forget about their polio experience. Those who study traumatic stress report that such prohibitions on speaking about trauma create fertile ground for the creation of post-traumatic stress-related symptoms to occur.

Post polio syndrome (PPS) has for many been a further trauma. After being told that polio was over and that they had done all the right things to triumph over it, polio survivors found that their bodies had betrayed them. For many, the reminders of the polio experience (braces, crutches, ventilators, physical therapy, medical care) that PPS has necessitated have caused post-traumatic symptoms to occur.

If I Experienced Trauma, Does that Mean I Have Post-Traumatic Stress Disorder?

No! Not everyone who experiences trauma develops post-traumatic stress disorder (PTSD) or other psychological problems. However, it may still be helpful for someone who experienced trauma to receive psychological treatment (see below).

The symptoms of PTSD include intrusive thoughts about the event(s), dreams, flashbacks, intense distress when faced with reminders of the event(s), avoidance of reminders of the event(s), amnesia for all or part of the event(s), sleep disturbances, muscle pain, restricted emotional range (can be coupled with a tendency to become intensely angry or a low level of constant irritability), difficulty concentrating, hypervigilance, and an exaggerated startle response. Some of these symptoms may alternate (e.g., intrusive thoughts with avoidance of reminders).

Why Should I Get Treatment for Trauma?

Unresolved trauma is a drain on the person's energy – something a person with PPS can ill afford! It takes considerable energy to keep experiences out of awareness. Sleep disturbance due to heightened physiological arousal can exacerbate post-polio fatigue. And physiological hyper-arousal can also contribute to muscle pain due to increased muscular tension.

Getting treatment for trauma also improves overall quality of life. Often relationships are affected due to issues trauma survivors have with trust. Difficulty concentrating makes it harder to engage in both work and leisure activities. Having a broader range of feelings enhances overall well-being for most people.

What Sort of Treatment is Available to Me?

Linda Bieniek created an extensive list of psychological treatments for trauma describing their risks and benefits (see Resources, below). Working with a psychotherapist who is well-trained and experienced in trauma is essential. Few will be familiar with polio or post-polio syndrome, but should be willing and open to learning more.

How Do I Choose a Therapist?

The most important factor in whether someone improves in therapy is the relationship between client and therapist. It is important to choose someone that is a good match. You should feel that you can talk with your therapist about the issues that are important to you, and that he or she makes an effort to understand and to be helpful to you. While you will feel uncomfortable in therapy at times, feeling that way all the time probably means that this isn't the therapist for you.

Resources

Books and Articles

Bieniek, Linda (2001). "Emotional Bridges to Wellness" *Polio Network News*, Fall 2001, Vol 17, No. 4. (this and the subsequent articles are the best ones on how and why to deal with the trauma of polio)

Bieniek, Linda & Kennedy, Karen (2002). "Improving Quality of Life: Healing Polio Memories" *Polio Network News*, Winter 2002, Vol 18, No. 1.

Bieniek, Linda & Kennedy, Karen (2002). "A Guide for Exploring Polio Memories" *Polio Network News*, Summer 2002, Vol 18, No. 3.

Bieniek, Linda & Kennedy, Karen (2002). "Pursuing Therapeutic Resources to Improve Your Health" *Polio Network News*, Fall 2002, Vol 18, No. 4.

Bieniek, Linda & Kennedy, Karen (2002). "Treatment Options Chart" *Polio Network News*, Fall 2002, Vol 18, No. 4 (addendum). (this is the most thorough resource I have ever seen for considering options for trauma treatment!)

Herman, Judith (1992). *Trauma and Recovery.*

Kabat-Zinn, Jon (1990). *Full Catastrophe Living: Using the Wisdom of Your Body and Mind to Face Stress, Pain, and Illness.* (this is an excellent introduction to mindfulness and yoga exercises that might be useful with trauma survivors)

Levine, Peter (1997). *Waking the Tiger: Healing Trauma.* (a book about somatic experiencing, a body-oriented treatment. Contains good info about how trauma affects the body).

Machell, Stephanie. (2003). "Psychological Services for Polio Survivors: More than 'And How Do You Feel About That?'" *IRCP at Spaulding Rehabilitation Hospital Network: A Newsletter From the International Rehabilitation Center for Polio,* Fall 2003. Reprinted in the *Post Polio News*, May 2004.

Phillips, Maggie (2000). *Finding the Energy to Heal: How EMDR, Hypnosis, TFT, Imagery, and Body-Focused Therapy Can Help Restore Mind-Body Health.* (an excellent introduction to some of the newer treatments available – highly recommended)

van der Kolk, B., McFarlane, A.C., and Weisaeth, L. (1996). *Traumatic Stress: The Effects of Overwhelming Experience on Mind, Body, and Society.*

Useful Organizations

International Society for Traumatic Stress Studies (www.istss.org).

International Society for the Study of Dissociation (www.issd.org). (for more information about more severe trauma-related disorders)

Sidran Foundation (www.sidran.org). (a great resource for info about trauma treatment, including therapist referrals)

The groundedness you need to fly as high as you can

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CAN WE TALK ABOUT IT? BEING PREPARED FOR MEDICAL CRISES, ADVANCED DIRECTIVES, AND LIVING WILLS

Allen I. Goldberg, MD, MBA, Master FCCP

Case Example: MP became totally quadriplegic due to poliomyelitis at the age of 15. After several years in a nursing home, she was encouraged to live independently. With the assistance of technical aids and volunteer personal attendants, she lived totally alone. She worked for years as a consultant for rehabilitation engineering research and development providing the consumer perspective. She was a recognized leader and advocate for persons with disability. After many years, she developed fatigue and drowsiness that required creative solutions using non-invasive ventilation which sustained her even during acute medical crises. A friend in the health field worked with her, shared her health related experiences for many years, and knew her personal wishes. Together they re-introduced the iron lung and other non-invasive devices into use to meet her acute care needs. Theirs was a crucial relationship when she was admitted at age 60 to the ICU for a life-threatening but reversible condition which required tracheostomy which would dramatically threaten her independent life style. Her wishes were known that she would rather die than have a tracheostomy. MP did not have written "advanced directives", but her friend was present the ICU at the moment of decision in the ICU.

The issue: How can a person with disabilities make known in advance their wishes regarding life-support decisions and end-of-life choices? How can the person really know what they would want to in advance when they do not know the nature of the situation they or their advocate will face when the decision needs to be made?

DEFINITION OF TERMS AND CONCEPTS

Advanced Directive: A written statement made in advance about future medical decisions. A legal document giving advanced directions about the kind of health care you want if you cannot make your own decisions. You have the right to accept/reject medical treatment and name a trusted friend/relative to communicate for you. *(Do not resuscitate)*

Health Care Power of Attorney/Proxy: a signed legal document naming your "agent" for health decisions if you are unable to do so. (IL Statutory Short Form POA for Health Care)

The agent (or successor agents) can make any decision you could make if you were able or you can limit/modify with special instructions by clearly stating them in your POA.

Talk personally with you agent to clarify wishes about life-sustaining treatment.

Living Will (Declaration): a signed document stating that you do not want your physician to use death-delaying procedures if you develop a terminal condition as certified by a physician. (Illinois Living Will Act).

"Terminal Condition": a condition that cannot be cured or reversed, where death is imminent, and the use of death-delaying procedures merely prolong the dying process

"*Death-delaying Procedure*": procedures that postpone moment of death (assisted ventilation, dialysis, medication, blood transfusion, tube feeding)

Health Care Surrogate: an individual who make medical treatment decisions for you if you do not have a POA/living will and are unable to make your own medical decisions.

(IL Health Care Surrogate Act). Appointed by your physician in order of priority: court-appointed guardian, spouse, adult children, parents, adult siblings, adult grandchildren, close friends, guardian to your estate. May not know your wishes without POA.

ANNOTATED REFERENCES* ON MAKING FUTURE HEALTH DECISIONS:
Kiplinger's Retirement Report, PO Box 3298, Harlan IA 51593-2478 (1-800--544-0155)
* Kiplinger Reports that provide access to more information (in print, by 1-800, or Internet)

Fine-Tune Your Health Care Directive. *Kiplinger's Retirement Report*, Oct 2003*
Practical advice to meet each state's requirements if you travel, live in more than one state.
Suggests important details re: selecting agents, witnesses, locating/using copies.
Provides more information/resources for a "universal directive": Five Wishes Document

Paving the Way by Having Your Say. *Kiplinger's Retirement Report*, Dec, 2003*
Practical recommendations in light of Terri Schiavo: educate yourself, integrate your beliefs and values, give your agent the necessary authority, communicate with your agent, keep directives up-to-date, consider state-specific proxies, how to make sure proxy can be located

Making Sure You Go Your Own Way. *Kiplinger's Retirement Report*, Jun, 2004*
Important suggestions to be sure advanced directives are followed: give one person authority, discuss wishes with your doctors, and review hospital policies (new Catholic hospital directives).

Single People Need Estate Plans, Too. *Kiplinger's Retirement Report*, Jun 2004
Appoint health-care agent vital or vulnerable to have court-appointed guardian (a stranger)

A Legal Document Everyone Needs. *Kiplinger's Retirement Report*, Aug 2004
Discussion about assignment of durable power of attorney for finances and healthcare.

When Advance Directives Don't Say Enough. *Kiplinger's Retirement Report*, Dec 2004
Discussion by a son (assigned health care power of attorney) who struggled to decide what his father would have wanted based on his living will. Reality testing in changing situations.
"It can be nearly impossible to write advanced instructions to address every circumstance".

A Son Struggles to Make the Right Decisions. *Kiplinger's Retirement Report*, Jan 2005
Discussion above continued whereby if son had followed the letter of Dad's original advance directive, he might have gotten into the very situation his Dad had always feared.
From theory to practicality: reality-testing t of a living will/advanced directives.

Demonstrates why differing documents, different perspectives, and uncertainty due to prognosis, multiple interacting conditions, and decisions make it impossible to know in advance what to do.

"Instructions were too simple for the situation that developed". Adhering strictly to the wording in a living will could have produced the opposite of what intended"
"Giving you healthcare power of attorney to someone who knows your intimately is best way to ensure that your wishes will be honored."

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CAN WE TALK ABOUT IT? BEING PREPARED FOR MEDICAL CRISES, ADVANCE DIRECTIVES AND LIVING WILLS

Kristi L Kirchner
Chicago, Illinois

Have you completed your Advance Directive?
▪What do you value most in life?
▪Under what circumstances would you think death preferable to continued life?
▪How certain are you?
▪What factors might influence you to change your wishes?

Advance Directives
We will focus on 2 specific Advance Directives:

–Living Wills
•*(Instructional Documents)*
–Durable Power of Attorney for Health Care
•*(Proxy Documents)*
•*Caveat: must know your State law– these documents can vary by State!*

Living Will
An instructional document that allows competent adults to direct physicians to withhold or withdraw "death-delaying" treatments. In Illinois– only if terminally ill. Also does not allow withdrawal of nutrition and hydration.

Durable Power of Attorney for Health Care
A proxy document that is designed to be more flexible than a Living Will and allows competent adults to name a trusted person to make decisions for them.
Substituted Judgment: Proxy is asked to make decisions that she believes the patient would make if able to do so.
Best Interests: The standard used if the proxy is unsure what the patient would decide if able to do so.

Limitations of AD
- Most patients have not completed an advance directive of any kind.
- The information contained in the advance directive is often not clinically relevant or useful.
- The document is often not available.
- Proxy decision makers have difficulty accurately predicting patient wishes even if they have general knowledge of the pt's values.

Disability & ADs
- It is difficult to predict how one may feel about living with disability in the future.
- Adjustment and Resilience tends to be the rule rather than the exception.
- Health Care providers may not frame treatment decisions in a value-neutral way.
- Health Care providers tend to rate pt's QOL lower than do pt's themselves.
- Time limited trials of treatment and the "window of opportunity"

In the Absence of an AD
- State Surrogate Laws – generally name a default proxy decision maker.
- The default proxy has powers that may be more restricted than one named in a DPAHC (Feeding tube withdrawal).
- Hierarchy of decision makers does not always clearly identify a proxy (adult children).

What have we learned about advance directives post-Schiavo?
- Primary Issues:
  - Family Conflict
  - Feeding Tubes
  - PVS vs. MCS
  - Default Decision-Makers
  - Legal Protections for Vulnerable Patients

Family Conflict
- There would likely be no public controversy if all relatives had agreed upon the treatment plan in this case.

- However, able-bodied family members with limited experience of life with impairments may devalue the lives of their relatives.

Feeding Tubes – Three Views
- Feeding tubes are life-sustaining medical treatments similar to mechanical ventilators and as such, competent patients or their surrogates can choose to have them withdrawn in certain circumstances.
- Feeding tubes are inherently different from other medical treatments because they involve "food and fluid" and are a high benefit / low burden intervention.
- Feeding tubes are an accommodation to a disability, not unlike a wheelchair for someone who cannot walk, because they are necessary for those unable to access nutrition and hydration orally.

Persistent Vegetative States / Minimally Conscious States
- Legal decisions were based on physician testimony that Ms. S was in PVS and was unlikely to improve. In IL default decision makers in these situations can request withdrawal of feeding tubes if they believe such action would be consistent with the patient's intent and desires.
- Some believe Ms. S may be Minimally Conscious and in need of additional assessment/treatment in order to reach her full potential. Many vulnerable patients – particularly those with cognitive and communicative deficits – fail to receive care when they cannot self-advocate.

Default Decision Makers
- If Ms. S had named somebody to make decisions on her behalf there would be more confidence in the decisions expressed by the surrogate.
- Not Dead Yet and some other groups would defer to the Health Care Power of Attorney in this case had there been one named. However, concerns still exist about any proxy's ability to make decisions about disability due to lack of knowledge about the experience.

Legal Protections & Vulnerable Groups
- All people with disabilities are vulnerable because of our societal biases.
- Patients with cognitive disabilities face even more discrimination than do patients with physical limitations.
- Society could take steps to provide greater protection for this group of citizens -- similar to the Baby Doe Laws.

A Disability Message

One Message has been: *"Life at all costs"* or *"Always err on the side of life"*

Another message has been: *"Better dead than severely disabled"*

A Disability Message is: *"Don't assume that our lives are not worth living"*

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EATING BETTER FOR BETTER HEALTH WITH YOUR FAMILY AND FRIENDS

Jann and John Hartman
Baltimore, Maryland

John and Jann Hartman enjoy sharing the cooking and clean-up in their kitchen. They are devoted to eating well despite the constraints of lack of energy and time. Sharing the tasks and planning ahead can make it easier than ever to make your own nutritious foods.

Eating well means that the foods we choose are going to be good for our body. Maintaining a healthy weight (or as near as possible) is a good goal as well as staying as active as possible. Eat heart healthy foods, and serve small portions. We need to eat well and to eat foods that are nutritious and delicious.

On the internet, you will find these helpful websites (some with newsletters):

Post Polio Health International: www.post-polio.org
Center for Science in the Public Interest: www.cspinet.org
American Dietetic Association: www.eatright.org
American Heart Association: www.americanheart.org
American Diabetes Association: www.diabetes.org

Joslin Diabetes: www.joslin.harvard.edu
Nutrition Navigator: www.navigator.tufts.edu
Q & A on many Nutrition Topics: www.dietitian.com
Lactose Intolerance: www.whymilk.com
American Cancer Society: www.cancer.org
American Association of Retired People: www.aarp.org/health/staying_healthy/
For those with Swallowing Problems: contact Muscular Dystrophy website for a MEALS cookbook and information: www.mdausa.org/publications/meals/

Nutrition articles on the PHI website:

"Healthy Eating: Fat Facts" -- www.post-polio.org/ipn/pph20-1c.html#hea
"Foods That Shut Down Stress" -- www.post-polio.org/ipn/pph19-3d.html#food
"Diabetes and PPS" -- www.post-polio.org/ipn/pph20-2a.html#dia
"The Glycemic Index: Good Carbs, Bad Carbs" -- www.post-polio.org/ipn/pph20-3c.html#good
"Nutrition and Post Polio" (Dr. Halstead's article): www.post-polio.org/ipn/pnn14-1B.html#nut

Bibliography:

"Power Nutrition for Your Chronic Illness" by Kristine Napier, MPH, RD. This is a guide to shopping, cooking, and eating to get the nutrition edge.

"Jane Brody's Nutrition Book" A basic nutrition book and good place to start learning nutrition basics.

"Better Homes and Gardens Cookbook" or "Junior Cookbook" for those who need to start with basics!

"The TVP Cookbook: Using the Quick Cooking Meat Substitute" by Dorothy R. Bates. This has basic recipes and ways to get protein without using meat.

"A Dietitian's Cancer Story" by Diana Dyer, MS, RD. Great recipes, especially smoothies with lots of nutrition for those with cancer or other chronic problems. Some good recipes are on her website: www.dianadyermsrd.com/recipe_page.htm

"Non Chew Cookbook" by J. Randy Wilson is helpful for those who have trouble swallowing.

Jann's Nutrition Webpages (my credentials are here): www.geocities.com/arojann.geo/ppsnutrition.html
Clickable webpage for these websites: www.geocities.com/arojann.geo/ppspages.html

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SESSION III OPTIONS

10:45 am – 12:00 noon

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SOLUTIONS FOR OVERUSE AND DISUSE WEAKNESS: Overuse

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Summary

Overuse can be defined as the chronic overloading of muscles in daily life activities resulting in physical complaints such as muscle fatigue and pain. Overuse can develop in case of a reduced capacity of muscle to endure loads due to paresis but also when normal muscle is chronically overloaded, for instance when a muscle has to compensate for other paretic muscles. This paper focuses on the overload of muscles but other structures such as tendons, ligaments and joint capsules may also suffer form overuse symptoms.

The treatment of overuse is individual and starts with a careful analysis of capacities and demands in daily life activities which is followed by an individually tailored treatment plan containing a mixture of life style alterations, bodily aids, environmental adaptations and exercise.

Overuse and cardiorespiratory conditioning

The symptoms of PPS such as muscle pain, increased fatigue after physical activity and delayed recovery following physical activity may signify that muscles are overused in conducting ordinary daily life activities.[1;2] Support for such a chronic overuse of muscles in former polio subjects has been found in studies showing elevated activities of serum creatine kinase that were related to the distance walked during the previous day,[3] and in studies showing a type I fibre predominance in lower leg muscles supposedly due to fibre type transformation from chronic overload.[4;5] Also, PPS subjects have been found to recover slower from fatiguing exercise than stable polio subjects.[6;7] Another factor that is said to contribute to the symptoms is a poor cardiorespiratory condition.[8-10] However, the cardiorespiratory condition of polio subjects was not worse than that of healthy, comparably active subjects.[11] In this study it appeared that the reduced submaximal performance capacity of the polio subjects was strongly correlated with the limited available muscle capacity and that movement economy was diminished compared with the control subjects.

Lower concentrations of some oxidative enzymes in muscles of polio subjects have also been reported while other oxidative enzymes were within normal ranges.[12;5;13] The clinical significance of these findings has been debated.[14]

It is important to distinguish between complaints of overuse in muscles with polio residuals and in non-affected muscles. The latter may result from increased compensatory muscle activity. This has been shown for upper extremity complaints [15] and may also be found in back muscles and leg muscles in case of postural deviations and altered gait patterns.

Abilities and handicaps

Growing restrictions to perform activities was mainly found for physical abilities such as walking, climbing stairs, and transfers.[16-22] In a recent study, physical functioning declined little over a 6-year period.[23] In agreement with the concept of overuse was the finding that the extent of paresis was the only prognostic factor for a decline in functioning. A significant increase in handicap severity for the categories mobility, occupation and social integration was found in PPS subjects over a period of 4-5 years, while in non-PPS subjects the handicap severity remained unchanged.[24]

In a recent study it was shown that energy cost of walking increased linearly with increasing severity of paresis of the legs.[unpublished data] Thus a reduced physical capacity was associated with an increased energy demand for a functional task, ie walking.

Management including treatment

No curative treatment is available for PPS. Management of PPS is preferably multidisciplinary in order to restore the balance between decreasing capacities and demands.

Pharmacological treatment

At present no medication for PPS symptoms is available. Pyridostigmine is the only drug that has been investigated in randomised double-blinded trials.[25;26] In a multicenter study pyridostigmine was found not to be effective.[25] In selected patients with proven neuromuscular transmission defects pyridostigmine did not reduce fatigue, although a limited beneficial effect on physical performance was found.[26]

Multidisciplinary management

To reduce overuse and rebalance the capacities and demands, conservative management consists of 3 essential components: exercise, assistive devices, and life style changes. Therefore, PPS patients are best treated within a multidisciplinary, specialized rehabilitation setting. Since individuals show considerable differences in polio residua, treatment is individually adjusted and should be preceded by a thorough customised medical and functional evaluation.

Exercise

Exercise can optimise cardiorespiratory fitness and may add to the patient's sense of well- being.[27-29] Exercise should be non-fatiguing and performed at submaximal levels to avoid overloading of the limited muscle capacity. Exercise can improve muscle strength especially in case of disuse and muscle groups which are only moderately affected.[30] Intensive strengthening exercises are not generally recommended, although they may occasionally be indicated. Functional training may also be useful to improve the efficiency of ambulation.

Orthoses and assistive devices

Braces may be helpful to support weak muscles and to stabilize (painful) joints. The condition of existing, often old braces should be careful examined and judged whether they are still adequate based on biomechanical evaluation of walking abnormalities.[31;32]
Assistive devices comprise crutches, the use of a wheelchair, motorized scooters and home adaptations such as elevators, seating devices in the kitchen or shower. All of these devices should be individually indicated.

Life style changes

Pacing of activities and taking rest intervals are of major importance to relieve symptoms. It has for instance been shown that upper extremity complaints often result from overuse of shoulder and arm muscles.[33] Usually PPS patients have successfully been learned to deny their symptoms from child on to achieve a normal life.[34] Therefore, PPS patients may have great difficulty with adapting their life style to their decreasing abilities and psychological support may be indicated.

From theory to practice in Amsterdam

Patient work-up

In our hospital the diagnostic work-up of an individual considering overuse contains some specific elements according to standard protocol.

Computerized tomography (CT or CATscan) of muscle tissue
At reference levels transversal scans of the body are made to reveal signs of subclinical affection of muscles resulting in atrophy and/or fatty infiltration of muscles. This is extremely informative for the large muscle groups of the trunk and the lower extremities because these muscles may appear normal from strength testing while in fact they are not.
Movement analysis of gait
This may provide detailed information on gait abnormalities and (compensatory) functional (over)loading of muscles.

Patient treatment
Patients are multidisciplinary evaluated by a team specialized in neuromuscular disorders.
The key-players are the physical therapist, the occupational therapist and the social worker.
If necessary the psychologist, the orthotist and the orthopaedic shoemaker can be added.
After the evaluation by each team member a treatment plan is formulated and executed.
Specific elements in the treatment plan are
The starting point is the problems as prioritized by the individual.
The evaluation of daily life activities with a diary inventory.
The involvement of the family members in altering daily life behaviour.
If possible an individualized aerobic exercise program.
Specific products

The optimization/innovation of orthosis: full carbon prepreg orthosis which are extremely stable, light-weight and full-contact fitted. This may result in a reduced energy cost of walking and therefore have a positive influence on overuse symptoms. Currently there is a research project running on this topic.
Group therapy: together with the Rehabilitation Center in Amsterdam we have developed a 12 weeks program aiming at providing practical tools to change behaviour in daily life. Each week deals with another topic, for instance work, family, sitting and standing and so on. The programs consists of theory and practice exercises and the group interaction is an essential component.

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General information

Frans Nollet (1958) is physiatrist and head of the department of rehabilitation medicine of the Academic Medical Center University of Amsterdam, the Netherlands. He was appointed as a faculty professor at the University of Amsterdam in 2003. Since 1994 he is doing research in the field of post-polio syndrome. In 2002 he received his PhD for his thesis: 'Perceived health and physical performance in post-poliomyeltis syndrome'.

The Academic Medical Center serves as the national referral center for polio late effects in The Netherlands. There are about 13-15,000 polio survivors in The Netherlands on a population of 16 million.

Research overview

In the past we have studied the relation between functioning, abilities and impairments and changes over time. We did a randomized controlled study on pyridostigmine. So far this has resulted in 3 PhD thesis.

At present we have 2 PhD studies running:
- a prospective study of changes in health status focusing on the influence of aging and comorbidity.
- a study on prepreg carbon leg braces and the effect on energy cost of walking and functioning.

Publications

17 peer reviewed publications have been published or are in press. Additional to the reference list:

1 Ivanyi B, Nollet F, Redekop WK, de Haan R, Wohlgemuth M, van Wijngaarden JK, de Visser M. Late onset polio sequelae: disabilities and handicaps in a population based cohort of the 1956 poliomyelitis outbreak in The Netherlands. *Arch Phys Med Rehabil* 1999;80:687-90

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SOLUTIONS FOR OVERUSE AND DISUSE WEAKNESS: Problems and Solutions Reported in a Qualitative Study of Women Aging with Childhood Onset Polio

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1. Examples of Studies of Weakness and/or Decline in Polio Survivors

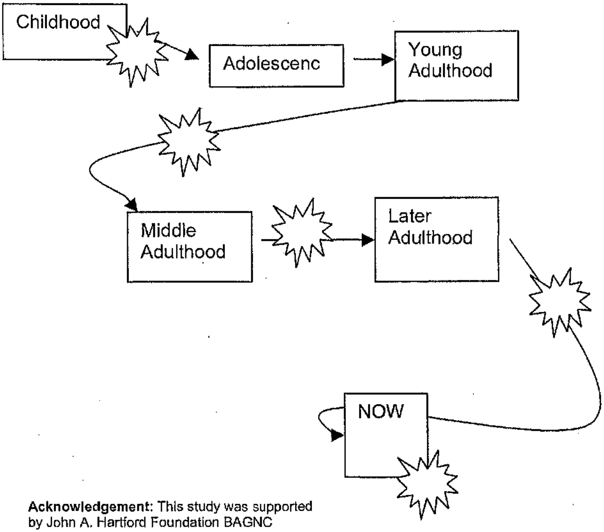
Author, Year	Design	Sample	Findings
Klein, Whyte, Keenan, Esqenazi & Polansky, 2000	Longitudinal with physiologic measures	120 persons with PPS	Muscle deterioration was present in the flexor muscles of ankle, hip and knee, but it was not strongly related to age, time since polio, or gender. Rate of deterioration greater than expected with normal aging.
Dalakas, Elder, Hallet, Ravits, Baker, Papadopoulos, Albrecht, & Server, 1986	Longitudinal with physiologic measures	27 with polio mean age 51 years	Rate of decline averaged 1% per year. The muscles showed evidence of chronic and new denervation. No loss of whole motor neurons. Slow disintegration of terminal nerve axons.
Allen, Gandevia, Neering, Hickie, Jones, & Middleton, 1994	Physiologic study	21 persons with polio and 20 healthy age matched controls	Group with PPS had more muscle fatigue than controls. Group with PPS had impaired activation of muscles when not fatigued.
Sorenson & Windebank, 2002	Questionnaires and physiologic measures using longitudinal design	23 with polio	10 had symptoms of late progressive motor deficits. The rate of progression was uniform over time. Severe residual impairments were associated with symptoms of decline.
Agre, Rodriquez, & Franke, 1998	Physiologic study	25 with polio related decline, 16 with polio and no decline, and 25 controls	Recovery time from muscular exercise was greater in those with complaints of decline. Those with polio without decline did not differ from controls.

2. Changes and strategies reported by women aging with Childhood onset Polio

Primary Changes	Consequences	Strategies
Physical Fatigue	Decreased time on projects Unable to multi-task	Rest breaks Planning and organization
Mental Fatigue	Mistakes made when on task too long	Frequent breaks Post-pone important decisions
Pain	Stopped or altered activities	Massage, exercise, medications, and assist devices

Balance Problems	Falls Fear of falls	Assistive devices Walking on even & textured flooring Planning and knowing lay out of surroundings
Decreased Dexterity	Do fewer complex activities that require full range of motion	Assistive devices for reach Asking for assistance Changing grooming practices Change clothing types Portable assist devices
Decreased Muscular Strength	Less lifting Decreased ability to clear lungs with diaphragm Decreased ability to push self in chair or pull self up from toilet	Ask for assistance Pneumonia shot Breathing aids Portable devices, such as toilet seats and ramps
Temperature Shifts	Decreased desire to go out	Layering with multiple clothes Heating pads
Secondary Changes	Consequences	Strategies
Obesity	Type 2 Diabetes Further decrease in strength Further change in clothing style Ulcers	Surgeries Exercise Resignation
Altered appearance	Decreased desire to go out in public Decreased self-esteem	Cut hair short but stylish Dye hair Ask for assistance
Fractures	Hospitalizations, surgeries, and further mobility impairment	Hire assistants
Fewer sexual experiences	Marital conflict	Sexual banter or other means of intimacy
Isolation	Fewer people to provide assistance when needed	Computer contacts via internet Telephone conversation
Side Effects from Medications	Falls, weakness, balance disturbances	Change medications &/or use alternative therapies
Emotional and psychological disturbances	Crying, anxiety, and nervousness	Decrease mental stimuli

Figure 1. Aging with polio:
Pointing out key times that influence health as described by women with childhood onset polio.



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ANALYZING YOUR SLEEP:
Is It Apnea, Hypoventilation ... or Both ... or Something Else?

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SLEEP APNEA

Definition

- An apnea-hypopnea index (AHI) > or =10 (Apnea: cessation of airflow. Hypopnea: reduction of normal tidal volume by greater than 30%). AHI is the number of episodes lasting 10 seconds or more per hour.

- Central sleep apnea (CSA) is caused by failure of the brainstem to respond to the chemical stimuli for breathing (increased carbon dioxide, decreased oxygen in blood).

- Most of current research is being done on obstructive sleep apnea (OSA), or obstructive sleep apnea syndrome as it is called (OSAS). This is the result of upper airway collapse during inspiration. CSA and OSAS can occur together. Neuromuscular weakness can cause OSAS, alveolar hypoventilation (failure to ventilate the lungs) or both.

- Prevalence of OSA: 4% in men and 2% in women. However, in 80-95% of patients this syndrome is not sufficiently diagnosed.

Medical comorbidities with or without a causal relationship

- Gastroesophageal reflux disease (GERD) and OSA frequently occur together. However, a study has found there is no relationship between the prevalence and severity of OSA and the presence of GERD.
- A study has shown that in an OSA population approximately 10% may have chronic obstructive pulmonary disease (COPD). This is known as overlap syndrome (OS). However, it was found that COPD was no more frequent in persons with OSA than in the general population. In the OS group mean arterial blood saturation for oxygen was lower and time spent in desaturation (decrease of arterial blood oxygen below normal) was longer than for OSA alone.

- About 30% of persons with OSA have a concomitant sleep disorder requiring treatment. The most common disorders are inadequate sleep hygiene and periodic limb movements.

Diagnostic Procedures

- Wearable, mobile phone-based respiration monitoring system: This system has a sensor attached to the chest wall that monitors respiration. A micro-controller determines when there has been an apneic period of 10 seconds or more. The respiration waveform during the episode and one minute before and after is sent by phone to the hospital server computer for apnea "filings".

- Ambulatory overnight oximetry: (noninvasive probe on finger or ear lobe measures oxygen saturation in arterial blood) Eighty percent of patients referred by internists for this study have abnormal results. However, internists prioritize the need and urgency for further evaluation based on the severity of desaturation with a minimum oxygen saturation of less than 80% (normal 95%) causing patients to be referred promptly for a sleep study.

- Capnography: Standard monitoring systems in intensive care units and stroke units monitor end-tidal $C0_2$ (carbon dioxide) values. An apnea-hypopnea index (AHI) based on these values correlates with the conventional AHI from polysomnography (comprehensive sleep study), and can be used for early diagnosis of sleep apnea syndrome (SAS).

- Measuring of pharyngeal sensitivity: Different airflow rates on the soft palate are delivered by an intraoral device. Impaired sensitivity to the airflow is correlated with the severity of OSA.

- Awake flow limitation on the flow-volume loop of the forced vital capacity with negative expiratory pressure (NEP): Pressures of –5 and –10 cm H_20 produce enough upper airway collapsibility (UAC) to correlate with the presence of OSA. Inspiratory UAC measurements without the negative pressure are not useful.

Access

- Access to sleep studies in a publicly funded healthcare system: Limited resources, language and cultural differences present barriers to detection and treatment. One study showed that only the most severely affected individuals are referred.

Pathology of the upper airway

- Oral pathology: Abnormal or unusual features within the oral cavity that could inhibit the upper airway were evaluated. Only a retro-positioned or narrow hard palate with a vertically positioned soft palate, oral breathing, and an enlarged uvula were associated with OSA.

- Pharyngometry: On standardized photographic measurement of the pharynx, the dimension of the free oropharynx, the width of the uvula and tonsil size were significantly related to OSAS.

- Magnetic resonance imaging of the upper airway: age-related reference data on 93 items related to the morphology of the upper airway and surrounding tissues has been published for further sleep and respiration research.

Outcomes/ Noninvasive therapy

- Sudden death in OSA: People with OSA have a peak in sudden death from cardiac causes during the sleep hours, in contrast to people without OSA.

- Cardiovascular outcomes in men with OSA with and without continuous positive airway pressure therapy (CPAP): In severe OSA without treatment the risk is increased for fatal (odds ratio 2.87), and non-fatal (odds ratio 3.17) cardiovascular events. CPAP reduces this risk.
- Mild OSA and CPAP: CPAP may be given a trial in those patients with severe sleepiness, but a recent study does not support the routine use of CPAP in this group of patients.

- OSA and the elderly: Sleep apnea-hypopnea syndrome (SAHS) in the elderly has a prevalence of 25%. CPAP is the treatment of choice with good compliance, and improvement in daytime sleepiness and cognitive function.

- OSA and anesthesia: If patient has a history of using CPAP, it should be continued in the perioperative period. Perioperative management includes evaluation of intubating conditions, search for cardiopulmonary morbidity, control of patient airway, cautious use of anesthetics, sedatives and narcotics, strict monitoring of vital signs and postoperative care in an intensive care unit.

- OSA, morbid obesity, bariatric surgery, and need for CPAP: With substantial weight loss, a CPAP pressure reduction of about 20% can be anticipated. Auto-titrating PAP units facilitate management.

- OSA, CPAP change with change in lung volume: Relatively small changes in lung volume produce significant change in the amount of CPAP needed to prevent flow limitation during non rapid eye movement sleep in OSA.

- OSA and use of mandibular (lower jaw) advancement splints: Sleep nasendoscopy with mimicking of the action of the splint can help determine patient selection.

Outcomes/ Surgical Therapy

- Radio-frequency velar (soft palate) coblation for snoring: Snoring decreased in about 80% of patients. Secondary uvulectomy decreased snoring in almost 100% of patients with complete resolution in about 50%.

- Radio-frequency tissue ablation of the tongue and palate for OSA: Useful therapy for mild to moderate OSAS.

- Midline laser glossectomy (tongue surgery) with palatopharyngeal surgery for severe OSA: If the retro palatal and hypo pharyngeal areas are identified as the sites of obstruction, these procedures are safe and effective.

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ANALYZING YOUR SLEEP:
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ANALYZING YOUR SLEEP:
Sleep Hygiene

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1) Why Sleep? – Symptoms of Sleep Deprivation
    - Fatigue
    - Irritability / Mood Swings
    - Impaired Concentration / Cognitive Performance
    - Depression / Anxiety / Marital, Family, and Work Issues
    - Pain – Muscular, Neuropathic

2) Insomnia (1/3 of population has suffered insomnia in past year, 10% chronic)
    Definitions are subjective –
    - American Sleep Disorders Association:
      A complaint of an insufficient amount of sleep
      or not feeling rested after the habitual sleep episode
    - American Psychiatric Association:
      Difficulty falling asleep, staying asleep, and/or nonrestorative sleep with associated impairment or significant distress for at least 1 month

3) Chronic insomnia is defined as lasting 6 months or longer

4) Poor Sleep Hygiene vs. Primary Sleep Disorders (e.g. Sleep Apnea, Periodic Limb Movement)

5) Pain / Insomnia Cycle

6) Sleep Log
   - Bedtime, Sleep time, Awakenings, Out of Bed, Napping

7) Sleep as a Trained Behavior
   - Essentials of Training – It's just like training your dog
     - Consistency
     - Pretraining Routine
     - Avoiding positive reinforcement of undesired behavior
     - Avoiding diluting positive reinforcement of desired behavior
     - Need for retraining when behavior deteriorates

8) Spirituality and Sleep

9) Cognitive behavioral therapy –
   - progressive muscle relaxation
   - guided imagery
   - biofeedback
   - stimulus control
   - medical hypnotherapy
   - restriction of time in bed

10) Frequent factors disturbing sleep
   - Alcohol – although it promotes sleep onset, alcohol leads to shallow, fragmented sleep
   - Caffeine – can stay in your system for 14 hours
   - Nicotine – at low doses, nicotine tends to act as a sedative, while at high doses it causes arousals during sleep
   - Daytime napping – only if sleeping well at night
   - Lack of exercise during day, too much exercise at night
   - Poor sleep environment – noise, distractions, other stressors associated with that space, temperature, positioning
   - Medications
   - Television
   - Pets

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SPINAL BRACING & NEW TECHNOLOGY IN LOWER EXTREMITY ORTHOTICS

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Many of us are striving to maintain our ability to independently ambulate. We notice that it takes just a little more effort to get going, maintain our balance and participate in our home and community activities/obligations. Some of us have decided to obtain help from our physicians who in turn refer us to therapists, orthotists, and other health care areas. (Pain management, nutrition clinics) We go, we listen and then we have to make decisions on what type of care we are going to accept, participate in.

Our minds want to keep going, but our bodies are telling us that a little less strain would be good for the day. Our joints are aching, our feet are yelping and our backs aren't as strong as they used to be and we find our knees buckling and once in a while we find ourselves on the ground trying to find a decent way to upright ourselves.. Thus, we make the decision to obtain help and eventually end up in front of a clinic team trying to figure out why we are having these problems and what to do for them.

Well, we all know why, whether or not we want to believe it. We are wearing out, getting weaker, getting older and getting tired. The clinic team evaluates us and talks their shop language to come up with a solution. Many of the solutions include the new technology that is slowly coming into the orthotic world. What is this new technology? How can it be applied and will I be safe with it? These are the questions that need to be asked and the orthotic plans using the new technology need to be considered very, very carefully.

When applying the new technology, physicians and orthotists alike need to make sure that patients are not put at any additional risk. This is most difficult when dealing with patients who have weak and or absent quadriceps/knee extensor muscles. The typical way of stabilizing patients with weak quadriceps was to always lock up their knee. Now, modern technology allows the knee to be locked in certain phases of gait and allows the knee to unlock at specific times during the gait cycle. If the need comes unlocked too early, the knee joint will flex prematurely and the patient is put at risk of the knee collapsing and a severe fall resulting in possible fractures and other damage.

Each and every patient dealing with post polio syndrome is unique, each patient has different muscle strength, skeletal development, and each one has a unique way of substituting for muscle weakness and imbalance and has done so for many years. Thus, understanding the complexities of polio gait, body substitution especially in the lower extremities is a necessity for polio clinic staff, physician and orthotists. Understanding the details of what a new knee joint will do and will not do becomes imperative. Not all new technological designs are going to work for everybody. Orthotic designs need to be distinctive individual for each and every patient. Careful fitting and involved follow-up programs are extremely important. New ways of walking, new ways of tolerating pressures and making a commitment to stay with and weaning into the new orthotic systems can bring some excellent success. However, catastrophic results can become nightmares when this new technology is used in the wrong way/ignorantly.

Polio patients who are seeking help must be their own advocates and make sure they are getting professional medical advice from qualified health care individuals. Patients need to take the time to ask around, call health care professionals and ask them about their qualifications. Many times, the local "down the street and around the corner type brace shops" may be alright for arch supports but may not be the ideal place to look for the type of assistance that will be needed to take care of the complex situations and challenges that will arise.

Polio patients need to recognize the quality of thorough evaluations and testing that may be necessary in order to understand the "big picture". Quality clinical evaluations and orthotic plans performed by qualified and experience health care professionals can and will help keep patients walking and limit the risks involved.

Remember, you the patient, are the most important member of the team and communication is the best tool you have in expressing your desires and concerns.

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SUMMARIES OF SELECT THERAPIES:
Experience Yoga

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This one-hour overview requires no previous experience with yoga or meditation and will be able to be done while sitting comfortably in your chair.

In 2003 Conemaugh Health System conducted research on an innovative approach to the management of post-polio syndrome made possible by an award from the Uniformed Services University (USU) of the Health Sciences. It was based on the work done by the Stanford University Chronic Disease Self Management study and included an exercise program based on Hatha yoga and a meditation program called Mindfulness-Based Stress Reduction. The results of this research are being used to develop an education program for patients with post polio syndrome and to create an ongoing data collection project documenting the results.

Most patients with PPS suffer from weakness, fatigue, and pain. Most medical research evaluating drug treatments for PPS (e.g., Prednisone, Amantadine, Pyridostegmine, and Anticholinesterases) have been disappointing. However, it has been shown that milder, less extreme forms of exercise may improve muscular strength and fatigue, leading some experts to suggest that the most viable treatment presently available involves reassurance and non-fatiguing exercise.

Our project involved 23 individuals with PPS. All participated in a 5 day retreat in Johnstown, PA followed by 12 weeks of home practice with a home study DVD specifically developed for this research project. All of the participants were asked a series of questions about how they were doing at three time periods during the research project; the first day of retreat, the last day of retreat and twelve weeks after the project was started. The PPS patients as a group noticed significant improvement over the course of the project in pain, fatigue, and weakness and as individuals, many felt that this program had been a transformation for them in their relationship to PPS.

These results showed significant improvement in a patient population where not much hope as been offered and where the lack of deterioration is often viewed as success. Not only did these individuals improve, but also at the end of 12 weeks they were actively involved in self-care.

In this session we will give you a taste of their experience beginning with an overview of self-management and living a healthy life with PPS and how our program helped empower individuals. We will then guide you through an overview of an adapted approach to Hatha yoga and finish with an exercise in Mindfulness-Based Stress reduction.

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SUMMARIES OF SELECT THERAPIES:
Experience Watsu

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Watsu: A Place to Start When You Are Physically Unable to Exercise

For people who are bedridden or in a wheelchair, exercise is a luxury that they can only dream about. Of course, movement is essential; it is life, it is health. Once regular and systemic movement becomes impossible, our entire quality of life begins to shift. So, is there an alternative to the state of "the spirit is willing, the body is weak"?

In my practice as a massage therapist, both on land and in water, I have discovered some gentle yet powerful moves that can be applied to individuals who can no longer exercise their own bodies. Like all good practices, the regularity and constancy is just as important as the actual modality that is chosen. Since the people that I see come in wheelchairs or on walkers, more coordination is involved because they also need a driver, someone to help lift, dress, etc. and sometimes actually someone to participate in each session with us. I fully appreciate how much more difficult it is to arrange for everyone and everything.

Due to all of these constraints, it is a tribute to my clients and their sheer will to make it happen, that I do see and have the privilege of working and learning with so many. Over the years, week after week, working with these fragile bodies has taught me so much about what is possible.

Aquatic therapy seems to be the best place to begin. The factors of water: buoyancy, hydrostatic pressure, resistance and sensory stimulation combined with warm water not only feels incredibly good, but makes the exercise of stretching and movement actually fun and enjoyable. How can something this fun be really good for you too?!? Having the client looking forward to the session and wholeheartedly participating is satisfying to the entire crew.

Watsu is a warm water (95 degrees) shiatsu massage that the client simply receives, no exertion is necessary and no lactic acid is produced. As the therapist, I am stretching, folding, rocking, cradling, pulling and twisting the client. Profound relaxation, rebalancing and a deep meditative state are the result. For anyone experiencing orthopedic or neurological problems, it can have amazing results. I see one young women (18) who is in a coma, another is an 83-year old man with Parkinson's, and another is a 33-year old man with brain injury. For individuals not so severely handicapped, Watsu can greatly assist them in returning more quickly to a healthier state and beginning their own exercise program. Again, I would recommend aquatic exercises, preferably AiChi (T'ai Chi) in the water. People with arthritis, fibromyalgia, hip or knee replacement or recovering from an injury find both of these modalities to have extremely rehabilitative effects.

Initially, the body feels tired and hungry, but after a few sessions, the body adjusts and begins to feel more energy and vitality. Health and balance have started to return. The effort is definitely worth it.

"It was said in Egypt, water is given to the soul as compensation for taking a bodily form. In water our bodies find the freedom the soul has lost."

Harold Dull

Accessing Holy, Sacred Realms While in an Aquatic Environment

Many of you have heard of Watsu, Wassertanzen and AiChi by now. These modalities have been available in St. Louis for over 6 years. Some coverage on TV, radio and magazines has brought some awareness of what these funny words mean.

Since I am the primary practitioner of this type of aquatic therapy and have given over 5,000 Watsus, and taught nearly 1,000 AiChi classes, I want to share with you some perspectives from these intense experiences.

Energy moves in our bodies at 100 times more powerfully in water than on land, i.e., an electric shock on land versus the same shock in water. It is our body's high electromagnetic conductivity in the water that makes all the difference. Interestingly, we also do not feel or sense pain as much in the water, and thanks to buoyancy and viscosity, we are able to move in ways that are literally impossible on land. These properties and more are what make aquatic therapy unique and an extremely powerful healing modality.

The temperature of the water is critical in achieving various results. In Watsu, a warm water shiatsu massage, skin temperature water is the most desired and beneficial, around 95 degrees. A comforting and deep state of relaxation is felt in all the muscle groups, as the body literally melts into the water. The client is then lifted and held by the practitioner while, very slowly, very gently, various stretches, yoga and tai chi moves, really a dance of movements, are commenced on the body. The eyes are closed and the ears are in the water and gradually this hypnotic state of being begins to release the body and mind in ways that are unspeakable, beyond words and thoughts. This profoundly altered state of being does not last for just a few moments, but for an extended period of time. Clients have commented that they escaped for awhile, but the truth is, they returned home to who they really are. And the more you receive the work, the deeper and more profoundly you move into this state of being for a longer time. It feels so heavenly, so unearthly, so peaceful and beautiful that all questions, concerns, and daily commitments and responsibilities simply are gone, erased, like they never existed. You are restored and feel better than you have in years and years. You have entered the state of silence with the degree of a master meditator, though you may know nothing of meditation or accessing this deeply altered state. It can be addictive, on the other hand, you feel more ready and willing to participate in your life and in your world than ever before. There's a renewed sense of courage and understanding, inner strength and peacefulness that fills the entire body and mind. The less you can talk about it, the more I know that you have received it.

Physically, some interesting aspects are noticeable immediately. Since I'm also a massage therapist and do land-based work, when I'm working on a body on the table, the body feels about its correct age. Either it is in good tone or not, but nonetheless, it 'feels' about the appropriate age. In the water, everything 'feels' much differently. The body returns to a child-like state of freshness, mobility, fluidity, and accessibility. It is truly amazing. The body, our divine child 'feels' truly lovely and ever so peaceful.

Watsu: Warm Water Shiatsu Massage

WATSU is a warm water shiatsu massage that is experienced more like a dancing meditation than a type of bodywork. The tremendous amounts of energy that are moved and released clearly makes Watsu a powerful form of bodywork, but the feeling that one has is mystical, very gentle, peaceful and healing.

Freeing the spine in a weightless environment is the cornerstone of a Watsu session. The therapist supports the client in 95°F water while gently rocking and stretching the back and limbs. Acupressure (Shiatsu) points are stimulated and muscles are massaged while the body is in a gentle motion. The body can then unwind to a profound degree easily and naturally and subtle healing energies, which are usually restricted, are allowed to circulate.

Movement and stillness are interwoven in harmony with the breath. This, combined with the feeling of weightlessness, warmth and the support of the water, induces a deep state of relaxation of body and mind. During Watsu, physical and mental tension, fear, muscle spasms, and joint restrictions dissolve. Clients find they have more flexibility and awareness.

Since all life began in the ocean and we are 70%, to 80% water, returning to an environment that closely resembles our conception and birth is healing to the deepest parts of our being. The key to the inner journey is allowing the mind to rest in a place of preconceptual thought and prelanguage. Watsu ever so gently assists the body and the mind in that delicate and beautiful process. It's a spiritual dance that calls forth healing in every cell of the body.

Energy moves 100 times more efficiently in water than on land. Working the energy centers of the body in the water is easier and more powerful than traditional bodywork. For people who are ill or deconditioned, Watsu is a soothing yet potent form of exercise that the body simply receives without exertion. No lactic acid is produced and the body grows stronger without tension. After several sessions, the client is usually ready to begin some simple stretching and movement on land, while continuing most of the exercising and strength building in an aquatic environment for a quicker and more stable healing.

In addition, in water our lower *Tan Tien* (about 2" below the navel and 2" deep) moves up to our middle *Tan Tien* or Heart Chakra to lend more strength to the opening of our Heart Chakra. Sometimes, Watsu is referred to as "Embracing and Opening the Heart."

During a Watsu session, the eyes are closed and the ears are in the water, so outside stimulation is minimized and the neocortex or higher rational brain, relaxes. A sense of space and time disappears, and if the body feels safe, the primitive brain, which directly or indirectly produces all the hormones in the body, is free to rebalance and repair. While the body is tense or experiencing various levels of distress, the neocortex is ever vigilant and on duty. Gently persuading the neocortex to relax and take a break is not usually an easy task. However, the warm water, flowing movements and support of the practitioner does facilitate very deep states of relaxation and rejuvenation of all the systems.

Land massage affects the various muscles of the body, but Watsu affects all the systems of the body, especially the inner organs. When the inner organs are massaged and relaxed, they release toxins which may feel like gas or bloating. Large quantities of fresh water are needed for the next 24 hours to facilitate the toxins flushing away. Immediately, the workload of the systems is easier and healing of the body can accelerate.

In spiritual terms, it has been likened to baptism or an initiation to the return of wholeness. One important feature of Watsu is the final movement or closure with the integration of mind and heart energies. To be balance, in harmony and fully integrated with body, mind, heart and spirit is the essence of inner peace and wholeness.

Watsu treatments are recommended for the following conditions: chronic pain, arthritis, neuromuscular disorders, chronic headaches, chronic fatigue, hyperactivity, autism, sleep disorders, anxiety disorders, cerebral palsy, multiple sclerosis, spinal cord injuries, polio, Rhett's syndrome, fibromyalgia, abuse issues, depression, addictions, Parkinson's disease and other diseases.

Aquatic Therapy: The Wonders of Water

Water is a miracle and a joy to experience and the long-term effects continue on the land, but generally, a person suffers a debilitating injury or illness before discovering the rehabilitative effects of water. Especially important in a good program are warm water, gentle movements and soothing music.

Outcomes of aquatic therapy include improved balance, coordination and motor skills (excellent for fall prevention), increased chest expansion and cardio-respiratory activity, increased weight bearing abilities, improved muscular endurance and strength, and decreased pain.

Therapy in the water works because of buoyancy, hydrostatic pressure, resistance and sensory stimulation. Water decreases joint compression and force reactions and therefore lessens arthritic, back, chronic pain or pain caused by surgery or injury . Water diminishes the effect of gravity. When submerged to shoulder depth, our bodies experience a 90 percent apparent weight loss. Clients move without joint stress and increase flexibility because buoyancy assists movement.

Movement is also less painful because of hydrostatic pressure, which tends to decrease edema and increase circulation to deep muscle groups. Hydrostatic pressure also assists in stabilizing unstable joints. Water supports the body and eliminates the need for walking aids.

Hydrostatic pressure on the chest wall stimulates chest expansion and deeper ventilation, which increases cardio-respiratory activity. With sedentary patients, there is a gradual decline in vital capacity. Movement in the water can improve it.

Muscular strength and tone will improve from working against the variable water resistance. The more force used against the water, the more "weight" the water carries. Moving through the water resistance requires co-contraction of the abdominal and back muscles, teaching central stabilization. Balance, proprioception and coordination can all be improved.

Water can have a positive effect on osteoporosis and bone density. It was once thought that heavy impact was necessary to maintain youthful bone density. It is now understood that working against resistance is what is required.

Sensory stimulation of the water increases kinesthetic awareness of body parts and also promotes greater relaxation. Water temperature is important and should be 87 F to 92 F for best results.

The socializing aspect is significant as well and clients enjoy meeting others and moving in a pain-reduced environment. Some of the clients' comment: "It's rejuvenating!" "It's addictive!" "My back no longer hurts." "Rapid recovery from knee surgery." "Aquatic therapy before and after surgery -- what a difference!" "Our hair and make-up don't get wet." "We like moving at our own pace." "The music is soothing." "For all ages, male or female, it's a great mix."

The program that is suggested by the Arthritis and Fibromyalgia Foundations are walking, gentle stretching, muscle and strength endurance, and relaxation.

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SUMMARIES OF SELECT THERAPIES:
Experience Reiki

Stephanie T. Machell, PsyD
Somerville, Massachusetts

What is Reiki?

Reiki (Ray-Key) is a word made up of two Japanese words (Rei and Ki) that translate as Universal Life Energy. Reiki energy is a positive healing energy that is present in everyone and everything throughout the universe. Everyone can utilize it for healing, though receiving the Reiki attunements allows one to utilize it in a more focused and powerful manner.

According to Einstein and quantum physics, matter and energy are interchangeable. All living beings, and all that is, can be seen as "denser" energy. When illness or disease is present, this energy is disrupted in various ways. The disruption of energy may even precede the onset of symptoms, and is therefore seen as the "fundamental" level at which treatment would be needed to produce full healing. Reiki and other energy treatments operate at this level to heal and rebalance the energy field.

Though the energetic level is viewed in energy medicine as more fundamental, Reiki is not a stand-alone treatment. It should be viewed as an adjunct to other medical and/or psychological treatment. When used as such, it can accelerate healing and the effectiveness of other treatment modalities.

Reiki is an "intelligent" energy. It goes where it is needed, whether that part of the body is treated directly or not. The recipient "draws" the energy that the body needs, and only that amount. Because it may not be clear to either practitioner or recipient what the greatest need is, it can be difficult to fully predict the outcome of a Reiki treatment.

During a Reiki treatment, the person being treated remains clothed (Reiki energy can penetrate a thick plaster cast). He or she sits or lies down on a massage table. The practitioner places his or her hands on or above the recipient's body in a series of hand positions. Areas needing more treatment may be focused on instead of or in addition to the standard treatment. Both practitioner and recipient can speak during the treatment.

The person receiving Reiki may experience heat, tingling, or even sometimes sensations like electrical shocks during treatment. Some individuals see colors or have "psychic" experiences. Most people experience a sense of relaxation and well-being that may persist after the treatment ends. Some experience pain relief that ranges from mild to significant. Research has found that Reiki treatments can accelerate wound and bone healing, recovery from surgery, and remission from depression and anxiety. It can also facilitate and accelerate healing from psychological trauma. It is helpful for all medical and psychological conditions, and is only contraindicated for those experiencing psychosis (NOTE: Insulin-dependent diabetics who experience Reiki should test carefully prior to using insulin, as Reiki can change dosage needed).

When Reiki is used for chronic (vs acute) problems, the recipient may experience an intensification of current symptoms or revivification of old ones. This is a healing crisis. While it doesn't happen to everyone, it is quite common. Other signs of a healing crisis may be increased output of bodily fluids and excreta (which may also have a stronger odor than usual), nausea and other "vague flu-like symptoms," fatigue, restlessness, more vivid dreams, and thoughts and memories of past unresolved events. These symptoms should pass in 24-48 hours. Supportive measures include drinking plenty of water and resting. Rescue Remedy (available at any health food store) can help if the discomfort is extreme.

Anyone can become a Reiki practitioner. Many healthcare professionals have taken Reiki training. Many excellent practitioners have no other training, but you may prefer to see someone who practices another modality as well. Many massage therapists have Reiki training, as do nurses and an increasing number of mental health professionals. There are even physicians who have taken Reiki training. While the highest level of Reiki training is Master Teacher, practitioners at other levels are quite competent to provide hands-on treatments (though not to teach).

Reiki is quite easy to learn. Level one classes are available just about everywhere, take 1-2 days to complete, and generally cost $150. Even children can learn Reiki. An advantage to taking Reiki training is that you will be able to self-treat. Many people take Reiki simply for this reason, and/or to treat family, friends, pets, and plants. You can interview a Master Teacher to see if you are comfortable with his or her approach, and possibly experience a treatment with him or her prior to taking a class.

The groundedness you need to fly as high as you can

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SUMMARIES OF SELECT THERAPIES:
Experience Myofascial Release

Nancy Caverly, OTR/L
Mexico, Missouri

MYOFASCIAL FREEDOM

Myofascial Release is a very effective hands-on technique that provides sustained pressure into myofascial restrictions to eliminate pain and restore motion. The theory of Myofascial Release requires an understanding of the fascial system (or connective tissue). The fascia is a specialized system of the body that has an appearance similar to a spider's web or a sweater. Fascia is very densely woven, covering and interpenetrating every muscle, bone, nerve, artery and vein as well as all of our internal organs including the heart, lungs, brain and spinal cord. The most interesting aspect of the fascial system is that it is not just a system of separate coverings. It is actually one structure that exists from head to foot without interruption. In this way you can begin to see that each part of the entire body is connected to every other part by the fascia, like the yarn in a sweater.

Fascia also plays an important role in the support of our bodies, since it surrounds and attaches to all structures. These structures would not be able to provide the stability without the constant pull of the fascial system. In fact, our bones can be thought of as tent poles, which cannot support the structure without the constant support of the guide wires (or fascia) to keep an adequate amount of tension to allow the tent (or body) to remain upright with proper equilibrium. In the normal healthy state, the fascia is relaxed and wavy in configuration. It has the ability to stretch and move without restriction. When we experience physical trauma or inflammation, however, the fascia loses its pliability. It becomes tight, restricted and a source of tension to the rest of the body. Trauma, such as a fall, whiplash, surgery or just habitual poor posture over time has a cumulative effect. The changes they cause in the fascial system influence the skeletal framework for our posture. The fascia can exert excessive pressure (more than 2,000 pounds per square inch) producing pain or restriction of motion. They effect our flexibility and are a determining factor in our ability to withstand stress and strain. The use of Myofascial` Release allows us to look at each person as a unique individual. One-on-one therapy sessions are hands-on treatments during which therapists use a multitude of Myofascial Release techniques and movement therapy. Independence through the enhancement of strength, flexibility and postural and movement awareness is encouraged.

For individuals who have paraplegia (paralysis of the trunk and legs) or paraparesis (weakness of trunk and legs), myofascial release is an important component of long-term care. Management of the body at and below the level of paralysis, paresis, generally includes neuromuscular reeducation, skin and joint protection, functional range of motion, and instruction in self-management of the legs in activities of daily living. There is a tendency to de-emphasize soft tissue management in areas at or below the level of paralysis. However, to do so is to risk decreasing the optimum function of the entire body.

An analogy can be drawn to wearing tights that have one leg twisted when you pull them over the feet and legs. A half twist in the foot creates significant torque by the time the material has been stretched over the thighs to the waist. The waist and thigh position can be readjusted; however, optimum comfort and ease of motion are not achieved until the twist in lower portion of the tights is corrected. Similarly, lower extremity and lower trunk myofascial restrictions, whether secondary to polio, spinal cord injury, multiple sclerosis, cerebral vascular accident, spina bifida, or some orthopedic surgeries have to be addressed to maximize comfort and ease of motion in the entire body. Such restrictions can add tension throughout the trunk and even into the neck, head and upper extremities. It is as if the twisted tights were part of a body suit. Individuals with this fascial tension an benefit by having their "body suit" periodically assess for myofascial restrictions and treated accordingly.

The hands of the therapist using myofascial release techniques are the change agents for the myofascial osseus system. With gentle pressure with both hands, the heat and piezoelectric effect produce change in the fascial system. Slow, sustained traction or compressions using the bony structure as levers can effect change, also. Patience and a heightened sense of awareness of subtle change are necessary for the therapist to practice. The body corrects itself, and the movement into the restriction and gradual release is controlled by the individual, not the therapist. Therefore, myofascial release is a safe treatment when performed by a competent therapist who has had training in the technique.

Another aspect of myofascial release is called myofascial unwinding. This occurs when, as noted above, there is created a flow of the body's bioenergy. his flow triggers the mind/body complex into spontaneous motion. The spontaneous therapeutic motion allows the body to assume positions in space that represent positions of past traumas. These positions of trauma represent one's subconscious fear, negative memories and/or pain that have created holding or bracing patterns which have impeded progress in the traditional therapeutic approach. It is these positions in space and the re-experiencing of this main memory which is never injurious, that take the threat out of the system and a the mind/body complex to let go of these holding or bracing patterns so that healing can commence. There must be the component of trust between therapist and client for the cleansing effect of myofascial unwinding to take place. An individual can learn unwinding, thus becoming his/her own therapist.

In the video, Myofascial Freedom, John Barnes PT, the founder and master teacher of Myofascial Release, discusses the components of the system and provides four techniques for self-therapy. The figures illustrate the positions for each technique.

Adapt the positions as needed if unable to maintain due to disability.

1. **Lower Leg Stretch – Gastrocnemius and soleus muscles.** Place one foot about two feet in front of the other; hold onto top of sturdy chair or table. Bend the knee of the foot in front, keeping the rear foot flat on the floor. Straighten up after lunge, repeat nine more times. Change front foot and repeat 10 times.

2. **Thigh-Hamstring muscles.** Lie down on bed or floor, on back. Flex (bend) both legs, placing feet on the surface. Put foot of one leg on the thigh of the other leg. Lift "other leg" off surface while pushing down with foot on thigh. Do this movement ten times, then change positions of both feet. Repeat movement ten times again.

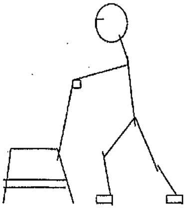
3. **Arm and Shoulder.** Using a bath towel, hold one end with right hand. Place towel over right shoulder and grasp with left hand behind chest. Pull with both hands ten times. Change positions with left hand and place towel over left shoulder, grasping behind chest with right hand. Repeat movement ten times.

4. **Head and Neck.** Hold bath towel ends in each hand, raising arms so that towel is just below the base of the skull on neck. Pull on both ends at the same time while gently pushing head back on towel. Relax. Repeat the movement nine times

Maintaining flexibility is important to the polio survivor, as the body parts – muscles and fascia of arms and legs in particular — will contract causing pain and pressure on weight bearing bones. Understanding the purpose and actions of the myofascial system allows the polio survivor to assist in having good posture and pain free movement.

Information for this presentation was compiled from articles by John T. Barnes PT from 1997 to 2004. To find out more about the Myofascial Release Seminars go to www.fascial.org or or call 1-800-FASCIAL. The Myofascial Release Treatment Centers are located in Paoli, PA, and Sedona, AZ. Seminars are open to therapists, physicians and lay people.

Positions for Flexibility-Strengthening Exercises:



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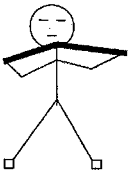

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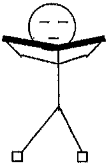

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EXPLORING STRATEGIES: Qi GONG

R. Charles Dumont, MD
Maywood, Illinois

What is Qi Gong:

Energy Mastery, Energy Exercise, "The (skillfull) practice of gathering, circulating and applying life-force energy." (Jeffrey Alan Johnson, *Chinese Medical Qi Gong Therapy*, 2000)

Benefits of Qi Gong:

- Calmness of mind
- Improved energy and sense of well-being
    - A Dentist's story
- Recovery from illness
- Functional physical problems
- Longevity
    - The story of Li Ching-yun

Origins and history of Qi Gong:

- Ancient origins, at least 5,000 years old
- Mixing with Indian and Tibetan energy work with introduction of Buddhism
- Evolution over centuries
- Term "Qi Gong" 20th century term

Elements of Chinese Medicine:

- An ancient and complex medical system > 2500 years old, Key principles are:
- Restoration of proper Qi flow
- Balance of Yin and Yang aspects of physiology
- Balanced relationship between organ systems

Qi and Meridians:

- Qi (Chi): The energy or life force which drives the functions of the body
- Qi moves through Meridians (channels) throughout the body
- Disturbance of the Qi flow causes disease/illness
- (Acupuncture) Inserting fine needles at specific points along a channel restores "balance"
- 12 principle meridians
- 8 curious meridians
- Over 350 "regular" channel points
- Discover Qi

5 elements and associated organs: Fire/Earth/Metal/Water/Wood
Principles of Yin and Yang

Stages of Qi Gong development:

1. Gather Qi 2. Circulate Qi 3. Purify Qi 4. Direct Qi 5. Conserve Qi
6. Store Qi 7. Transform Qi 8. Dissolve in Qi 9. Transmit Qi

Virtues: Discipline, Patience, Process, Intention, Effortless effort, Relax, Zen mind

Posture of Qi Gong: Relaxed, Open, Soft; Straight Back, Pelvic Tilt, Soft, relaxed shoulders, Slightly Bent knees, Head pulled to Heaven, Legs rooted to Earth

Breath: Breathing into the abdomen

Mind: Letting go of stray thoughts

"Learn to practice breathing in order to regain control of body and mind, to practice mindfulness, and to develop concentration." -Thich Naht Hahn

Time and Timing:

- First goal is commitment: This should be considered an important undertaking.
- Time
  - Don't overdo in beginning – 5-10 minutes
  - Build up time as seems appropriate –don't push
  - Best if 1-2/day
- Timing
  - Consistancy is important – this time should be sacred
  - Dependent on convenience and frame of mind at different times of the day.

The Setting:

- One should be able to do Qi Gong anywhere
- Clothing: comfortable
- Place
  - Quiet, peaceful setting: consider surroundings in the room or area, is this a peaceful room?
  - No distractions
  - If possible create a sanctuary
- Atmosphere
  - Silence or peaceful sound

Right Attitude:

- Zen Mind Beginners Mind: One's approach should always be fresh
- Maintain an accepting attitude
  - Its not about being perfect
  - Accept whatever happens

Resources:

From the Neijing Suwen: The Yellow Emperor's Classic of internal medicine,
translation by Maoshing Ni

Jahnke, R. *The Healer Within.* San Francisco: Harper Collins, 1997.

Jahnke, R. *The Healing Promise of Qi.* New York: McGraw-Hill, 2002.

Re'quena, Y. Chi Kung *The Chinese Art of Mastering Energy.* Vermont: Healing Arts Press, 1997.Cohen, K. Qigong: *THeArt and Science of Chinese Energy Healing.* New York: Ballantine Books, 1997.Chuen, LK. Chi Kung: *The Way of Healing.* New York: Broadway Books, 1999.

Website: National Qi Gong Association: nqa.org

R. Charles Dumont, MD
Associate Director, Integrative Medicine
Loyola University Health Systems
Maywood, Illinois

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EXPLORING STRATEGIES:
Acupuncture

Sue Harris, LicAc
Whole Person Health
Canton, Massachusetts

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PHI'S WEBSITE – www.post-polio.org:

What It Can Do for You and What You Can Do for It

Sheryl Rudy
Saint Louis, Missouri

WHAT www.post-polio.org CAN DO FOR YOU:

Post-Polio Health International's mission is to enhance the lives and independence of polio survivors and home ventilator users through education, advocacy, research and networking.

There are two main divisions of the website:

1. **Post-Polio Health International**
   For polio survivors, families and friends, and health professionals.
2. **International Ventilator Users Network**
   For home ventilator users, families and friends, and health professionals and manufacturers of equipment.

There are four sections within each division that addresses PHI/IVUN's mission:

1. **Education**
   Explore information for polio survivors, home mechanical ventilator users, families and friends, and health professionals.
2. **Advocacy**
   Investigate current issues related to the rights of people with disabilities.
3. **Research**
   Learn about PHI's Research Grant and opportunities to participate in research.
4. **Networking**
   Connect at meetings/conferences; receive and/or offer help.

What is offered from these sections?

1. Education

Post-Polio Health International publishes information related to the late effects of polio:

Post-Polio Health
A quarterly newsletter containing current information about the late effects of polio, updates about post-polio related and neuromuscular respiratory research, as well as articles that offer practical and useful advice by experienced survivors and health care professionals. An extensive list of past articles have been posted online and can be accessed easily from a "By Topic" list or from a "By Issue and Date" list.

Handbook on the Late Effects of Poliomyelitis for Physicians and Survivors

Easy-to-use and highly informative, PHI's 120-page book contains 90 post-polio related topics and is the compilation of the research and experience of over 40 experts.

Information about the late effects of polio ...
for polio survivors, for families and friends and for health professionals

Basic information about the late effects of polio for polio survivors, for their families and friends and for health professionals. (Also available online in Chinese, Farsi, French, German, Italian, Japanese and Spanish.) This is offered as a three-part brochure that can be easily separated to be given to the appropriate people. One copy is free and bulk rate fees are available for support groups and health professionals who provide educational information for their patients.

The Late Effects of Polio: An Overview

Basic information about the late effects of polio. Also available in French, German and Portuguese.

Post-Polio Health International's Presentations

PHI's Executive Director, Joan L. Headley, and other members of PHI present at meetings and conferences hosted by other organizations and we have provided access to her Powerpoint presentations online.

Polio and Post-Polio Fact Sheet

Information about polio and the epidemics, poliomyelitis in the world today and statistics about the late effects of polio. Also available in Chinese, Farsi, and French.

Post-Polio Task Force

Although disbanded in 1999 because the research was completed, the information in this section of PHI's website remains relevant today and includes a CD-ROM program developed for physicians and patient education about post-polio syndrome.

Wellness

Post-Polio Health International (PHI) encourages wellness for polio survivors and users of home mechanical ventilation.

FOR HEALTH PROFESSIONALS

Educational information specifically for health professionals. To be expanded on in the near future, this section begins with "For Physical Therapists and Physical Therapist Assistants." We welcome other health professionals to submit information for this section. Please contact Joan Headley at director@post-polio.org.

PHI will offer on the website other information that is pertinent.

Examples include:

- A Statement about Exercise for Survivors of Polio ... Written by the Medical Advisory Committee of Post-Polio Health International and endorsed by 29 post-polio experts.
- Summary of Anesthesia Issues for Post-Polio Patients ... Selma H. Calmes, MD, Olive View/UCLA Medical Center, provides cautionary advice for polio survivors. Also available in French and Spanish.

International Ventilator Users Network publishes:

Ventilator-Assisted Living

IVUN's quarterly newsletter that links ventilator users, their families, and peers with each other and with health professionals committed to home mechanical ventilation. An extensive list of past articles have been posted online and can be accessed easily from a "By Topic" list or from a "By Issue and Date" list.

Information about Ventilator-Assisted Living

A 12-page brochure that is an introduction to mechanical/assisted ventilation: what is it? who uses it? what types of ventilators? what types of interfaces? and more. One free copy is available as well as bulk pricing for large orders.

PHI continues to disseminate the following brochures for the March of Dimes ...

- "International Conference on Post-Polio Syndrome: Identifying Best Practices in Diagnosis and Care" (for health professionals) and
- "Guidelines for people who have had people who have had polio" (for polio survivors)

2. Advocacy

Investigate current issues related to the rights of people with disabilities. Stay informed and be pro-active.

Recently posted information includes:
Updates about activities in governments such as MiCASSA, the Medicaid Community Attendant Services and Supports Act that has been re-introduced in the Senate

Or updates from David Jayne who led the National Coalition to Amend the Medicare Homebound Restriction for Americans with Significant Illness (NCAHB)).

We connect to other groups involved in advocacy issues for people with disabilities, such as:

- AAPD and Justice For All Email Network, or connect to reports from President George Bush's New Freedom Initiative for people with disabilities.
- The National Council on Disability (NCD), an independent federal agency making recommendations to the President and Congress on issues affecting Americans with disabilities. www.ncd.gov.

3. Research

Learn about PHI's Research Grant and opportunities to participate in research. PHI established The Research Fund in 1995 dedicated to "seeking scientific information leading to eventual amelioration of the consequences of poliomyelitis and/or neuromuscular respiratory diseases."

The one million survivors of poliomyelitis in the United States, and the 12 million worldwide, know there are consequences of living and aging with a disability. They also know that funding for research into their problems is limited.

A panel made up of peers and people with disabilities reviews all grant applications that meet established requirements for respiratory research or post-poliomyelitis research. This panel's recommendations are reviewed by the PHI's Board of Directors, who make the final funding decisions.

Post-Polio Health International is a not-for-profit 501(c)(3); Federal ID No. 34-0961952. Tax deductible contributions can be made payable to Post-Polio Health International.

We have provided online copies of reports from the first two grant recipients. Ventilator Users' Perspectives on the Important Elements of Health-Related Quality of Life, presents the perceptions of the health-related quality of life of 26 individuals living in the community (Toronto and Edmonton, Canada) with long-term use of home mechanical ventilation due to neuromuscular disability or traumatic injury.

And, from the second grant recipient, "Women with Polio: Menopause, Late Effects, Life Satisfaction and Emotional Distress" presents the results of a nationwide study of the effects of aging on the lives of polio survivors comparing the problems of men and women.

4. Networking

- Information about Post-Polio Health International's conferences.
- Community Calendar. Meetings and conferences for polio survivors, users of home mechanical ventilation, health professionals, and other disability-related events.
- Polio & Post-Polio in the News. Media events, activities, etc. of the post-polio community.
- Ventilator Use in the News. Media events, activities, etc. of the community of people who use home mechanical ventilation.
- Can You Help? Send questions and receive answers about equipment, resources, ventilator use, etc., from online readers.
- IVUN'S Ventilatory Equipment Exchange. Offers of donated ventilatory equipment and aids are listed and requests can be submitted.
- What Works for Me. Shared peer advice from polio survivors and ventilator users.
- Post-Polio Directory. Clinics, health professionals, and support groups with knowledge about the late effects of polio.
- Resource Directory for Ventilator-Assisted Living. Health professionals, ventilator users, ventilator equipment and aids, manufacturers' addresses, and related organizations, associations, and foundations.
- Disability Resources. Websites and contact information for organizations, USA's governmental agencies, etc. with useful information for people with disabilities.
- People We Know. News about people who have made significant contributions to the disability community.

Other information on our website includes:

- Our Board of Directors, members of our Honorary Board, as well as our Medical Advisory Committee and Consumer Advisory Committee members, as well as editorial and web policies and contact information, as well as an explanation of PHI's history.
- Annual Reports
- Copyright requirements and a simple online request form
- Editorial policies for our print and online publications

WHAT YOU CAN DO FOR www.post-polio.org:

Become a Member!

You can access the Membership Opportunities page from most pages on the website, and select the level that suits your needs.

Register easily online, where we provide a secure site on which you can safely enter your information.

Help us keep the Directories current by responding to our requests to update.

Stay involved and informed!

Submit your articles, advice, requests, and comments to director@post-polio.org or webmaster@post-polio.org.

Spread the word!

Tell your associates about PHI. One benefit of Sustainer Membership is an additional complimentary Subscriber Membership for a person of their choice or for a person who has expressed financial need to PHI.

www.post-polio.org

Featured in recent article, "The Informed Patient: Web Grows as Health-Research Tool"
in *The Wall Street Journal*

SESSION IV OPTIONS

3:15 pm – 4:30 pm

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PAIN AND POLIO: PITFALLS, MYTHS AND REALITIES

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FINDING TECHNOLOGY TO MAINTAIN INDEPENDENCE

David Gray, PhD
Saint Louis, Missouri

What is the EMC?
The Enabling Mobility Center (EMC) is a facility open to persons with disabilities, their families, independent living specialists, healthcare professionals, researchers, engineers, vendors and the general public.

Mission: Improve the quality of life and increase community participation of people with mobility impairments.

Goal: Provide a new approach to testing, training and recommending assistive technology and services for the disability community.

Research: Use assistive technology outcome measures to track participation in community activities by people who use mobility devices.

What the EMC offers:

- Community-based Research
- Accessible Exercise Programs
- iBOT 3000 Evaluation & Training
- Assistive Technology Education
- Mobility Skills Course (evaluation & training)
- Assistive Technology Consumer's Fair
- Vendor Demonstrations
- Demo Equipment Available
- Cushions & Pressure Mapping
- Peer Consultant Groups
- Volunteer and Student Placement Opportunities

Enabling Mobility Center (EMC)
6665 Delmar, Saint Louis, Missouri 63130
314-725-6676, ext. 101, TTY: 314-567-5552
morgank@wustl.edu, http://enablemob.wustl.edu

FINDING TECHNOLOGY TO MAINTAIN INDEPENDENCE:
Assistive Technology

Laura Ryan, OTR/L
Kristine Muldoon, MSPT
Framingham, Massachusetts

Assistive Technology: Any item, piece of equipment, or product system, whether acquired commercially, off the shelf, modified or customized, that is used to increase, maintain or improve the functional capabilities of an individual with disabilities. (29 U.S.C. Sec 2202-2)

Goal of AT:

-- To provide physical assist due to weakness
-- To reduce energy consumption
-- To reduce pain and/or chance of injury

"Low Tech" Assistive Technology

"High Tech" Assistive Technology

Driving

Role of OT :

-- To establish the individual's needs from a physical perspective
-- Act as a liaison between the client and the Adaptive Driving Specialist

Case Study

Resources/References:

Goldtouch	www.goldtouch.com
Contour Design	www.contourdesign.com
Ergonomic Concepts	www.ergoconcepts.com
Kinesis Computer Ergonomics	www.kinesis-ergo.com
Sammons-Preston Rolyan	www.sammonspreston.com
Alimed, Inc.	www.alimed.com
Workrite Ergonomics	www.wrea.com
National Mobility Equipment Dealers Association	www.nmeda.org
National Highway Traffic Safety Administration	www.nhtsa.dot.gov
CJ-Education Resources	www.cj-education.com

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HOW SELF ASSESSMENT CAN HELP YOU OBTAIN BETTER CARE FROM HEALTH PROFESSIONALS

Mary Kinane, BA, PGCE, Chair
Hilary Hallam, FIST, Founder, Secretary and Newsletter Editor
Denise Carlyle, BA, MA, PhD, LRAM, Treasurer
Lincolnshire Post-Polio Network, U.K.

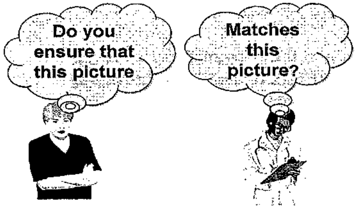
The most reported problem to our Network, not only from the U.K., but from around the world, is that the assessment that has taken place did not find evidence of the symptoms/level of symptoms being reported.

Polio Survivors often spend months, sometimes years, putting off going to a doctor to find out why they are experiencing pain, fatigue and functional decline. To then be told that there is nothing or little wrong with them causes considerable stress. Each negative appointment causes frustration, anger, and more stress that makes our medical condition worse

Again and again, through lack of knowledge about polio, they tell us that they had what must have been a mild case of polio because they recovered so well and managed so much in their lives. Regardless of level of recovery they are so proud of their achievements. Then comes the but ... But, after a fall, an operation, an accident, a period of huge stress, something changed because from then on the harder they pushed the worse they got. Their lives are changing so much why are they having such a hard time getting medical help?

So why is this happening? We have highlighted eight possible reasons that we believe should be taken into consideration.

1. Not enough facts about Polio and its late effects are being taught in Medical Schools.
2. Interpretation of facts in medical articles.
3. Diagnoses were made using test results, physical examination and clinical observation of the weakest part of the body.
4. The extent of recovery from Polio is often not realised.
5. There are no tests for PPS. It is a diagnosis of exclusion.
6. The way we present our symptoms.
7. The ways questions are asked, and the ways we answer.
8. Manual Muscle Testing – validity and reliability.



Lincolnshire Post-Polio Network - 2003

We will then show how self assessment can provide us with more information so that we can answer questions more accurately and ensure that the picture in the health professionals mind matches ours.

We do ourselves no favours when asked, "Can you get up a flight of stairs?" in just saying "Yes", without adding, "but I go up one step at a time pulling myself up each stair with my arms, and for the last year or so have had to stop halfway and rest, but five years ago I was able to walk up and down normally and carry items.'

Polio Survivors are notorious for being strong willed, determined and not requiring help to do even quite heavy tasks. Unfortunately we are also highly skilled in not 'seeing' or wanting to 'see' that we now need some help, human and/or aids and assistive devices. We expected that we might have to change the way we lived our lives when we got old – about 90 – but not in our 40's, 50's and 60's.

Polio Survivors have a variety of muscle weaknesses in a variety of areas. There is no set pattern – a nightmare for health professionals. We will demonstrate a few of the changes that we have noticed in how we go about our lives. If they way you do an action of daily living has changed in the last few years then there has to be a reason or number of reasons for this.

We know that making notes is a good idea so we don't forget anything, but arriving with pages of them and articles off the Internet is more likely to set up a barrier than be helpful.

Appointment times are limited – there will probably not be time to discuss more than a couple of issues. To help you remember dates and medical facts it is an excellent idea to make up a large file on yourself containing anything you consider relevant, including newspaper items, certificates, a couple of photographs, covering:

1. Medical History
2. Work History
3. Physical Ability before current problems [Include sports, exercise, hobbies, crafts, d.i.y., housework, etc].
4. Problems with diagnosis, assessment, treatment, employer's understanding of your new problem, welfare applications etc.
5. Current problems.

We can be better prepared if we write notes on what we want to discuss at the appointment. We can look at the file and take out the relevant information. Now look at your notes again as if you were the health professional at this appointment. If you were doing the report at the end of this appointment, what facts would you write down?

Health professionals have a variety of ways of running their appointments and we cannot dictate how the appointment will go. We can however set the scene with a 'Good morning Dr. X, thank you for seeing me about my ...." "I have made a few notes so that I don't forget anything and thought you might like a copy for your records."

Remember the health professional is seeing you as you are now, they do not know what you were capable of five, ten, twenty or more years ago. They may think Polio, and go back to the short lecture they were given at College and assume you have been as you are now since your polio.

What is important is the change in how you do actions of daily living. Why have you changed the way you do this action?

As an aide to writing your own report we provide a three columned sheet of actions of daily living. See next page. We appreciate there is little room in each block to write down more than a few words. You can either write up the information on a separate sheet of paper, making short notes that will fit, or use this as a basis for your own chart. If you can show a series of changes for some actions, then do a chart just for them with added columns.

Then grade them starting with the action that shows the highest level of change. The two or three actions that show the biggest change are the ones to demonstrate.

With the assistance of Gill Weir, a Senior Physiotherapist in the U.K. we also provide an assessment chart that can be used when examining you. It is important for continuity that the position you are examined in is recorded, e.g. if you were standing or sitting.

	Before	Now
Posture		
Gait		
Walking without aids		
Walking with aids		
Walking carrying items		
Standing without aids		
Standing with aids		
Going up and down stairs		
Using stairs carrying items		
Getting in/out of dining chair		
Getting in/out of arm chair		
Getting in/out of bed		
Turning over in bed		
Getting in/out of car		
Getting up/down from floor		
Working whilst sitting on floor		
Using bath		
Using shower		
Washing hair		
Shopping for food		
Shopping for other items		
Housework - dusting		
Housework - vacuuming		
Changing duvet cover/bed		
Kitchen - stand/sit		
Kitchen - use hands at sink		
Kitchen - hands peeling veg		
Kitchen - beating/cutting		
Using desktop computer		
Using laptop computer		
Clapping action		
General work in workshop		
Sawing, sanding etc.		
Gardening - heavy work		
Gardening - planting/weeding		

Decorating - wallpapering		
Decorating - painting		
Craft -		
Sport -		
Driving in town		
Driving long distances		
Driving - change to auto?		

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PHI SECOND RESEARCH AWARD: Women with Polio and the Menopause Study – Practical Advice Behind the Data

Claire Kalpakjian, PhD
Sunny Roller, MA
Ann Arbor, Michigan

The primary objective of this study was to begin to understand the experience of menopause in women who are post-polio – from their symptoms to their emotional well-being to their use of hormone replacement therapy (HRT). At the heart of this exploration is to better understand whether menopause has an impact on post-polio symptoms, and if so, in what way or whether post-polio symptoms and functional limitations have an impact on menopause. We had three primary objectives for this study: To explore the: 1) relationship of menopause, post-polio symptoms and physical functioning; 2) relationship of menopause to life satisfaction and emotional distress; and 3) efficacy of HRT in reducing menopause symptoms and improving physical functioning and emotional well-being.

There were 909 women who participated in this study – the youngest was 34 years old and the oldest 91. One of the ways that we compared women on a variety of factors related to menopause was by *menopause status*. One of the most common ways to establish where a woman is along this continuum is by her menstrual cycle characteristics. Pre-menopause refers no change in the menstrual cycle; not surprisingly, only 20 women (2%) were pre-menopausal. Peri-menopause refers to a time when changes in the menstrual cycle and symptoms begin to emerge; the time of peri-menopause can vary greatly and is difficult to clearly identify its beginning. In this study, 89 (9.8%) women were peri-menopausal. The final menstrual period or FMP is the threshold over which a woman moves into the final phase of the reproductive life cycle, that is postmenopause. Twelve months after the FMP and a woman is considered post-menopausal. The average age of the FMP for women in the United States is 50 years old.

Natural menopause refers to the ending of menstruation by natural means, that is no hysterectomy or other cause. For women in this study, 43.2% (N = 392) of whom were naturally menopause, they experienced their FMP at an average age of 50 ± 3 years, just like the average for their non-disabled peers. Some researchers have asserted that women with disabilities experience their FMP early, but it is not entirely clear why. Nevertheless, for the women in this study, their age at FMP was normal. Postmenopause can be further sub-divided into *early* and *late* stages. Early post-menopause is defined as less than 5 years since the FMP and late postmenopause is the time thereafter. For women in this study , the majority were in the late postmenopausal (N = 640, 70.3%) stage with far fewer women who were in the early postmenopausal stage (N = 112, 12.3%); 47 women were missing FMP data and could not be classified as early or late.

Approximately a third of women in the sample had had a hysterectomy, with 16.6% (N = 151) having had a hysterectomy without ovary removal and another 17.6% (N = 160) who had a hysterectomy with ovary removal. The average age at the time of their hysterectomies was 40 ± 8 years. Rates of hysterectomy from the polio sample were compared to the 2002 CDC's BRFSS Survey. First, the overall rate of hysterectomy between all BRFSS women (N = 148,702) and the polio sample was compared and a significant difference was found (34.7 vs. 20.8%, respectively). However, upon closer examination, approximately a third of BRFSS sample was comprised of women under the age of 40 (N = 50,070) and for whom hysterectomy rates are quite low. So we took a sub-sample of women 40+ years of age and compared them to the polio sample and there was no significant difference in overall hysterectomy rates. Further examination of hysterectomy rates by age groups found no statistically significant differences except for women 65+ years; significantly fewer women with polio than expected had had hysterectomies compared to the BRFSS women.

There are many factors that influence a woman's experience of menopause symptoms. For example, a woman's ethnic background, stressful life events, psychological disposition, social circumstances and attitudes towards menopause can affect the kind of symptoms she experiences and their intensity. As a result, there continues to be much debate over whether there is a true menopause "syndrome." Symptoms most closely associated with declines in estrogen are hot flashes and though they are experienced by a majority of women (50% to 80%), the underlying mechanisms of them are not well understood. Despite many womens' belief in the connection between depression and menopause, psychological symptoms have been the *least* associated with hormones; instead, many argue that around the time in life that menopause occurs, so do other stressful life events such as simultaneously caring for children and aging parents, declines in health or bereavement and that these life circumstances, rather than hormonal changes, are more influential on emotional well-being. Some also have suggested that menopause is a sort of *vulnerability factor*; for women who already have a stressful life, menopause serves to heighten that stress thus making psychological symptoms worse. One of the challenges in measuring menopause symptoms in women with physical disabilities is that some symptoms overlap which makes it hard to distinguish whether problems are due to menopause or post-polio or perhaps even both.

Among women in this study, the majority (N = 649; 71.4%) had used HRT at one time; less than half (N = 357; 39.3%) were currently using it. The majority of HRT users were taking either oral unopposed estrogen or oral estrogen/progestin. Using 2002 HRT prevalence data from a combined sample of 16,586 women [32], rates of HRT use by oral combined estrogen/progestin and oral unopposed estrogen alone were compared to the polio sample. For both types of HRT, rates of use among women with polio were significantly higher than expected. There were no differences between HRT users and non-users on any of the menopause factor groups, emotional well being, post-polio symptoms or physical functioning.

Because little is known about the risk-benefit ratio of HRT use among women with disabilities and in light of these findings, a woman's decision to use HRT should be carefully considered with her physician and within the context of her own individual risk profile.

Because so little is known about menopause – a normal biological milestone in every woman's life – and its unique characteristics in women with physical disabilities, women who are post-polio are, fairly or not, are put in the position of having to educate both themselves and their health care providers about how they may differently experience menopause. The findings from this study provide them with some of the first evidence that their experience of menopause – physiologically, physically, psychologically – may be different in some important ways from their non-disabled peers. *Optimizing their health at all levels and knowing their own unique risk profile as it relates to both menopause and aging is perhaps the most important message from this study's findings.* While there remains much to be learned about menopause in the context of disability, this study – the first of its kind with such a large population of women with physical disabilities – has taken the important first step to what we hope will be the start of a generation of menopause studies that no longer ignore women with disabilities.

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MAINTAINING PULMONARY HEALTH:
Monitoring and Preventing: What You Can Do

Diana Guth, RRT
Home Respiratory Care, Los Angeles, California
Betsy Thomason, RRT
Millennium Respiratory Services, Whippany, New Jersey

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MAINTAINING PULMONARY HEALTH:
The Importance of Cough

Augusta Alba, MD
Roosevelt Island, New York

What is a cough?

A cough is a reflex that results from stimulation of airway sensory nerve receptors. Fibers from these receptors send impulses to a brainstem cough center This center triggers a motor response of full inspiration, closure of the larynx, rapid buildup of tension in expiratory muscles, opening of the larynx with maximal contraction of the expiratory muscles producing an expiration with supramaximal force.

In a normal adult 2 liters of air are expelled at flows of up to 20 l/sec. Cough flows less than 162 l/min (2.7 l/sec) have been found to be ineffective in clearing secretions.

During respiratory infections the vital capacity and peak cough expiratory flow (PCEF) are decreased because of fatigue, increased respiratory muscle weakness and mucus plugging. When a person is sick, any bulbar weakness, which produces dysphagia, also worsens. There is incomplete or weak laryngeal closure and poor swallowing, which leads to aspiration into the lungs.
(Note: There are over 4 million references to COUGH on the Internet.)

Cough peak flows and extubation outcomes:
A study was performed on patients who were on a ventilator attached to an endotracheal tube and who had passed a spontaneous breathing trial. They were extubated. Those with unsuccessful extubations had a peak expiratory flow (PEF) equal or less than 60 l/min (l.1 l/sec). Those with successful extubations had a PEF equal or greater than 80 l/min (1.4 l/sec). The patients with the lower PEF were five times more likely to have an unsuccessful extubation, and were 19 times more likely to die during that hospital stay than the group with the higher PEF. Both of these values are remarkably low compared to the 2.7 l/sec needed to move secretions, but still a difference was found.

Simulated cough:
The Cough Assist machine (J.H. Emerson Co., Cambridge, MA, USA), with a two-stage centrifugal blower, provides an inspiration close to total lung capacity, and then abruptly applies negative pressure to the airway to produce high expiratory flows. Maximal insufflation-exsufflation (MI-E) settings and cough peak expiratory flow (CPEF) are closely related. Maximum pressure applied is 60 cm H20. Each cycle is usually 2-3 seconds.

This machine can produce a CPEF of more than 7.5 L/sec as compared to 4.3 L/sec with a deep inspiration followed by manually assisted forceful expiration with abdominal compression.

One treatment is usually five cycles followed by a period of normal breathing or ventilator use for 30 sec to avoid hyperventilation

Studies were done with a standard lung model to establish pressure, volume, and flow relationships on the Cough Assist machine.

Pressures of 40 to -40 cm H20, an insufflation time of 3 sec and exsufflation time of 2 sec produced an exsufflation flow of 4 l/seconds A plateau insufflation volume of 3.8 l was reached after 4.9 sec of insufflation.

Pulmonary emptying time constants (expiratory time) range in vivo from 500 to 2000 milli-seconds, or 0.5-2.0 sec. An artificial cough generator, and a lung-airway model showed that if emptying time was 0.5 sec, the CPEF was 7-9 l/sec, whereas if 2 seconds emptying time was used, the CPEF was reduced to 1-2 l/seconds. A maximal compression of 55 cm H20 was used.

Decreased pulmonary compliance and increased airway resistance produce a decrease in exsufflation flow and volume. Pressures of 40 to -40 cm H20 are adequate for most patients, but higher settings are required when lungs inflate less freely, as in obesity, scoliosis or bronchospasm.

MI-E and pulmonary disorders:
In amyotrophic lateral sclerosis (ALS) it has been shown that oxygen saturation and peak inspiratory pressure increased; mean airway pressure and work of breathing decreased with MI-E through the tracheostomy tube to clear secretions. Only work of breathing decreased with tracheal suctioning.

In neuromuscular disorders with scoliosis surgery, post-operatively tracheostomy has been avoided with MI-E.

In airway disorders such as bronchial asthma, pulmonary emphysema, and bronchiectasis MI-E has also been shown to be of value in managing secretions.

MI-E and noninvasive ventilation:
Secretion removal is of utmost importance for the person who is using noninvasive ventilation.

Positioning the individual in an upright sitting position increases the resting volume of the lungs (functional residual capacity or FRC) by 20-30% from passive descent of the diaphragm with gravity.

This makes the bronchial tree larger, airway resistance is less and secretions are more easily removed. Patients who can bend forward can increase intra-abdominal pressure and further assist the cough.

High frequency oscillation (HFO) of the airway and chest wall as an alternative for simulated coughing for secretion removal:
It is postulated that high-frequency chest wall compression (HFCWC) acts by:
- reducing the viscosity of mucus, making it easier for the mucus to be moved to the larger airways by expiratory airflow;

High frequency oscillation (HFO) of the airway and chest wall as an alternative for simulated coughing for secretion removal (continued):
- reinforcing mucus interaction with the airway cilia and the natural harmonics of the chest wall with optimal frequencies for clearance of 13-15 Hz;
- stimulating the release of fresh secretions by a vagal reflex mechanism. These secretions are more easily mobilized.

HFCWC is considered to be more effective than HFO of the airway in mobilizing secretions. HFCWC is produced by The Vest (Advanced Respiratory, St Paul, Minnesota). It can be self-administered with a foot pedal. Pulse frequencies vary from 5-25 Hz, with pressure in the vest ranging from 28 mm Hg at 5 Hz to 39 mm Hg at 25 Hz.

HFCWC is also available as one feature of the Hayek Oscillator ventilator, which uses a chest cuirass (Breasy Medical Equipment Ltd, London, United Kingdom)

Percussion therapy is a physical therapy technique in which an electrically driven pad vibrating at frequencies of 29-49 Hz with the patient in a reclining position is used to assist mucus clearance. Experiments have not shown it to be as effective as HFCWC, which operates at lower frequencies.

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PEDORTHIC SOLUTIONS:
Improving Balance and Stamina through Pedorthics

Edith James, C.Ped.
Saint Louis, Missouri

I. Stamina and Energy

- A. Maintaining stamina and strength means movement
- B. Conserving stamina through efficiency via pedorthics
  1. Our foundation
  2. Improving and shoring up foundation
  3. Being good to yourself

II. Stability and Safety
  A. Proper fit
  B. Wider is better
  C. Shoes shaped like feet
  D. Healthier functioning
  E. Leg length discrepancies

III. Case Studies

IV. www.cpeds.org to locate the certified pedorthists in your area
  A. Pedorthists are the shoe fitting experts of the medical field
  B. Insurance benefits

Edith A. James, C.Ped. and founder of Comfort Shoe Specialists
12133 Manchester Road, St. Louis (Des Peres). MO 63131
www.ComfortShoe.com

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PEDORTHIC SOLUTIONS: Pedorthic Management of Post Polio Using Baby Steps

Dennis Janisse, C.Ped.
Milwaukee, Wisconsin

Conditions that may need to be treated
1. Pes Cavus foot (High Arches)
2. Varus heel
3. Forefoot valgus
4. Inverted forefoot
5. Metatarsalgia
6. Mis-mated feet
7. Leg length discrepancies

Treatment objectives
1. Accommodate toe deformities
2. Relieve pressure (metatarsals, lateral border)
3. Control flexible conditions
4. Accommodate rigid conditions
5. Provide shock absorption
6. Balance weight bearing
7. Improve gait
8. Proper shoe fit

Modalities to accomplish objectives

1. In shoes
2. Custom shoes
3. Shoe modifications
4. Foot orthoses

In Depth shoe/custom shoes

INCLUDE

1. Strong counter
2. Adequate toe box
3. Shock absorbing sole
4. Removable insole
5. Wide range of sizes and widths

PROVIDES

1. Shock absorption
2. Control varus heel
3. Cushion metatarsals
4. Accommodate toe deformities
5. Accommodate custom foot orthoses
6. Mis-mated sizes/proper shoe fit

Shoe Modifications

SOLE AND / OR HEEL EXTENSION

1. Accommodate leg/foot length
2. Balance weight bearing
3. Improve gait

LATERAL SOLE AND HEEL FLARE

1. Control varus heel
2. Control supination

ROCKER SOLE WITH APEX PROXIMAL TO METATARSAL HEADS

1. Relieve metatarsal heads
2. Provide shock absorption
3. Decrease motion and take off stress
4. Replace lost motion

CUSHION HEEL

1. Absorb shock at heel strike

FIBER GLASS LATERAL COUNTER

1. Control varus heel
2. Control supination

FOOT ORTHOSES

1. Cushion foot
2. Relieve metatarsals
3. Control varus heel

FLEXIBLE ORTHOSES WITH METATARSAL RELIEF AND P.Q. VISCO ELASTIC POLYMER FOR METATARSALS

1. Cushion foot
2. Relieve metatarsals
3. Control varus heel
4. Extra relief for metatarsal heads

FLEXIBLE ORTHOSES WITH METATARSAL PADS AND P.Q. RELIEF FOR 5TH METATARSAL SHAFT AND 5TH METATARSAL HEAD

1. Cushion foot
2. Relieve metatarsals
3. Control varus heel
4. Relieve pressure on lateral border of the foot and metatarsal heads

LATERAL FOREFOOT POST

1. Help control varus heel
2. Compensate for forefoot valgus
3. Relieve pressure on lateral border

HEEL EXTENSION

1. Accommodate equinus deformity
2. Balance weight bearing
3. Improve gait

Summary

BIOMECHANICAL KNOWLEDGE IS NECESSARY WHEN PRESCRIBING

TREATING ONE OR A COMBINATION OF ALL MODALITIES MAY BE NEEDED

1. Shoes
2. Foot orthoses
3. Shoe modifications
4. Custom shoes

RIGID AND FLEXIBLE CONDITIONS ARE TREATED DIFFERENTLY

COMPLETE PRESCRIPTION IS NECESSARY

RETURN VISITS AS NEEDED

OPEN COMMUNICATIONS

1. Doctor
2. Patient

National Pedorthic Services, Inc.
7283 W. Appleton Avenue
Milwaukee, WI 53216
414-438-1211, 414-438-1051 fax

POST-POLIO HEALTH
INTERNATIONAL

POST-POLIO HEALTH INTERNATIONAL
INCLUDING INTERNATIONAL VENTILATOR USERS NETWORK

Gini Laurie

Founder of PHI

Gini was the nickname of Virginia Grace Wilson Laurie, the catalyst for the post-polio and independent living conferences that began in 1981.

Gini often claimed that polio was the motif of her life. Named after two sisters who died during a polio epidemic in Saint Louis, Gini was born the following year in 1913. She grew up sensitized to disability issues by her close relationship to her brother Bobby who had been disabled by polio during the same epidemic that took the lives of their older sisters. In the 1950s, Gini lived in Cleveland, Ohio during the polio epidemics and served as a Red Cross volunteer at the respiratory polio ward, the Toomey Respiratory Center.

In 1958, Gini inherited editorship of the *Toomey j Gazette*, a small mimeographed newsletter to help polio survivors keep in touch with each other. Over the years, this newsletter evolved into *Rehabilitation Gazette*, an international journal of independent living by people with disabilities. *Rehabilitation Gazette* connected people with disabilities and provided accurate, practical information, earning Gini the title of "one of the grandmothers of the independent living movement." In 1974, she helped found the American Coalition of Citizens with Disabilities.

Gini recognized the significance of a 1979 letter from a polio survivor describing what is now known as the late effects of polio. In 1981, she instigated the first international conference on post-polio problems.

In 1986, Gini received the prestigious St. Louis Award, recognizing her work "as an historian, researcher, and advocate for the right of persons with disabilities to live independently."

Gini Laurie died in 1989, not long before the Americans with Disabilities Act at last realized her goal of equal rights for people with disabilities. She is remembered as a motivator for everyone, demanding that each individual, with a disability or without, live life to its fullest. She believed in the dignity of each individual and believed, as she often said, that "Peopleness is the only thing that matters."

The Missouri History Museum (314-746-4599, www.mohistory.org), at the junction of Lindell and DeBaliviere Boulevards in Forest Park in Saint Louis, honored Gini Laurie within a display on disability rights, "Seeking St. Louis - Reflections," located on the upper level of the McDonnell Douglas Gallery.

THE POST-POLIO HEALTH INTERNATIONAL AND INTERNATIONAL VENTILATOR USERS NETWORK LEGACY AWARDS

June 3, 2005 Friday evening
Dinner 6:30 to 7:30 p.m. (ticket required)
Presentation of Awards 7:30 to 8:00 p.m. (open to all registered participants)
Entertainment 8:00 p.m. (open to all registered participants)

SPONSORED BY RESPIRONICS, INC.

Post-Polio Health International including International Ventilator Users Network grew out of the work of founder Gini Laurie. She was a remarkable woman who left an impressive legacy of service, advocacy, and dedication to the health and independence of polio survivors and individuals who use home mechanical ventilation to help their breathing. In honor of Gini Laurie, the Post-Polio Health International's Board of Directors and Executive Director have initiated the Post-Polio Health International and International Ventilator Users Network Legacy Awards.

These awards recognize individuals, organizations, and a foundation for their own exemplary accomplishments. Their outstanding past, present, or ongoing achievements reflect Post-Polio Health International's value of health education, networking, advocacy and research.

March of Dimes

Post-Polio Health International presents the March of Dimes with a 2005 Post-Polio Health International Legacy Award in recognition of past and more recent exemplary contributions to polio survivors. In the past, March of Dimes funded medical care and research that developed effective polio vaccines. More recently, March of Dimes has supported PHI's mission by donating funds and underwriting the publication of the 1999 *Handbook on the Late Effects of Poliomyelitis for Physicians and Survivors*. In 2000, the organization sponsored the "International Conference on Post-Polio Syndrome: Identifying Best Practices in Diagnosis and Care" inviting post-polio experts from around the world. Their findings, published in two booklets – one for consumers and another for health care providers – have increased the understanding of post-polio syndrome facing polio survivors today.

The March of Dimes is a national voluntary health agency with chapters in all 50 states and more than three million active volunteers. Today it works to save babies from birth defects, premature birth, and other leading causes of infant death and disability. The March of Dimes accomplishes this through programs of research, community services, education and advocacy.

President Franklin D. Roosevelt, a polio survivor, founded the March of Dimes. Over 40 years ago, the organization completed its original mission by supporting the development and widespread use of safe and effective polio vaccines. However, it has not forgotten its historic legacy. In 1999, the March of Dimes convened a Steering Committee of experts charged with identifying the best practices in diagnosis and care for post-polio syndrome. In 2000, the Committee held an international conference on post-polio syndrome. The results of the findings from this conference produced two March of Dimes publications: *Post-Polio Syndrome: Identifying Best Practices in Diagnosis and Care*, for health care providers, and a second report to assist people with post-polio syndrome, *Guidelines for People Who Have Had Polio*. These reports are available free online at: www.marchofdimes.com/files/PPSreport.pdf and www.marchofdimes.com/files/p-psbro.pdf

For more information, visit the March of Dimes web site at: www.marchofdimes.com or its Spanish language web site at: www.nacersano.org

March of Dimes
Saving babies, together

"In developing countries, where polio outbreaks still occur or have only ended recently, medical systems will face post-polio syndrome for decades into the future with little knowledge or understanding of this condition. Even in advanced countries, including the United States, many doctors are not trained to recognize post-polio syndrome or are reluctant to recognize it as a new condition. The March of Dimes is honored to receive a 2005 Post-Polio Health International Legacy Award and proud of its partnership with Post-Polio Health International and the International Ventilator Users Network to advance provider and consumer awareness of post-polio syndrome and to improve the lives of polio survivors worldwide". -Christopher P. Howson, Ph.D., Vice President for Global Programs

Christopher P. Howson, Ph.D., Vice President for Global Programs, will represent the March of Dimes.

Judith Raymond Fischer, MSLS

International Ventilator Users Network presents Judith Raymond Fischer, MSLS, with a 2005 International Ventilator Users Network Legacy Award in recognition of her many years of dedicated service as volunteer editor of the newsletter, *Ventilator-Assisted Living*, her exemplary contribution of countless hours to various projects aimed at educating ventilator users and health professionals, her publications on respiratory health for people with neuromuscular diseases, her responses to ventilator-related questions via the web site, and her many years of representing IVUN in networking with health professionals and equipment manufacturers.

"As a college-age volunteer for Gini Laurie in Ohio in the late 1960s, I never imagined that the connection and commitment would continue for decades. After Gini moved back to St. Louis, I continued as a long-distance volunteer. Finally in 1984, I seized the opportunity to work with Gini (for pay!), helping her to carry on the networking and information dissemination at which she and the organization excelled.

"Gini died in 1989, not long after I married D. Armin Fischer, MD, a pulmonologist to many polio survivors in Southern California, and moved there. Joan Headley, my successor, accepted my volunteerism, in the form of editing *IVUN News* (now the quarterly *Ventilator-Assisted Living*). That role expanded into editing other IVUN publications on respiratory health for people with neuromuscular diseases, representing IVUN at conferences of respiratory health professionals, searching for experts on living long-term with a home ventilator, networking with equipment manufacturers and distributors, and compiling the annual *Resource Directory for Ventilator-Assisted Living*, among other IVUN projects."

"Gini would be proud of IVUN's accomplishments and contributions that salute and affirm the lives of ventilator users. Ave atque vale."

Doris Jones

Post-Polio Health International presents Doris Jones with a 2005 Post-Polio Health International Legacy Award in recognition of her 34 years of dedicated service to PHI and IVUN. Since 1971, Doris has served as PHI's accountant for minimal compensation but soon will be retiring from that position. Doris exemplifies the value of connections with Post-Polio Health International and other polio survivors, enabling her to achieve greater mobility and independence.

"I had polio in 1946, at the age of eight, and then spent the next four years in and out of hospitals for rehabilitation and several corrective surgeries. I was tutored at home or in a hospital ward for grades three through eight. During high school, I attended regular classes. Since I used a wheelchair, the school arranged for all my classes to be held on one floor. With assistance from the Missouri Department of Vocational Rehabilitation, I attended Saint Louis University and majored in accounting.

"In 1971, I received a call from Gini Laurie who had learned from a dear friend of mine that I majored in accounting in college. Gini asked me if I was interested in "doing the books" for *Rehabilitation Gazette*. That connection resulted in a long relationship with the organization. Knowing that I wanted to learn how to drive, Gini showed me what "doors to knock on" and in 1974 I obtained my license. Driving opened up many opportunities. I coordinated a post-polio support group in Saint Louis bringing polio survivors together to share information that helped us simplify our lives. I have fond memories of the many international conferences because they provide an opportunity for participants to gather from the four corners of this earth to exchange and share ideas."

"I am very honored to receive a Legacy Award in memory of Gini Laurie. I learned a great deal from her as she gave me the support and encouragement to become more independent."

David Jayne

International Ventilator Users Network presents David Jayne with a 2005 International Ventilator Users Network Legacy Award in recognition of his tireless efforts in working with legislators and policy makers to amend Medicare's homebound restriction that requires beneficiaries with significant illness to remain at home or else lose vital medical homecare benefits, in founding the National Coalition to Amend the Medicare Homebound Restriction for Americans with Significant Illness, and for advocating for issues that affect the members of IVUN.

David Jayne of Rex, Georgia, was diagnosed with Lou Gehrig's disease at age 27. Otherwise known as amyotrophic lateral sclerosis (ALS), this degenerative neuromuscular condition causes his muscles to atrophy, leaving him unable to eat, breathe or move on his own. Though his mobility is limited to moving three fingers, Jayne, now 41, has demonstrated to everyone who knows him or has read about him that the human spirit is indomitable. Jayne founded The National Coalition to Amend the Medicare Homebound Restriction for Americans with Significant Illness (NCAHB), with former Senator Robert J.

Dole as honorary chairman. Jayne has been a tireless advocate and spokesman for changing the Medicare regulations concerning the definition of homebound.

Because of his commitment and advocacy efforts, Medicare now includes a provision for demonstration projects to clarify the definition of "homebound." The provision creates a two-year trial project in three states: Colorado, Massachusetts and Missouri. The projects will gauge the effect of loosening Medicare rules that require people to stay confined in their homes in order to receive home health services. In 2002, *New Mobility*, a magazine about disability issues, recognized Jayne as its "Person of the Year."

"I am advocating that the homebound restriction follow in the spirit of the ADA, the Olmstead decision, the Ticket to Work Program, and President Bush's New Freedom Initiative. People with disabilities want the opportunity to forget about their disabilities, enjoy life, and participate freely in community and family activities. The system I paid into, that I expected to protect me, is now robbing me of the opportunity to live out my life long dream to be a father and participate in my precious children's childhood. I started a ripple that grew into a successful national campaign. I hope this serves to inspire individuals who believe they can not make a difference."

Edouard Foundation

Post-Polio Health International presents the Edouard Foundation with a 2005 Post-Polio Health International Legacy Award in recognition of their exemplary support and generous contributions to the PHI Research Fund over the past 6 years. These contributions resulted from the efforts of PHI and IVUN member, Morton Freilicher.

The Edouard Foundation is a private foundation which seeks to relieve distress and improve the quality of people's lives around the world, with some emphasis on the communities where the Foundation's directors reside. Funding is focused on disaster relief, assistance to the poor, education, medical research and care, improving the condition of people with disabilities, and environmental protection. Each director of the Foundation is charged with the task of separately finding, investigating, and recommending to the group appropriate recipients of the Foundation's aid. The directors take pride in their willingness to respond to the urgent needs of distressed people, wherever and whenever these needs occur, free of any ethnic or religious bias.

"Much of our Foundation's work seeks to improve the quality of life of people who face special challenges. Because many polio survivors contend daily with such challenges, our support for Post-Polio Health International and its research program embodies the spirit of what we strive to accomplish. We're very pleased and grateful that Post-Polio Health International has chosen us to receive this award. It's deeply satisfying for us to learn that our assistance is recognized by so fine an organization."

Morton Freilicher, a polio survivor and ventilator user, will represent the Edouard Foundation. He is a Director and Officer of the Foundation and also serves as the Foundation's attorney.

Japanese Ventilator Users Network (JVUN)

International Ventilator Users Network presents the Japanese Ventilator Users Network with a 2005 International Ventilator Users Network Legacy Award in recognition of their exemplary advocacy, networking and education on behalf of ventilator users. JVUN has developed a strong network that promotes independent and community living, and in 2004, they organized a countrywide symposium that featured international speakers.

The Japanese Ventilator Users Network was founded in 1990 by Kimiyo Sato, a ventilator user. That same year she began to live independently and initiated activities to promote community living for other ventilator users.

JVUN considers a ventilator as "a source of power." The organization is a powerful resource for ventilator users, caregivers and health providers. It offers remarkable health education information, training sessions, and advocacy for independent living.

JVUN publishes the newsletter, *Another Voice*, and translates every issue of IVUN's *Ventilator-Assisted Living* into Japanese. It has produced a manual on suctioning for caregivers, a video about "enjoying life" for ventilator users with a tracheostomy, and other booklets and tapes.

In 1997, Kimiyo and others came to Saint Louis where they attended sessions on home mechanical ventilation at Post-Polio Health International's conference. Inspired by their experiences, they returned to Japan determined to raise funds to sponsor a similar conference. In 2004, their hard work produced very successful symposia in three major cities of Japan, featuring international speakers and drawing over one thousand attendees.

Japanese Ventilator Users Network
JVUN
ベンチレーター使用者ネットワー

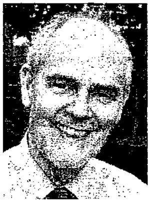
"In 2004, our dream was fulfilled when over 1,000 people attended the symposia we sponsored. This began a process of planting seeds. We hope they grow into leaves that will blossom. Rather than being afraid, we want people to view a ventilator as a valuable source of power."

Lauro S. Halstead, MD

Post-Polio Health International presents Lauro S. Halstead, MD, with a 2005 Post-Polio Health International Legacy Award in recognition of his exemplary contributions and leadership as a health educator. Dr. Halstead has trained and advised health care providers about the needs of polio survivors in the US and abroad; educated polio survivors through his clinical practice; presented at and organized polio conferences; and written and edited numerous publications. As a physician and polio survivor, he is a strong advocate for research and has raised public awareness about polio survivors and post-polio syndrome through media interviews.

Lauro S. Halstead, MD is Director of the Post-Polio Program at the National Rehabilitation Hospital (NRH) in Washington, DC and is Professor of Rehabilitation Medicine at Georgetown University School of Medicine. He is a graduate of the School of Medicine at the University of Rochester and holds a Master's Degree in Public Health from the Harvard School of Public Health. Dr. Halstead had severe paralytic polio at 18 while hitchhiking in Europe in 1954. In 1983, he began experiencing symptoms of post-polio syndrome, which led him to take the lead in organizing the first two International Medical Conferences on the Late Effects of Polio in 1984 and 1986 at Warm Springs, Georgia.

In 1984, he established one of the first post-polio clinics in the country at The Institute of Rehabilitation and Research and co-founded the Texas Polio Survivors Association, both in Houston. Since then, his passion has been to work on behalf of polio survivors everywhere by lecturing, writing, researching, and providing clinical services. In 1998, he reduced his activities at NRH to part-time and began a retirement project of helping to establish support groups and post-polio clinics in Peru and Italy. Dr. Halstead has published widely on the post-polio syndrome and other topics in rehabilitation medicine. He is an Honorary Board member and also on the Medical Advisory Committee of Post-Polio Health International.



"Post-Polio Health International is the only organization that represents the far flung but sizable polio community here in the United States and abroad. Like its founder, Gini Laurie, it is the glue that continues to hold us together. Over the past 20 years, I have been impressed with how PHI has continued to evolve and mature as an organization with limited resources. It provides outstanding services to countless individuals on many levels. But most importantly, PHI offers us a home base that helps create a sense of community around the world. Finally, it is the only organization that has the standing to give an award that confers a genuine and lasting honor on each of its recipients."

Rotary International

Post-Polio Health International presents Rotary International with a 2005 Post-Polio Health International Legacy Award in recognition of their exemplary PolioPlus program to protect children worldwide from polio, their global leadership and collaboration and outstanding contributions to disease prevention and their goal of eradicating polio.

Rotary International is a worldwide organization of business and professional leaders that provides humanitarian service, encourages high ethical standards in all vocations, and helps build goodwill and peace in the world. Approximately 1.2 million Rotarians belong to more than 33,000 Rotary clubs located in 168 countries.

Rotary's main objective is service – in the community, in the workplace, and throughout the world. Rotarians develop community service projects that address many of today's critical issues, such as children at risk, poverty and hunger, the environment, and illiteracy. The Rotary motto is *Service Above Self.*

Through its flagship PolioPlus program, established in 1985, Rotary continues to play a crucial role in global efforts to eradicate polio. More than one million Rotary members have volunteered their time and personal resources to protect more than 2 billion children in 122 countries from polio. Rotary provides urgently needed funds. To date, the organization has contributed more than $500 million, has raised an additional $123 million, and has played a major role in gaining over $1.7 billion from donor governments. Rotary members also volunteer in polio-endemic countries where they promote and assist during mass polio immunization campaigns.

"I am honored to accept this award in recognition of Rotary's efforts to eradicate polio worldwide," said Ray Klinginsmith, Trustee of the Rotary Foundation of Rotary International. "Though children in parts of Africa and Asia are still threatened by this crippling and sometimes fatal disease, we are closer than ever to achieving a polio-free world. The legacy of this accomplishment will be that no one will ever suffer from the immediate or long-term consequences of polio."

Ray Klinginsmith, Trustee of the Rotary Foundation of Rotary International, will represent Rotary International.

POST-POLIO HEALTH
INTERNATIONAL

Post-Polio Health International
Including International Ventilator Users Network

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Jose Isola, Peru
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International Ventilator Users Network Consumer Advisory Committee

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Richard Daggett, California, USA
Mary Garrett, New York, USA (parent of vent user)
Laura Hershey, Colorado, USA
Larry Kohout, Minnesota, USA
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Adolf Ratzka, Sweden
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Sheryl Rudy
Webmaster and Graphic Designer

Mary Stephen
Assistant to the Executive Director/
Member Services.

Justine Craig-Meyer, BA
Assistant to the Executive Director/
Member Services.

THE RESEARCH FUND

The one million survivors of poliomyelitis in the United States, and the 12 million worldwide, know there are consequences of living and aging with a disability. They also know that funding for research into their problems is limited.

Post-Polio Health International (formerly Gazette International Networking Institute) established The Research Fund (formerly The GINI Research Fund) in 1995 dedicated to "seeking scientific information leading to eventual amelioration of the consequences of poliomyelitis and/or neuromuscular respiratory diseases."

Q: What research will PHI support?
A: The grants will help support researchers, scientists, and clinicians worldwide to investigate the cause(s), treatment, and management of post-poliomyelitis and neuromuscular respiratory disease.

As it approves grants, PHI will foster new innovative research – both basic science and clinical – that will result in improved quality of life for people with disabilities, as well as support valid ongoing research.

Q: How will funding decisions be made?
A: A panel made up of peers and people with disabilities will review all grant applications that meet established requirements for respiratory research or post-poliomyelitis research. This panel's recommendations will be reviewed by the PHI's Board of Directors, who will make the final funding decisions.

Q: How can contributions be made?
A: Post-Polio Health International is a not-for-profit 501(c)(3); Federal ID No. 34-0961952. Tax-deductible contributions can be made online (www.post-polio.org) or sent to Post-Polio Health International (PHI), 4207 Lindell Boulevard, #110, Saint Louis, Missouri 63108-2915 USA

Checks should be made payable to "Post-Polio Health International" (US dollars only). PHI also accepts VISA, MasterCard, and Discover.

The Research Fund now with a corpus of $420,000 awarded its first grant from the interest in the fall of 2000.

THE FIRST AWARD (2001)
Ventilator Users' Perspectives on the Important Elements of Health-Related Quality of Life

THE SECOND AWARD (2003)
Women with Polio: Menopause, Late Effects, Life Satisfaction and Emotional Distress

THE THIRD AWARD (2005)
Timing of Noninvasive Ventilation: Does earlier use result in prolonged survival?

Visit www.post-polio.org/resrch.html to read the reports.

POST-POLIO HEALTH
INTERNATIONAL

POST-POLIO HEALTH INTERNATIONAL
INCLUDING INTERNATIONAL VENTILATOR USERS NETWORK

MEMBERSHIP OPPORTUNITIES

International and USA membership levels are the same.
(US dollars only)

$15 Supporter

Access to www.post-polio.org
Access home mechanical ventilation information at www.post-polio.org/ivun
Networking opportunities
Information about relevant events
Support of Post-Polio Health International's educational, research, and advocacy efforts
Opportunities to participate in research
100% tax-deductible

$25 Subscriber

All of the benefits of Supporter, AND ...

Quarterly 12-page newsletter of your choice: *Post-Polio Health* OR *Ventilator-Assisted Living*
100% tax-deductible

$45 Subscriber Plus

All of the benefits of Subscriber, AND ...

Both quarterly newsletters: *Post-Polio Health* AND *Ventilator-Assisted Living*
100% tax-deductible

$75 Contributor

All of the benefits of Subscriber Plus, AND ...

Post-Polio Directory
Resource Directory for Ventilator-Assisted Living
Discounts on special publications, such as *Handbook on the Late Effects of Poliomyelitis for Physicians and Survivors*
Discounts on meetings sponsored by Post-Polio Health International
100% tax-deductible

$125 Sustainer

All of the benefits of Contributor, AND ...

One additional complimentary Subscriber Membership for another person designated by the Sustainer or to a person who has expressed financial need to IVUN
$100 is tax-deductible.

Use the form below to join today!

If you are a current member, give this form to a friend, family member, or health professional.

MEMBERSHIP APPLICATION

International and USA membership levels are the same.
(US dollars only)

PLEASE SEND TO

Name ______________________________
Institution ______________________________
Address ______________________________
City ______________________________
State/Province ______________________________
Zip/Postal Code ______________________________
Country ______________________________
Phone ______________ (area/country code) Fax ______________ (area/country code)
Email ______________________________

PAYMENT OPTIONS

☐ Enclosed is my check made payable to Post-Polio Health International. (US dollars only)
☐ OR, charge my: ☐ VISA ☐ MasterCard ☐ Discover
Card # ______________________________
Name on card ____________________ Exp. date __________
Signature ______________________________

MEMBERSHIP LEVEL

☐ **Supporter**, $15
☐ **Subscriber**, $25
☐ *Post-Polio Health* OR ☐ *Ventilator-Assisted Living*
☐ **Subscriber Plus**, $45
☐ **Contributor**, $75
☐ **Sustainer**, $125 ...
Please send the additional subscription of
☐ *Post-Polio Health* OR ☐ *Ventilator-Assisted Living*
TO: Name ______________________________
Address ______________________________
____
City, State/Province ______________________________
Country ______________ Zip/Postal Code __________
☐ Or, donate this complimentary subscription to person selected by Post-Polio Health International.
☐ **Other** $__________

Send to:

POST-POLIO HEALTH
INTERNATIONAL
4207 Lindell Blvd., #110
Saint Louis, MO 63108-2915 USA
314-534-5070 fax

CONF

Note Cards Available!

Post-Polio Health International remembers the survivors of polio...

To commemorate the 50th anniversary of the development of the Salk vaccine, Post-Polio Health International chose to honor those for whom the vaccine was too late. Since its inception in 1958, the organization has focused its resources and efforts on improving the health and independence of polio survivors and ventilator users and is committed to continuing this practice.

Artist Deborah Goodwin and polio survivor Mickie McGraw teamed up to create a visual reminder that millions of polio survivors are citizens of the world community who are in need of information, advocacy and research. (The artwork is in shades of blue and yellow with green accents.)

> *The nautilus shell represents an external stillness and static mobility. Contained and protected within is a rich and active life force that radiates outward from the central creation point of its spiral to reach beyond the limits of its boundaries.*
>
> *The butterfly depicts the ephemeral, unique beauty of each life that begins encased within a cocoon and emerges in its time, transformed, to color the world and give wings to the future.*
>
> *Together they celebrate our human potential to transcend limitations. They commemorate the 50th anniversary of the development of the Salk polio vaccine, which forever changed our lives and our future.*

To help PHI remind the world of this anniversary, and to support our work, order your set of 10 note cards for $13.50 (s&h included).

Send the form below to PHI, 4207 Lindell Blvd. #110, Saint Louis, MO 63108 (314-534-5070 fax) or order online at www.post-polio.org/order-card.html.

Please send _____ sets of the 50th Anniversary Commemorative Note Cards.

For larger orders or international orders, please contact 314-534-0475 or info@post-polio.org.

TOTAL AMOUNT FOR ORDER: $ ____________

Payment Options:

☐ I am paying by credit card. (PHI accepts VISA, MasterCard and Discover.)

☐ I am sending my check made payable to "Post-Polio Health International" (US dollars only)

☐ Please send an invoice.

QUANTITY	PRICE
1 set	$13.50 per set, s&h included
2-4 sets	$11 per set, plus total s&h of $2.50
5-10 sets	$11 per set, plus total s&h of $5.00

PHI Member ID No. (if known) ____________

Name ____________

Affiliation ____________

Address ____________

City ____________

State/Province ____________

Zip/Postal Code ____________

Country ____________

Phone (include area/country code) ____________

email ____________

Complete if using a credit card ...

☐ Visa

☐ MasterCard

☐ Discover

Card No. ____________

Exp. Date ____________

Authentication No. (on back of card) ____________

Name on Card ____________

Signature ____________

NINTH INTERNATIONAL CONFERENCE ON POST-POLIO HEALTH AND VENTILATOR-ASSISTED LIVING:

STRATEGIES FOR LIVING WELL

June 2-4, 2005 ■ Saint Louis, Missouri

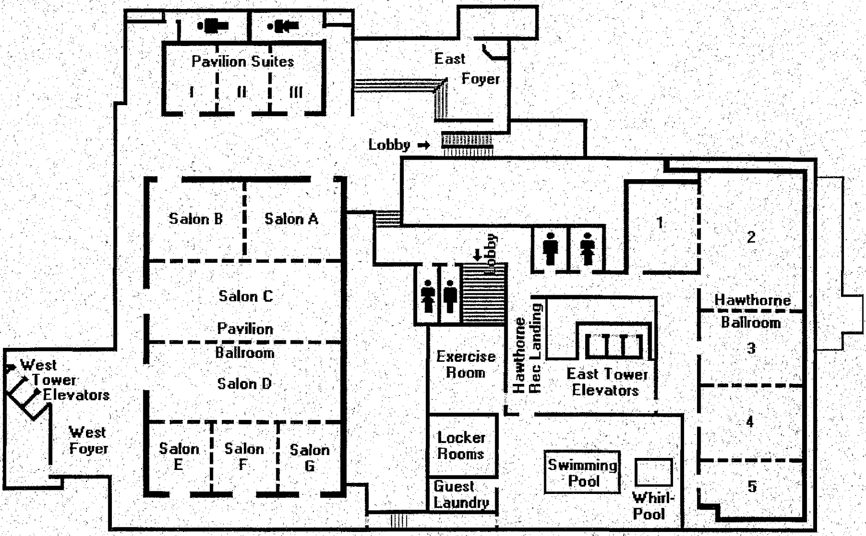
PROGRAM FOR SATURDAY, JUNE 4, 2005

This book belongs to:

POST-POLIO HEALTH
INTERNATIONAL

POST-POLIO HEALTH INTERNATIONAL
INCLUDING INTERNATIONAL VENTILATOR USERS NETWORK

4207 LINDELL BOULEVARD, #110
SAINT LOUIS, MISSOURI 63108-2915 USA
314-534-0475, 314-534-5070 FAX
INFO@POST-POLIO.ORG, WWW.POST-POLIO.ORG



Details

Please wear your NAME BADGE; it is your "ticket" for the sessions.

The time schedule will be strictly adhered to because the sessions will be audio taped. TAPES are available on site. An order form is included in the conference bag. Personal recording (audio, video, etc.) of the sessions is prohibited.

EXHIBITS are located in Pavilion Suites I-II-III.

The Thursday, June 2, 2005, "MEET FOR HEALTHY TREATS" in the East Foyer is open to all full and Thursday registrants and those who purchased a ticket.

The Friday, June 3, and Saturday, June 4, MORNING BREAKFASTS are open to all full and daily registrants and will be available in the West Foyer and the East Foyer. Seating will be available in Salon D and the East Foyer.

MEAL TICKETS will be collected at the doors of Salon C & D. Meal tickets for the luncheons and Friday dinner are no longer available. All registrants are invited to the awards presentation and entertainment on Friday, June 3 at 7:30 pm in Salon C & D.

In case of an EMERGENCY, call the hotel operator "O" and request that they call "911" so they are alerted and can direct the emergency crew to you.

QUESTIONS from the audience will be submitted to the speaker/moderator in writing unless otherwise announced in the session.

Post-Polio Health International's mission is to enhance the lives and independence of polio survivors and home ventilator users through education, advocacy, research and networking.

Welcome to PHI's Ninth International Conference on Post-Polio Health and Ventilator-Assisted Living ...

On behalf of the Board of Directors and staff of Post-Polio Health International and the *I*nternational Ventilator Users Network, we welcome you to Saint Louis and to this ninth unique symposium since 1981.

We gratefully acknowledge the expertise and commitment of our presenters, and thank them for their valuable abstracts, outlines, fact sheets and other materials enclosed in this book. If you wish to share this information, we respectfully ask that you acknowledge the presenters and their institutions and then add the following statement:
"This information was disseminated at Post-Polio Health International's Ninth International Conference on Post-Polio Health and Ventilator-Assisted Living, June 2-4, 2005."

We also would appreciate you informing PHI as well as the presenter that you are disseminating this material and where, so that we can track the ripple effect of the conference.

Audio tapes and CDs of the sessions will be available on site and also may be ordered after the conference from Network Communications (800-747-1426, 636-677-1912 fax, www.swiftsite.com/nettapes/PostPolio2005.html). Ordering information also will be available on www.post-polio.org and in future issues of *Post-Polio Health* and *Ventilator-Assisted Living.*

Personal recording (audio, video, etc.) of the sessions is prohibited.

This ninth symposium has been created and designed from the information needs, requests and suggestions of today's polio survivors and ventilator users. The purposes and outcomes expected are:

- To learn personal STRATEGIES FOR LIVING WELL
- To provide information and support to families and friends of polio survivors and ventilator users
- To exchange ideas with polio survivors and ventilator users
- To exchange ideas with health professionals
- To contribute to the worldwide activities supporting the improved health and independence of polio survivors and ventilator users
- To renew old acquaintances and make new friends

Our wish is that each and every one of you, whether consumer *or* health professional, or both, will return home with numerous strategies for living well and with a commitment to implementing them. We also sincerely hope that you leave with a continued commitment to supporting the work of PHI and IVUN. Your personal and professional contributions, both financially and in deed, are vital to us as we continue our much-needed efforts on behalf of polio survivors and ventilator users.

Audrey J. King
Conference Co-Chair
Audrey King

William Wischmeyer
Conference Co-Chair
William Wischmeyer

Joan L Headley
Executive Director
Joan L. Headley

Post-Polio Health International's mission is to enhance the lives and independence of polio survivors and home ventilator users through education, advocacy, research and networking.

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Audrey J. King
Conference Co-Chair
Audrey King

William Wischmeyer
Conference Co-Chair
William Wischmeyer

Joan L Headley
Executive Director
Joan L. Headley

Program for Saturday, June 4, 2005

8:00 am – 1:30 pm
Registration Desk
REGISTRATION

8:00 am – 9:00 am
Salon E
Meetings of Honorary Board and Medical and Consumer Advisory Committees *(Continental Breakfast will be available)*

8:15 am – 9:00 am
East and West Foyers
CONTINENTAL BREAKFAST

8:30 am – 1:30 pm
Pavilion Suites
EXHIBITS OPEN

9:00 am – 10:15 am
SESSION I OPTIONS

Salon B
THE TRACHEOSTOMY OPTION
Management of Neuromuscular Breathing Problems: The Danish Way
Jesper Qvist, MD
Respiratory Centre East, Copenhagen, Denmark
What, Why and When
Augusta Alba, MD
Rehabilitation Medicine (retired)
Coler Goldwater Specialty Hospital and Nursing Facility, Roosevelt Island, New York
Diana Guth, RRT
Home Respiratory Care, Los Angeles, California
Betsy Thomason, RRT
Millennium Respiratory Services, Whippany, New Jersey
Angela King, BS, RPFT, RRT-NPS
Pulmonetic Systems, Inc., Minneapolis, Minnesota

Salon C
RESEARCH II: WHAT IS BEING DONE? WHAT NEEDS TO BE DONE?
Moderator: Lauro Halstead, MD
National Rehabilitation Hospital, Washington, DC
Immunopathogenesis of the Post-Polio Syndrome
Kristian Borg, MD
Karolinska Hospital, Stockholm, Sweden
Update on Stem Cell Research for Neuromuscular Disorders
David Gottlieb, MD
Washington University School of Medicine, Saint Louis, Missouri
Update on Research at USU
Olavo Vasconcelos, Jr., MD
Physician Research Coordinator, Uniformed Services University, Bethesda, Maryland

Salon D
EXERCISE, PART 1: A DEBATE ABOUT THE DEBATE
Moderator: Frederick Maynard, MD
U.P. Rehabilitation Medical Associates, Marquette, Michigan
Clinical predictors of electromyographic findings of remote polio in "unaffected" limbs of patients with a history of acute paralytic poliomyelitis
Chanda Mayo, MD
Physical Medicine & Rehabilitation, National Rehabilitation Hospital, Washington, DC
Opinion of an Experienced PT
Holly Wise, PT, PhD
Medical University of South Carolina, Charleston, South Carolina
Opinions from Polio Survivors
Jane Atkey
Toronto Peel Post-Polio Community, Toronto, Ontario, Canada

Salon E
SCOOTERS AND POWER CHAIRS
The Care and Feeding of a Scooter or Power Chair
John and Jann Hartman
Baltimore, Maryland
Choosing and Funding a Scooter or Power Chair
Jean Csaposs
New Jersey Polio Network, Maywood, New Jersey

Salon A
PREVENTING AND MANAGING SECONDARY CONDITIONS FOR POST-POLIO HEALTH
Alexa Stuifbergen, PhD, RN, FAAN
Tracie Harrison, PhD, RN, MSN, FNP
University of Texas, Austin, Texas

Salon F/G
NEW BRACING: THE CHALLENGE AND THE PAYOFF
Marny Eulberg, MD
St. Anthony's Family Medical Center West, Denver, Colorado
Marmaduke Loke
DynamicBracingSolutions, Encinitas, California

10:15 am – 10:45 am
BREAK

10:45 am – 12:00 noon

SESSION II OPTIONS

Salon C

OPTIONS FOR MANAGING THE MULTIPLE CAUSES OF FATIGUE

Martin Wice, MD
Physical Medicine & Rehabilitation, St. John's Mercy Medical Center, Saint Louis, Missouri
Alexa Stuifbergen, PhD, RN, FAAN
University of Texas, Austin, Texas

Salon D

EXERCISE, PART 2: WHAT STEPS TO TAKE

Moderator: Frederick Maynard, MD
U.P. Rehabilitation Medical Associates, Marquette, Michigan

Suggestions from ...

Mary Klein, PhD
Director, Post-Polio Project, Moss Rehab Research Institute, Philadelphia, Pennsylvania
Barbara Duryea, RN
John P. Murtha Neuroscience & Pain Institute, Conemaugh Health System, Johnstown, Pennsylvania
Holly Wise, PT, PhD
Medical University of South Carolina, Charleston, South Carolina

Reactions from Polio Survivors

Jane Atkey
Toronto Peel Post-Polio Community, Toronto, Ontario, Canada

Salon B

VENTILATOR USERS: GETTING YOUR ACT TOGETHER AND TAKING IT ON THE ROAD

Audrey King
Toronto, Ontario, Canada
Barbara Rogers
Respiratory Resources, Inc., New York, New York
SPONSORED BY PULMONETIC SYSTEMS, INC.

Salon A

CHOOSING TO FLOURISH: WHAT WORKS FOR ME

Linda Wheeler Donahue
The Polio Outreach of Connecticut, Southbury, Connecticut
Dorothy Woods Smith, PhD, RN
Houses of Healing, Portland, Maine

Salon F/G

LONG-TERM CARE: BUYING IT AND SECURING IT

Moderator: Saul Morse
Springfield, Illinois
Matt McCann
Darien, Illinois

12:15 pm – 1:15 pm
Salon C and D
LUNCHEON *(ticket required)*

1:30 pm – 2:45 pm

SESSION III OPTIONS

Salon C

OPTION IF A POST-POLIO CLINIC IS NOT AN OPTION

Moderator: Mary Louise Dickson
Toronto, Canada
Carol Vandenakker, MD
Physical Medicine & Rehabilitation, University of California Davis Medical Center, Sacramento, California
Reactor: Armand Zilioli, MD
Bay Pines VA Medical Center, Saint Petersburg, Florida

Salon A

EXPRESSING SEXUALITY: WHAT WORKS FOR ME

Moderator: Linda Bieniek, CEAP
La Grange, Illinois

Salon B

INTERFACES: NEW, TRIED AND TRUE, AND CUSTOM

Barbara Rogers
Respiratory Resources, Inc., New York, New York
SPONSORED BY PULMONETIC SYSTEMS, INC.
Diana Guth, RRT
Home Respiratory Care, Los Angeles, California

Salon E

COLLABORATION WITH PHI AND WITH EACH OTHER

Moderators:
Beth Kowall, MS, OTR
Greenfield, Wisconsin
Joan Headley
Post-Polio Health International, Saint Louis, Missouri
Meeting of Post-Polio Organizations

Salon D

BREATHING TRAINING: DEVELOPING A USER FRIENDLY BODY

Betsy Thomason, RRT
Millennium Respiratory Services, Whippany, New Jersey

Salon F/G

ACUTE, POSTOPERATIVE PAIN

Selma Calmes, MD
Olive View-UCLA Medical Center, Sylmar, California

2:45 pm – 3:15 pm
BREAK

3:15 pm – 4:15 pm

SESSION IV (PLENARY) Salon C and D

TRANSLATING GOOD IDEAS INTO PRACTICE, WHAT ABOUT TOMORROW?

Kristi Kirschner, MD
Rehabilitation Institute of Chicago, Chicago, Illinois

4:15 pm – 4:30 pm

CLOSING SESSION Salon C and D

SESSION I OPTIONS

9:00 am – 10:15 am

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THE TRACHESTOMY OPTION:
Management of Neuromuscular Breathing Problems: The Danish Way

Jesper Qvist, MD & Grethe Nyholm, RN
Copenhagen, Denmark

52 years after the Danish polio epidemic, where 3169 out of more than 7000 patients suffered paralytic polio we see increasing numbers of patients who encounter respiratory failure as part of the Post Polio Syndrome (PPS).

The Centre for Rare Respiratory Handicaps in Copenhagen, Denmark cares for the majority of polio patients having different degrees of respiratory failure: All 69 patients live at home, seven patients are on full time mechanical ventilation through a tracheostomy since the epidemic, 29 PPS patients are ventilated with a BIPAP ventilator at night – by nose or full-face mask – and 17 patients are on 24-hour ventilation through a tracheostomy. Nine of the patients with PPS have been treated with BIPAP night ventilation for 2 to 7 years before starting full time ventilation through a tracheostomy. After tracheostomy, patients are ventilated with volume-controlled ventilators using uncuffed tracheostomy tubes.

By not using cuffs and expiratory valves patients are able to speak freely during ventilation, allowing them to maintain their jobs as lawyer, teacher, judge etc. This technique has been used in Denmark for the past 50 years but is rarely seen outside of the country – even in the other Scandinavian countries.

Another unique Danish feature is the use - around the clock – of privately hired assistants who monitor the function of the respirator and do all the chores of respiratory care including tube changes, suctioning etc. The assistants are also the hands and legs of the patient - being chauffeurs, moving patients in and out of bed, electric wheel chair and bathroom.

The assistants are paid for by the university or county hospital according to legislation passed in 1990.

They are entirely responsible for the respiratory care after training and certification by the staff of the Respiratory Care Centre. Thus, the hospital is no longer responsible for the care per se but patients will be followed life long by the Centre.

We will demonstrate by an 8-10 minute video the utility of using cuffless tubes and the omission of an expiratory valve system, which allows patients to speak freely. In addition, we will discuss some of the barriers that might hinder patients in other countries to use our ways of handling patients on mechanical ventilation at home.

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THE TRACHEOSTOMY OPTION:
What, Why and When

Augusta Alba, MD
Rehabilitation Medicine (retired)
Coler Goldwater Specialty Hospital and Nursing Facility, Roosevelt Island, New York
Diana Guth, RRT
Home Respiratory Care, Los Angeles, California
Betsy Thomason, RRT
Millennium Respiratory Services, Whippany, New Jersey
Angela King, BS, RPFT, RRT-NPS
Pulmonetic Systems, Inc., Minneapolis, Minnesota

Comparison of Noninvasive positive pressure ventilation and tracheostomy positive pressure ventilation

Topic	NPPV	TPPV
Speech	✓ Usually normal ✓ Interface may interfere somewhat	✓ Depends on type of trach tube ✓ Inflated cuff: no speech ✓ Deflated cuff or fenestrated tube: allows speech ✓ Cuffless with speaking valve: allows speech
Taste & Smell	✓ Usually normal	✓ Depends on type of trach tube ✓ Inflated cuff: reduced ✓ Deflated cuff or fenestrated tube: allows air flow and therefore smell/taste
Humidity	✓ High flows may dry out oral/nasal mucosa somewhat, but generally tolerable	✓ Will require HME (heat moisture exchanger) ✓ Most likely will require heated humidifier
Eating	✓ Swallowing is preserved ✓ May be awkward to eat with interface, but patient may tire without	✓ Swallowing may be impaired, inflated cuff exacerbates ✓ Decreased mobility of the trachea
Infection	✓ No incision ✓ No access to lower airway	✓ Local infection and granulation / inflammatory reactions ✓ Direct access to lower airway increases infections
Upper Airway Obstruction	✓ May be a problem	✓ Tracheostomy bypasses this problem
Face	✓ Interface involves the face	✓ Face is free, tubing may be worn under clothing
Respiratory Care	✓ Minimal	✓ Increased amount needed: ✓ Trach care ✓ Trach changes ✓ Suctioning
Life Support	✓ Generally, NPPV devices are not considered "life support". ✓ However, some patients are using life-support vents and using 24 hpd	✓ Devices used for TPPV must be "life-support" with full alarms and battery capability

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RESEARCH II: WHAT IS BEING DONE? WHAT NEEDS TO BE DONE?

Immunopathogenesis of the Post-Polio Syndrome

Kristian Borg, Henrik Gonzalez, Georgios Kaponides and Tomas Olsson
Stockholm, Sweden

Many polio patients experience new or increased symptoms decades after the acute polio infection. This condition is known as late effects of polio or the post-polio syndrome (PPS). Weakness and atrophy in skeletal muscles are explained by an ongoing denervation. The denervation is compensated by muscle fibre adaptation and reinnervation. Both these mechanisms finally reach an upper limit where insufficiently compensated denervation leads to muscle weakness. The cause of the ongoing denervation is at the moment unknown. An ongoing inflammatory process has been described in some studies but has not been found in other studies.

In the study by Gonzalez et al (2002) we found a chronic inflammatory process was in the CNS of PPS patients by means of studying key cytokine expression of mononuclear cells in the cerbrospinal fluid. The levels of cytokine expression was comparable with those of patients with Multiple Sclerosis. The cytokine levels were down-modulated to normal values by means of treating the patients with intravenous immunoglobulin (Gonzalez et al 2004). In order to study if the decrease of cytokine levels was followed by a clinical improvement with a gain of function, muscle strength and quality of life using the SF-36 questionnaire was evaluated during intravenous immunoglobulin treatment (Kaponides et al 2005). A trend towards an increase of muscle strength was found. All sub-scales of SF-36 increased significantly. The sub-scale that increased the most was vitality. To confirm these results a multi-center, double-blinded and placebo-controlled study was performed. A total of 135 PPS patients were included in the study (Gonzalez et al 2005). A statistically significant increase of muscle strength, increased physical activity and descreas of pain were found. Furthermore, there was a statistically significant difference between the treated and the placebo group regarding increase of quality of life for the two sub-scales general health and vitality.

It is, thus, concluded that there is an inflammatory process in the CNS of patients with PPS. The origin of the inflammatory process is unknown but it may play a part in the pathophysiology of PPS. The inflammation is down-modulated by means of treatment with intravenous immunoglobulin leading to a clinical improvement. This might lead to new therapeutic strategies for the treatment of patients with PPS.

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Gonzalez H, Stibrant Sunnerhagen K, Sjöberg I, Kaponides G, Olsson T, Borg K. Intravenous immunoglobulin for the Post Polio Syndrome; a randomized controlled trial. 2005, subm for publication

Kristian Borg, Henrik Gonzalez, Georgios Kaponides and Tomas Olsson
Division of Rehabilitation Medicine, Department of Public Health Sciences and Karolinska Institutet at Danderyds Hospital and Centre of Molecular Medicine, Karolinska Hospital, Stockholm, Sweden

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RESEARCH II: WHAT IS BEING DONE? WHAT NEEDS TO BE DONE?

Update on Stem Cell Research for Neuromuscular Disorders

David Gottlieb, MD
Washington University School of Medicine
Uniformed Services University
Bethesda, Maryland

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RESEARCH II: WHAT IS BEING DONE? WHAT NEEDS TO BE DONE?

Update on Research at USU

Olavo M. Vasconcelos, MD
Bethesda, Maryland

Post-Polio Syndrome (PPS) Fatigue: Hard to Study, Hard to Fix

Post-Polio Syndrome (PPS) describes the reemergence of new symptoms several years after recovery from acute poliomyelitis. PPS symptoms include increasing muscle weakness, atrophy, muscle and joint pain, disabling fatigue and other symptoms that, in conjunction, lead to gradual loss of function. The cause of PPS and its debilitating symptoms is not completely understood. In the same way, the reason (s) why some polio survivors develop PPS while others do not, and the basis for the significant variability (mild in some cases Vs severe in others) are not clear.

Among the PPS symptoms, fatigue is the earliest and, probably, the most debilitating. The exact mechanism of PPS fatigue is not all understood. In a similar fashion, effective pharmacological therapies to reduce it are not known. In the past, researchers investigated intensely the cause of, and a treatment for PPS fatigue. Several treatment trials were unsuccessful. The reasons for so are multifold and likely include problem areas, including: 1) the vague understanding of the mechanism of the complex fatigue faced by polio survivors, as well as how can one best define and measure it), and 2) the difficulties in ascertaining subjects for studies, in other words, which criteria to use for recognizing PPS. In year 2001 the PPS Program was funded. The Program, which is sponsored by the Uniformed Services University (USUHS) and administered by the Henry M. Jackson Foundation (HJF), has as its mission to advance knowledge on the cause and treatment of PPS. Several independent studies are taking place in the program, including a clinical trial to test the effect of a medication called modafinil (brand name: Provigil).

The PPS Program is enrolling volunteers to participate in a clinical trial on PPS fatigue. This study will test if a medication called modafinil can help reduce the fatigue in PPS patients. This research is being done because currently there is no effective treatment for fatigue, the most debilitating problem in persons with post-polio syndrome.

Like in previous studies we are confronted with critical issues in PPS research: the diagnosis of PPS and the assessment of its fatigue. This occurs because definite diagnostic tests for PPS are not available. Standard tests of the blood and muscle often show the same abnormalities in polio survivors with post-polio syndrome as in those without it. Therefore, diagnosis relies primarily on systematically clinical evaluation to rule out other causes. Because of this various classification frameworks have been proposed over the years. Although these definitions have greatly helped physicians and researchers, they present significant inconsistencies despite the fact that they share a close structure. The erratic ascertainment rate between four published PPS criteria shown here illustrates this problem well. The other layer of difficulty relates to defining and measuring fatigue in PPS subjects. This is caused by the lack of specific tools for the PPS population, as well as the lack of standardization regarding the use of available instruments. As shown, when traditional fatigue questionnaires were administered to PPS patients with severe fatigue we observed the instruments discriminate fatigue differently. In addition, their scores agreement was, at best, modest. We conclude that lack of standardized approach in this area continues to be a major obstacle.

Olavo M. Vasconcelos, MD
Director, Post-Polio Syndrome Program
Henry M. Jackson Foundation
Bethesda, Maryland

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Epidemiological Study of Disability Evolution in a Polio Survivor Population Sample

L.Arrondini MD, E.Corbella MD, D.Pellegatta MD
Fond. IRCCS Don Gnocchi of Milan - Italy

Objectives:

- Neuromotor and functional evolution assessment in patients with acute anterior poliomyelitis late effects;
- Identification of factors contributing to decreased functional performance after long functional stability;
- Useful steps to maintain QoL.

Materials and methods:

- Clinical and lab test data base;
- Inclusion criteria: outpatients with paralytic acute anterior poliomyelitis under physical observation;
- Exclusion criteria: patients with non-polio paralyses
- Admission to the study: 150 patients with complete lab tests prescribed on the basis of clinical evaluation;
- Modified Barthel Index for ADL evaluation and Hauser Index for deambulation disorder classification.

Results

The study was performed on a sample of 72 men with an age range between 16 and 84 years (mean age 55.81± 10 SD) and of 78 women with an age range between 15 and 83 years (mean age 58.11± 10 SD). The sample was scored using Modified Barthel Index as follows: fully independent patients (67%), patients requiring minimal assistance (23%), patients requiring moderate assistance (9%), totally dependent patients (1%).

96% of the individuals had decreased physical functioning after long functional stability lasting for 41-50 years since polio onset (49%), lasting longer than 50 years (12.50%), lasting between 36 and 40 years (8%).

Among 144 patients with decreased physical functioning, 90% were found to have deambulation disorders, 25%, had difficulty in climbing stairs, 18% in standing up from a chair, 16% in personal care.

Some of the reported symptoms were: new weakness (80%), muscle and joint pain (58%), general fatigue (34%), paraesthesiae, blood circulation disorders (14%), sleep disorders (3%), breathing difficulty (2%), slow strength recovery after exercise (2%), irritability, cold intolerance and dysphagia (1%), reduced concentration ability (0,69%).

The majority of patients with reduced walking ability had new weakness (82%), followed by patients with muscle and joint pain (35%), general fatigue (35%), slow strength recovery after exercise (2%).

The most functionally impaired areas were found to be: the lower extremities (92%) with a major involvement of the limbs originally affected by polio (55%) and the upper extremities (24%) with a major involvement of the originally less affected limbs (80%).

A causative factor was found for 26% of the patients with diminished function: bedding over 15 days (39%), traumas (32%), surgical interventions (21%).

The weight gain was correlated with the onset of biomechanical complications (53%) and with a reduced walking ability (47%).

The diagnostic conclusions often associated with the findings seemed to point to: biomechanical complications due to functional overload (76%), progressive muscle atrophy due to unit motor degeneration (62%), overlapping pathology (23%), radicular complications (13%), entrapment neuropathies (8%).

The treatment approach comprises: counseling (40%), massokinesitherapy (28%), assistive devices (17%), drug treatment (4%), physical rehabilitation (8%), functional surgery (3%).
Patients with diminished walking ability were prescribed for the first time: 9 hip-knee-foot orthoses, 28 monolateral walking aids, 7 wheelchairs (4 for patients with a Hauser score of 6, i.e. who occasionally use a wheel-chair, 3 for patients with a Hauser score of 7, with a residual walking capacity of few steps).

Conclusion

Our study confirmed that a performance reduction occurs after long stability. The most significant factors often associated with this evidence and leading to diminished function were: age, weight gain, bedding for over a fortnight, traumas, surgical interventions. In the study sample the functional deficit mainly affected the walking ability. The reduced walking ability was associated with new muscle weakness, with a major involvement of the lower extremities originally affected by polio and/or of less affected upper extremities.

Late-onset muscle weakness was correlated with electromyographic evidence of unit motor degeneration at acute and chronic stage.

Therapy was aimed at preventing the factors leading to diminished function, managing biomechanical complications by a suitable rehabilitation counseling, and using new assistive devices to spare residual resources.

Basic References:

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EXERCISE PART 1: A DEBATE ABOUT THE DEBATE

Clinical Predictors of Electromyographic Findings of Remote Polio in "Unaffected" Limbs of Adults with a History of Acute Paralytic Poliomyelitis

Chanda Mayo, MD
Co-Investigators: Lauro S. Halstead, MD, MPH, Elizabeth Kilgore, MD, Pei-Shu Ho, PhD
Washington, DC

Introduction

Paralytic poliomyelitis is a neuromuscular disease in which the poliovirus invades primarily the anterior horn cells resulting in weakness or paralysis of one or more muscles. In the United States, there have not been any acute epidemics of poliomyelitis for many years. According to the World Health Organization, in 2001, there were approximately 10 to 20 million survivors of poliomyelitis in the world.[1] The National Health Interview Survey from 1996 estimated that there were one million survivors of polio in the United States; of these 450,000 had some degree of permanent paralysis.[2] In addition, approximately 120,000 – 180,000 polio survivors experienced new symptoms related to their old polio.[2]

Post-polio syndrome (PPS) is a neurologic disorder based on a set of clinical criteria affecting adults with a history of acute paralytic poliomyelitis (APP) following at least a 15 year period of functional and neurological stability.[3] To help guide exercise prescription for adults with a history APP and/or PPS, Halstead et al. developed a five-class post-polio limb taxonomy, ranging from no remote polio to severely atrophic polio, used to grade individual limbs of adults.[4]

An adult with a history of APP who has a limb that he/she believes was not affected with weakness or paralysis during the acute phase of paralytic poliomyelitis has an "unaffected" limb. To classify this limb as having no remote polio versus subclinical polio electromyographic (EMG) studies are performed. A limb with no remote polio would have both no history of weakness or paralysis during the acute phase of paralytic poliomyelitis and no EMG evidence of anterior horn cell disease. On the other hand, a limb with subclinical polio is defined as no obvious signs/symptoms of polio involvement but has EMG evidence consistent with anterior horn cell disease.

Previous studies using monopolar EMG (MNEMG) show that the prevalence of subclinical polio ranges from 21% to 29% in "unaffected" limbs.[5, 4] While these studies estimated the frequency of subclinical involvement in "unaffected" limbs, they did not identify risk factors that predict the presence or absence of subclinical polio in "unaffected" limbs.

The purpose of our study was to determine clinical predictors of subclinical in "unaffected" limbs. We hypothesized that there were four risk factors: (a) a history of progressive new weakness (referred from this point forward as new weakness), (b) a history of new pain, either muscle or joint pain (new pain), (c) atrophy, and (d) muscle weakness as determined by manual muscle testing (muscle weakness by exam).

Methods

A retrospective medical chart review of all subjects seen in a post-polio clinic over a 12 month period. All data was obtained during a comprehensive evaluation in the same clinic.

Results

A total of 55 individuals with 111 "unaffected" limbs met the study criteria. Twenty-one were men and 34 were women. The average age of the adults was 58 ± 12 years (range 22 to 88 years). The average age of onset of APP was 5 ± 6 years (range 2 months to 29 years). The participants' average number of years since APP episode was 52 ± 10 years (range 17 to 74 years). Of the limbs believed by the participant to be unaffected, 45 or 40.5% had subclinical polio on EMG exam.

A positive EMG was 5.3 times greater in "unaffected" limbs with muscle weakness by exam than in those without muscle weakness by exam ($P< 0.001$). Clinical predictors associated with a positive EMG were: (1) muscle weakness by exam (n=29, $P<0.001$), (2) atrophy (n=5, $P=0.011$), (3) new weakness by history plus muscle weakness by exam (n=17, $P=0.017$), (4) new pain plus muscle weakness by exam (n=19, $P=0.049$), and (5) new pain plus new weakness by history plus muscle weakness by exam (n=12, $P=0.050$). A negative EMG was correlated with the absence of muscle weakness by exam (n=45, $P<0.001$) and the absence of atrophy (n=13, $P=0.011$). Forty-five out of the 111 "unaffected" limbs (40.5%) had subclinical polio.

Discussion

Muscle weakness by exam is the most important clinical determinant of subclinical polio in "unaffected" limbs. Other significant clinical predictors are (1) the presence of atrophy, (2) the presence of the combination of new weakness and muscle weakness by exam, (3) the presence of new pain combined with muscle weakness by exam, and (4) the presence of the combination of new pain, new weakness and muscle weakness by exam. The absence of subclinical polio was significantly associated with the absence of muscle weakness by exam and the absence of atrophy. Additional studies with larger numbers are needed to determine if additional risk factors are significantly associated with remote polio in "unaffected" limbs.

Conclusion

The best clinical predictor of subclinical polio in an "unaffected" limb is the presence of muscle weakness by exam. The presence of atrophy is another important clinical determinant for subclinical polio. An EMG is the diagnostic tool currently used by many physicians to determine whether or not "unaffected" limb(s) have subclinical polio. In situations where an EMG is impractical or unavailable due to cost or patient and/or physician preference, physicians should perform a thorough exam looking specifically for the presence or absence of muscle weakness by manual muscle testing as well as presence or absence of atrophy. Knowing the status of the presence or absence of subclinical polio is helpful for establishing a cardiovascular program for patients using the unaffected limb(s).

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EXERCISE, PART 1: A DEBATE ABOUT THE DEBATE

Opinion of An Experienced PT

Holly H. Wise, PT, PhD
Medical University of South Carolina

I. Introduction

II. **PRO: The Importance of Exercise**

A. Healthy People 2010
   1. Comprehensive nationwide plan for health promotion and disease prevention
   2. Recommendation: at least 30 minutes moderately intense physical activity most days of the week

B. Benefits of Exercise
   1. Reduction: adult death rates, risk of heart disease, developing diabetes, hypertension, depression, etc.
   2. Aids in weight control
   3. Improves: sense of well being and muscle and bone strength (can affect balance, falling, and function)

C. The Evidence on Exercise for the Individual with Polio
   1. Exercise can help maintain and possibly strengthen muscles ≥ 3+ as long as overuse avoided
   2. Exercise can be detrimental/harmful to muscles that are ≤ 3.

D. Barriers to Exercise
   1. Lack of time
   2. Access to convenient facilities
   3. Safe environment for physical activity
   4. Lack of knowledgeable health providers

III. **CON: Risks of improper exercise**

A. Overuse
   1. Muscles affected by polio resulting in pain, weakness and fatigue
   2. Joints
      a. Abnormal walking with back/leg pain
      b. Upper extremity abuse

B. Signs of Improper Exercise:
   1. Pain
   2. Muscle twitching or cramping,
   3. Fatigue

IV. **Best Solution: Evaluation by a Polio Team with recommendations for exercise from PT**

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OPINIONS FROM POLIO SURVIVORS:
Polio Athletes

Jane Atkey, Polio Survivor
Toronto, Canada

- We are fortunate in having professionals both researching and developing recommendations for polio survivors to exercise. We thank them and urge that studies in this area continue.

- Their advice in general is that most of us should undertake a careful exercise program under the supervision of a health care professional. But there are some practical realities.

- Those of us who got polio when we were old enough remember the gruelling rehabilitation we went through. The upshot is that some of us really don't much like the thought of exercising. We need a motivator.

- For most of us, daily activities take up much of our effort. There is very little or no of what I call "muscle margin" left. If we truly look at what we do each day, given the muscles we have, it would not be surprising to find that we are all super athletes, at peak performance most of the time. How much do we *really* need to exercise?

- Another reality is weight gain. How can we expect our poor muscles to do the same work as they used to, when they have much more to move around? Athletes at their peak of performance keep that weight down. They have to, and so do we.

- It is well known that because we have been so athletic, we may have some worn-out joints. It is important to know what is going on with underlying structures. But it is not always practical to have MRIs or bone scans just to make sure. Exercising can often tease out underlying problems that can then be addressed.

- We do not always recognise that with changed circumstances will come a change in abilities and conditioning. This is especially so when one goes from walking to a more sedentary life. Why wouldn't we get weaker and out of condition?. And yet, we tend to ignore this possibility or attribute it to something else. We need to work out more.

- Finally, supervision of a professional knowledgeable about polio would be wonderful but just try to find one. For example, in the Province of Ontario, the only way you can access a physio, short of paying privately, is if you have an injury or illness or following surgery and then treatment is specific to the problem. There has to be a potential rehabilitation outcome. We have already been rehabilitated. I do not know of any physio providing supervision for a general exercise program.

- So, what to do. The advice is available. The literature is there. There are those we can consult. But often we need to find our own way of doing what is best for us. Some of us may be lucky enough to find a knowledgeable health professional. Others may do Yoga or Tai Chi. My way is fitness training. I simply prefer to think of myself as an athlete rather than a patient.

- Since we've been athletes all our lives, fitness training seemed appropriate. Fitness training has the same goals as an exercise program – enhance performance and feel good. It has the same components – stretching for flexibility, cardiorespiratory workouts, and strength building. The caution is that fitness trainers tend to push too hard for us. I found one who said she was interested in working with seniors and people with disabilities. She did home visits and was creative. She listened to me and read the literature. She came to understand that polio paralysed muscles would not come back. She also came to understand that she had to go very slowly. She respects my request to stop when it hurts or the muscles tire. As a trainer, she knows that repeated overuse can cause damage to joints and muscles for any athlete. The same principle applies to us. I think of her as a coach. It's fun!

- My message is -- do something if you can, be careful, recognise your athletic accomplishments, find a good coach (health professional or otherwise), and, most of all, have fun!

Jane Atkey, Polio Survivor
Toronto Peel Post-Polio Committee
Toronto, Canada

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SCOOTERS AND POWER CHAIRS:
The Care and Feeding of a Scooter or Power Chair Battery

John and Jann Hartman
Baltimore, Maryland

A gel cell battery is the most popular sealed lead-acid battery used with mobility equipment. It's maintenance free. But, it must be cared for properly.

Lifespan of your battery depends on several factors:
1. how the battery is used
2. how it is treated
3. how it is charged
4. temperature

Battery capacity is reduced as the temperature goes down. At 32 degrees F (freezing) capacity is reduced by 20%. Battery life is affected as the temperature increases. Most manufacturers agree that there is a 50% loss of battery life for every 15 degrees of temperature over 77 degrees F.

Batteries are designed to be used on a daily basis--inactivity can be harmful. Do not buy new batteries and save them to use later. It is best to buy them when you need them.

Recharge batteries right after using them. When a battery discharges (through use or just setting) sulfate forms on the plates. Recharging takes sulfates off the plates, so they can't harden and shorten the life of the battery.

Batteries should be stored ideally between 32 degrees and 80 degrees F.

When you take your scooter or power chair in for its annual check-up, the batteries will be checked.

All batteries will die eventually. For battery replacement, check your durable medical insurance or Medicare. If you need to buy new batteries, shop around for the best price, but consider things like service and freshness of stock. For example, a battery warehouse may have the best price, but they don't provide service.

Internet Resources:
Battery Care (Tutorial): http://www.batterystuff.com
Mobility Equipment: http://www.ibsa.com
How Batteries Work: http://www.execulink.com/~impact/batteries.htm
Battery Safety (Fact Sheet): http://ohioline.osu.edu

John and Jann Hartman
Baltimore, Maryland

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SCOOTERS AND POWER CHAIRS:
Who chooses? Who pays?

Jean Csaposs
Maywood, New Jersey

An Overview

Acquiring a motorized scooter or power wheelchair may be the most important "mobility decision" you will make during your post-polio life. Or perhaps you already own a power-operated vehicle. If it is serving you well, rejoice! But sadly, many people are unhappy with their choices. There's the rub--did you even *have* a choice? Or did someone else decide for you? If so, you may be among thousands of people with disabilities who have been misled into purchasing, or acquiring through Medicare or private insurance, a motorized vehicle that hasn't served them well. My own experience was quite different, and that difference bears on this topic.

I first saw an Amigo scooter at a disability conference in Washington, D.C. in 1976. The late Ray Cheever, founding publisher of "Accent on Living" magazine, was at the event; he encouraged me to take a spin in his scooter. I did, and was immediately hooked. I said to myself, "As soon as I can afford it, I'm getting one of those!" In 1978, a new job found me with a need to propel my manual wheelchair from one federal building to another in Washington's summer heat--not only did I decide on the spot that I could afford the $900, but I also determined that an Amigo would be a career investment! And I loved the idea that it didn't have that wheelchair look. Pedestrians stopped me on the street, in long hallways, in stores--and still do--to say, "I wish I had one of those."

As a polio survivor who has had a lifetime need for "wheels," I realize that my experience, my needs, and my approach to solving my problems may differ dramatically from that of many other individuals whose polio seemed to be largely "in retreat" over their busy and active lifetimes. The need for "wheels" came late to them and the recognition of this need, for many, came even later, accompanied by extreme reluctance to admit new weakness due to PPS. For them, the decision to acquire a mobility device was harrowing, fraught with "image" issues and a sense of defeat. In my opinion, denial is the greatest roadblock to independent decision-making. One of my polio friends recently told me that it took her two years to come to grips with her need for a scooter, but now she can't imagine life without it. So, for you reluctant ones--get over it!!

Like any other important purchase, the choice of a mobility device cannot be left to others--one must be a patient, thorough, and discriminating shopper. It pays to spend time reviewing how the vehicle will fit into your home and into your life. If you can look on it not as a "last resort," but as a "new beginning," you've won most of the battle. A scooter or power chair helps the user to get more enjoyment out of life, to be more productive, to conserve energy, and yes, often to ward off pain, particularly in hands, arms, and shoulders. Knowledgeable doctors, therapists, vendors, and other polio survivors who own power vehicles can help, but the final decision must rest with you.

People often ask me: Which is better, a scooter or power chair? It's the wrong question. The answer is: It depends on the needs and the physical condition of the individual. For some people, with limited hand or arm strength and dexterity, a power chair operated with a joystick on the armrest may be essential; for most others, a scooter generally offers greater flexibility. My scooter has three features essential to my independence: a 360-degree swivel seat that locks in any position, a power seat lift, and removable, flip-back arms. Some power chairs now offer one or more of these features. What *only you* can decide is: Which of these vehicles is going to work best for me? Will it work well in my home? How will it be transported? Demand a home demonstration of any vehicle recommended for you, and ask lots of questions. If possible, the advice of a seating specialist may be invaluable. Above all, plan ahead--start looking into the home modifications that may be required--if not now, down the road--to expand the use of your scooter or power chair. Bear in mind that Medicare looks more kindly on claims based on enhancing the activities of daily living (ADLs) in the home.

Cost and Funding. Scooters are less expensive than power chairs. The joystick technology on the power chair accounts for the difference in cost. Vehicles that require two batteries instead of one also raise the price, both initially and in replacement, for both power chairs and scooters. Power chairs are generally heavier and more difficult to transport than scooters, although more streamlined models are appearing on the market.

An unfortunate result of the recent Medicare fraud scandals, which have revolved mostly around the sale of power chairs, is the increasing difficulty in getting Medicare approval for legitimate power wheelchair claims. A bit of history: When scooters (also known as POVs) were approved by Medicare in 1977 as Durable Medical Equipment (DME) after years of resistance, it was still a requirement that only four physician specialists could sign off on applications: physiatrists, neurologists, orthopedists, and cardiologists. The fear was that scooters were unsafe, and moreover would be prescribed frivolously and for "sporty," non-medical uses. But when power wheelchairs came onto the marketplace in greater numbers, they were not bound by such restrictions, with the result that any M.D. could authorize a prescription, and not necessarily even be acquainted with the "patient." Millions of wasted dollars later, Medicare is still trying to "get it right," and advocates, both individuals and groups like the United Spinal Association (formerly Eastern Paralyzed Veterans Association) have been working hard to restore the concept that the individual patient's needs should govern eligibility for funding.

Over the years, the relative ease of getting Medicare funding for a power chair over a scooter has denied for thousands of potential users what should be the most important criterion: the patient's best interests. Many people haven't even been shown what they are going to get after treatment at a rehab clinic -- they have simply been told, "This is your chair. Medicare has approved it." Many of these chairs are now white elephants, gathering dust.

Obviously, those who can afford to pay for a power vehicle independently are in the best possible position with regard to choice. But many people are unaware that their private insurance carriers are often more amenable than Medicare to provide full or partial funding. Unions and local benevolent organizations are often willing to assist, and the proliferation of both power chairs and POVs over the years has opened up a large market of used mobility vehicles in good condition. Local Centers for Independent Living (CILs) are often good sources of information on availability of good used equipment. A word of caution: in acquiring a mobility vehicle, a wise buyer will investigate how the vehicle will be serviced, what are the most likely repair problems, and the "care and feeding" of those essential components, the batteries.

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PREVENTING AND MANAGING SECONDARY CONDITIONS FOR POST-POLIO HEALTH

Alexa K. Stuifbergen , PhD, RN, FAAN
Tracie Harrison, PhD, RN, FNP
Austin, Texas

Secondary Conditions

- New conditions or problems that develop in the life course of a person with a primary disabling condition and are causally related to the primary condition (e.g. polio). These new 'secondary' conditions may interact with old impairments and together they may substantially limit functional abilities.
- Secondary conditions may be new pathology, an additional impairment, a new functional limitation or an additional disability (Pope & Tarlov, 1991).
- Secondary conditions reported include: urinary tract infections, contractures, depression, pain, fatigue pressure sores, deconditioning, osteoporosis, obesity, bowel problems and poor cardiorespiratory function
- Orthopedic complications are common in polio survivors including scoliosis, arthritis, osteoporosis, and progressive instability of the joints. Other secondary conditions known to occur in polio survivors include peripheral nerve entrapment due to skeletal deformity and respiratory insufficiency.

Process of Secondary Disablement (Institute of Medicine)

- The process of secondary disablement is influenced by the interaction of behavioral, environmental and biological factors. These factors interact with the primary disabling condition to influence the process of secondary disablement – a process that ultimately results in greater impairment, limitation and disability.
- Essential to consider factors that can influence both the occurrence and prevention of other secondary conditions.

Occurrence of Secondary Conditions Among Polio Survivors

- **Sample**
  - 2,153 participants – all fifty states
  - Average age of 62 years and average of 15 years of education
  - Majority were female (69%), married (66%) and not presently in the labor force (73%)
  - Average age at time of polio infection – 9.5 years
  - Use of Assistive Devices
  - Most (76%) had been diagnosed with post-polio syndrome
  - Number of secondary conditions ranged from 0 to 16; average was 5.6

- **Most Frequent Secondary Conditions**
  - New muscle weakness in previously involved muscles (88%)
  - Sensitivity to temperature in extremities (85%)
  - Fatigue (82%)
  - Chronic pain (72%)
  - More than half reported sleep problems (71%), new muscle weakness in previously uninvolved muscles (62%), scoliosis, kyphosis or lordosis (55%) and depression (50%)
  - Other Secondary Conditions

- **Extent of Difficulty with Various Secondary Conditions**
  - Difficulty over last 3 months
  - Relationship to Life Satisfaction

Strategies to Prevent and Manage Secondary Conditions

- **Environmental Changes**

- **Lifestyle and Behavioral Factors**

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NEW BRACING: THE CHALLENGE AND THE PAYOFF

Marny Eulberg, MD
Denver, Colorado
Marmaduke Loke, CPO
Encinitas, California

To enable the ultimate goal of efficient walking requires much more than making a brace for a limb. It requires a greater understanding of the Individual in need. Efficient walking must be planned. There are a plethora of issues that must first be recognized before they can be solved. The bracing of the future will no longer just be molded materials around a limb; it will improve the alignment of the limb better than ever before, it will offer more functional possibilities, the movement strategy and the brace will be designed to work together symbiotically for the person as a Solution based program, with efficient outcomes planned. In order to enable a person to reach new potentials, even potentials once thought unobtainable, an involved commitment by all involved is necessary.

We have all seen amputees walk and run with ease and grace. Why can't a brace user do that? Even people with very low-level paralysis involvement rarely can emulate what many amputees can do functionally. Why is that? The Solution development is more complex. Utilizing new clinical theories in lower-limb orthotics that are evidence based can enable a brace user to stand, walk, and even run more efficiently. New bracing solutions are now making it possible to close the gap between prosthetic's and orthotic's capabilities. These new bracing solutions are based on new or expanded concepts, designs, and advanced materials.

Chal-lenge vt. 1)to invite somebody (or oneself) to participate in a (activity), fight, contest, or competition; 2)to dare somebody to do something, 3)to stimulate somebody by making demands on the intellect (Neuro stimulation)
n 1) to invite somebody (or oneself) to participate in a (activity) fight, contest, or competition, 2) a test of somebody's abilities or a situation that tests somebody's abilities in a stimulating way
The word **en-a-ble** vt 1) to provide somebody with the resources, authority, or opportunity to do something, 2) to make something possible or feasible *from Encarta World English Dictionary copyright 1999*

Is the challenge worth it?

The new bracing solutions only *enable an* individual with a greater potential than they had before; what the person does with it is critical to the outcome. The people who have faced the challenge and overcame the obstacles are living a better life. Outcomes once thought unobtainable are now being realized. Activities thought lost forever are being reclaimed. A majority of the users can do more and use less energy and experience a reduction in fatigue. Many have a reduction in pain and many people feel stronger. Balance and security are improved with better mechanics and patterning; standing and walking are more efficient. Majority of individuals have downgraded the need for other assistive devices (canes, crutches) and majority of users are more active. Some people have regained muscles or muscle strength caused by disuse atrophy syndrome(s). Psychological benefits for users and members of their support systems have been witnessed.

The challenges will be unique and somewhat different for each individual but some common themes are: [one brace user's (M.E.) personal experiences in brackets]

- Understanding how this new technology works, how it could benefit the individual, and confronting myths and old paradigms about bracing: e.g., that hyperextension of the knee can only be controlled with posterior support or that a weak/absent quadriceps can only be supported or treated with a KAFO. [overcoming skepticism about claims that, initially, seemed "too good to be true".
- Unlearning old, inefficient patterns of walking. [old patterns felt "normal" to me; was, and *still is, hard to self-monitor and self-correct faults in gait pattern]*
- Learning to TRUST that the device will stably hold the person upright during single leg stance on the weak leg. [this has been very, very difficult for me].
- Hours of repetition of new body positioning and new gait pattern – practice, practice [making the time to practice the exercises until each move felt natural and was *automatic*]
- Believing that you are worth the investment!!
- [Being able to *look* at myself in mirror as I walked]
- [Confronting the reality that knowing how gait should be intellectually doesn't translate into being able to **do it!!!**]
- [Being patient with myself – I walked the old way for 54 years; it was unrealistic to expect to perfect the new way in only a few months]

The payoffs:

1) improved safety and stability which results in decreased falls/injuries. [noticeable excellent knee support—*no sensation that knee is going to buckle*]

2) improved walking efficiency & decreased energy output [I am able to walk about 4 times further 'hands free' than I was with a conventional AFO, can walk faster, and have decreased trunk lean with each step on the weak leg by at least 80%; therefore a much less obvious limp]

3) *no metal and usually no straps*, buckles or Velcro [avoided having to start using a locked knee KAFO and all its disadvantages and do it with only an AFO!!]

4) more fluid walking pattern with nearly equal stride length & stance time.

5) can be worn/used for many activities – in water, for cycling or, for running. [can go up some stairs one foot after another, instead of only one step at a time]

6) Increased confidence and self esteem [Incentive to begin weight loss program **and** be successful losing 50 pounds!]

Efficiency
- Stand, Walk, Run
- Point A to Point B

Conventional Orthotic Systems
- History

Mechanical Science
- Quantified & measured
- Governed by Law of Physics

What an Orthosis should do!
- Corrective Forces in 3 dimensions
- Improve & Maximize alignment
- Compensate for structural deficits
- Compensate for functional deficits
- Enable

Why we should quantify Outcomes
- Drives innovation
- Improves outcomes
- Allows comparison to other designs

Body Compensations
- Cost of Walking Speed

The Challenge – is it worth it?
- Commitment
- Training
- Outcome

Cost of Energy
- Compensations
- Braking & Accelerating

Outcome Measurement

Orthotic Design
- Functional
- Security Issues
- Support Systems

Solutions
- Floor reaction Designs
- Structural Control
- Functional Outcomes
- Security & Efficiency

Stance & Swing Phase
- Conventional – primarily swing phase
- Stance is most important

Gravity: Friend or Foe?

Balance & Efficiency

Walking Better

Comparisons: Bare foot --% of normal = 19.8 % of normal
Graphite Solid Ankle -- % of normal = 30 % of normal
Dynamic Graphite Composite -- % of normal = 67.9% of normal

Video Comparisons:

Marny Eulberg, MD
Denver, Colorado
and
Marmaduke Loke, CPO
Encinitas, California
www.DynamicBracingSolutions.net
619-972-3853
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SESSION II OPTIONS

10:45 am – 12:00 noon

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OPTIONS FOR MANAGING THE MULTIPLE CAUSES OF FATIGUE

Martin Wice, MD
Physical Medicine and Rehabilitation
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OPTIONS FOR MANAGING THE MULTIPLE CAUSES OF FATIGUE

Alexa Stuifbergen, PhD, RN, FAAN
Austin, Texas

Understanding Fatigue

- Acute versus Chronic Fatigue – Source of Misunderstanding
- Primary and Secondary Fatigue
- Disuse and Deconditioning
- Antecedents of Fatigue

Strategies You Can Use to Manage Fatigue

- Energy Conservation
  - Prioritize – Do Less
  - Innovate – "Working Smart"
  - Slow down and conserve
  - Ask for help from others

- Recharge Efforts
  - Diversion
  - Rest

- Enhancing Resistance to Fatigue
  - Physical Activity/Exercise (selected)
  - Temperature Control
  - Nutritional Intervention

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EXERCISE, PART 2: WHAT STEPS TO TAKE

Exercise and Post-Polio Syndrome

Mary Klein, PhD
Philadelphia, Pennsylvania

- "Advising all polio survivors not to exercise is as irresponsible as advising all polio survivors to exercise." (*Post-Polio Health*, Spring 2003, Vol. 19, No.2, part A).

- The benefits of exercise are endless. It can make you feel better physically and emotionally. These benefits can be achieved by performing as little as 30 minutes of exercise 3 times a week.

- Exercise can give you more energy, help strengthen your muscles and bones, decrease pain, increase flexibility, balance, coordination, and stability. Exercise can also help you lose weight, reduce stress, and help you maintain your independence with activity. If it is performed consistently it can be empowering, because it can leave you feeling like you are taking control of your body instead of fearing the negative changes.

- There are many conflicting articles that have been published regarding exercise and polio survivors. Some are in favor of exercise and others are against exercise. As a researcher, I cannot provide the answer for everyone of whether they should exercise or not. For polio survivors, exercise needs to be prescribed individually, just like medication.

- Individual. That is the most important word to remember when considering participation in an exercise program, especially as a polio survivor.

- Each polio survivor was affected in a unique way by the virus, both physically and mentally. When you are seeking treatment or being evaluated, your provider needs to be aware of what you have endured or overcome through your lifetime. That is why it is helpful for the provider to get a complete background of when you had polio, what areas were affected, what was the course of treatment, and how you recovered so that he or she can determine whether your body can tolerate exercise.

- Exercise must be done with planning and common sense and under the supervision of an experienced professional educated in exercise and knowledgeable in the effects of polio on the body. The professional will monitor your tolerance to the program and adjust it as needed. It may be helpful to keep an exercise journal to monitor your progress and reaction to the program.

- In general, a proper exercise program should involve three key components: a warm-up, exercise program, and a cool-down. The warm-up and cool-down are very important. The warm-up allows your muscles to stretch, your blood to start flowing, and your heart to pump a little harder. The cool-down slows your body down after the exercise and prepares it for rest. It allows you to slow your heart down gradually after the exercise.

- When we talk about stretching, we mean moving your body part to the point of feeling a pull in the muscles. If you feel pain, back off of the stretch and always avoid pain. In some cases, muscle tightness may be the body's way of compensating for muscle weakness. Stretching can undo this benefit and you could end up with less function than you had before the exercise. This is one reason why it is critical that polio survivors have a clinical evaluation from their physician or physical therapist prior to beginning any exercise program, including stretching exercises.

- **For polio survivors it is very important to avoid pain and fatigue. If you experience either symptom, you need to stop the exercise immediately.** Pain in this instance is a sharp pain that may affect your everyday movements. Fatigue is an overwhelming tiredness that requires you to stop what you are doing and rest. These two symptoms could predict if the exercise program is too easy or too difficult. These symptoms may also occur up to two days after the exercise is performed. It is important to respect these symptoms in order to avoid doing irreversible harm to your muscles.

- The majority of the recent studies that have been published about exercise and polio survivors recommend exercising every other day. If you are fatigued prior to your workout, do not exercise that day and try to do a less intense workout on your next session. It means that your last workout was too strenuous for your body and should be decreased until you build up your tolerance.

- Another very important aspect of an exercise program for polio survivors is rest breaks. Pace yourself. Frequent rest breaks should be incorporated into your program. This needs to be done, even though you may not feel tired when exercising. You need to listen and respect your body and the signals of fatigue.

- Review of Important Exercise Tips:
- ➢ Start with a one-on-one, in-person evaluation and testing by a trained healthcare professional in order to determine what will work and what will not work for you.
- ➢ Start slowly, recognize limitations and be willing to make adjustments along the way.
- ➢ Do not hold your breath while exercising (count out loud to promote proper breathing).
- ➢ Exercise slowly and build rest breaks into your program.
- ➢ Alternate exercises regularly so that no one muscle group becomes overused.
- ➢ If the program increases your pain, stop the exercise, or perform the exercise in a pain-free range of motion.
- ➢ Do not push to perform the extreme of the motion or exercise.
- ➢ Stop exercising if you have muscle twitching, muscle cramping, or muscle fatigue that does not subside after a 2 minute rest break.
- ➢ Do not exercise to the point of fatigue. You could do irreversible harm to your muscles.
- ➢ Try to figure out whether you feel better when you exercise in the morning, afternoon, or evening. Some individuals prefer to exercise in the morning because they have the most energy. Others exercise later, so that they make sure they can tolerate their daily activities prior to the exercise session, and they can rest afterwards. Lastly, others may divide their exercise program into two sessions to pace themselves.
- ➢ Remember, you are unique and only you can tell how you really feel and what works best for you. Figure out what works best for you and stick with it. There are no specific formulas that will work for everyone.

- As polio survivors, you must remember that all of the recommendations for healthy living are even more important for you.
- ➢ Don't forget to eat a healthy, well-balanced diet, which could help control your weight. It is very important for you stay fairly slim so you do not have greater difficulty with your mobility.
- ➢ Get the proper amount of sleep, because fatigue may be decreased with rest.
- ➢ Do your most strenuous activities during your greatest period of energy and take rest breaks throughout the day. It is very important to pace yourself and rest when you are getting fatigued.
- ➢ Take a nap during the day if you need it, and it may give you the regeneration that you need to finish your daily activities.
- ➢ Remember to exercise under the care of a specialist trained to prescribe and monitor your progress. Do not exercise to the point of fatigue.
- ➢ Those of you who use assistive devices and have weak legs are prone to overuse injuries of your arms. You have to be protective of your arms and shoulders, and sit on higher surfaces and in chairs with arms.

- It is also very important to keep moving. If you can tolerate exercising, studies have shown that you can maintain or improve your strength when properly supervised and performed.

- **"Beware of Inactivity !"** (The National Center on Physical Activity and Disability) This statement counteracts the old advice that warned against having polio survivors exercise. The thought is now that no matter what level of disability you are dealing with, you can participate in an individualized exercise program that is monitored by a professional.

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EXERCISE, PART 2: WHAT STEP TO TAKE
Suggestions from ...

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John P. Murtha Neuroscience & Pain Institute
Conemaugh Health System
Johnstown, Pennsylvania

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EXERCISE, PART 2: WHAT STEP TO TAKE
Suggestions from ...

Holly H. Wise, PT, PhD
Medical University of South Carolina

I. Introduction

II. **The First Step: Education and Self Examination**
- A. Benefits
  - 1. Reduction: adult death rates, risk of heart disease, developing diabetes, hypertension, depression, etc.
  - 2. Aids in weight control
  - 3. Improves: sense of well being and muscle and bone strength (can affect balance, falling, and function)
- B. Types of Exercise: relaxation, stretching, strengthening, coordination, weight bearing, endurance and cardiorespiratory
- C. Risks: overuse of muscles affected by polio resulting in pain, weakness and fatigue
- D. Signs of Improper Exercise: Muscle or joint pain, muscle twitching or cramping, muscle fatigue
- E. Barriers to Exercise

III. **The Second Step: Baseline Examination by Polio Team**
- A. Muscle Testing
  - 1. Manual: 0-5 Grades
  - 2. Torque: Exercise equipment
- B. Range of Motion
- C. Body Mechanics
  - 1. Posture: sitting, standing, sleeping, etc.
  - 2. Gait: efficiency, safety important
- D. Evidence
  - 1. Can help maintain and possibly strengthen ≥ 3+ if overuse avoided
  - 2. Can be detrimental/harmful to muscles that are ≤ 3

IV. **The Third Step: Action with Determination**
- A. Needs: type of exercise, how much, which muscles are at risk, safety issues
- B. Capabilities: which muscles can tolerate exercise, accessible resources, etc
  National Rehabilitation Hospital Guidelines for exercise
  Exercise Prescription: avoid overuse with select exercises
- C. General Guidelines
  - 1. Stretching: best when armed up, no bouncing, hold 20-30 seconds
  - 2. Strength/Endurance: slow increase in weight, repetitions, sets, do not train same muscles 2 days in a row
  - 3. Cardiorespiratory/aerobic: 30 minutes of moderately intense on most days

V. **Step by Step**
- A. Desired Results:
  - 1. Increase Safety, Function, Quality of Life
  - 2. Prevent Further Pain/deterioration
  - 3. Promote Health and Wellness
- B. Selection of Exercise Activities
  - 1. Aquatics: pros and cons
  - 2. Circuit Weight Training
  - 3. Cardio-respiratory: Upper Body Ergometer, Nu-Step, etc

VI. Conclusion: **Finding the Balance**

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EXERCISE, PART 2: WHAT STEPS TO TAKE
Reactions from Polio Survivors

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VENTILATOR USERS: GETTING YOUR ACT TOGETHER AND TAKING IT ON THE ROAD

Audrey King
Toronto, Ontario, Canada
Barbara Rogers
New York, New York

SPONSORED BY PULMONETIC SYSTEMS, INC.

Synopsis of Session:

Audrey King, a polio survivor and ventilator/wheelchair user since 1952, will share highlights, adventures and "lessons learned" during her many decades of travel. Accompanied by an ever evolving variety of electrical, mechanical and personal assistance, she has travelled throughout Canada, USA, Europe and, most recently, Japan (2004).

Barbara Rogers, a non-invasive ventilator user for over 15 years and a part time oxygen user, will share the experiences and challenges she has faced as a "Frequent Flyer." She will discuss the differences she has confronted when traveling domestically and internationally and impart tips for easier navigating through the transport systems.

Five Successful Travel Tips:

- RESEARCH
  Long before you go, discover as much as you can about your destination, how you will travel there, what the accessibility and electricity are like and how you will be able to manage in the unfamiliar environment.

- ASSISTANCE
  Recognize that dependence on others increases in an unfamiliar environment. Anticipate what extra help you might need and plan for it. Spend time together with your travel partner long before you go so you both are comfortable. Think about how you will manage with respect to being lifted, getting on a plane, toileting, transferring and so on.

- BACK UP EQUIPMENT
  Take back up and emergency equipment as well as tape, string, extra extension cords, tools, wrenches and whatever else you might need.

- LOCAL RESOURCES
  Learn what resources are in the area for repairs, extra attendant or medical assistance, if you should need it. Purchase or design what you think you might need.

  Take documents, including manuals, physician letters and so on.

- "TOP TEN" TRAVEL ATTRIBUTES
  1. Sense of adventure and challenge
  2. Patience and optimism
  3. Creativity and problem solving skills
  4. Positive people skills, – appreciation consideration, graciousness & gratitude
  5. Flexibility and adaptability
  6. Sense of humour
  7. Know your own limits
  8. Negotiation skills, (with a mix of positive assertiveness when necessary)
  9. Confidence
  10. Ability to take initiative in unexpected situations

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Choosing to Flourish: What Works for Me

Linda Wheeler Donahue
Southbury, Connecticut

A smooth sea never made a skilled mariner. –English proverb

Cognitive restructuring is a process of replacing unhelpful thought patterns with constructive thoughts and beliefs. In this presentation, I will share how cognitive restructuring enabled me to erase my negative self-image and replace it with empowerment.

Adversity, such as living with the aftermath of polio, can actually be a good thing. Helen Keller said, "Character cannot be developed in ease and quiet. Only through experience of trial and suffering can the soul be strengthened, ambition inspired, and success achieved."

For me, polio resulted in negative body image problems which led to low self-esteem
- My emotions and thoughts were flooded with painful embarrassment
- Therefore I became agonizingly self-conscious
- My first step toward happiness was choosing to be happy
- I learned that you are your thoughts

What is cognitive restructuring?

You can use cognitive restructuring as an action-oriented form of psychosocial therapy that assumes that maladaptive, or faulty, thinking patterns cause maladaptive behavior and "negative" emotions. Maladaptive behavior is behavior that is counter-productive or interferes with everyday living. It is possible to change an individual's thoughts and cognitive patterns in order to change his or her behavior and emotional state.

- It is a way of ridding yourself of negative thought patterns

- Restructuring your mind and attitude for the better
- It can enable you to reduce stress and live joyfully
  - It helps you stay positive in all aspects of your life

What is self-actualization?

- Dr. Abraham Maslow coined the term "Self-Actualization" as the pinnacle in the hierarchy of human needs
- We can reach self-actualization by replacing old malignant internal messages with self-affirming thoughts
- By making healthy lifestyle choices
- By surround yourself with positive people
- By serving and helping others

How does Journaling help?

A useful technique is to keep a detailed diary recounting your thoughts, feelings, and actions when specific situations arise. The journal will help you to become aware of unhelpful thoughts and to show their consequences on your behavior.

What is Self-Talk?

In the 1970s, a self-instructional approach was developed by psychologist Donald Meichenbaum who pioneered the "self-talk" approach to cognitive-behavioral therapy. This approach focuses on changing what people say to themselves, both internally and out loud. It is based on the belief that an individual's actions follow directly from this self-talk.

What are Schemas?

Schemas are the fundamental core beliefs or assumptions that are part of the perceptual filter people use to view the world. Schemas organize our thoughts and perceptions and are an integral influence on our emotions and behaviors. Cognitive-behavioral therapy seeks to change unhelpful schemas. In my case, my schema was informed by negative input so I made a solid decision to remedy that problem.

How long will this process take?

- Personal growth is not something one does once and then it is completed
- It is an ongoing way of living
- We must put our "choice to flourish" on project status

I learn so much from my rose bushes. They are constantly dealing with adversity and yet continually renewing themselves. That's how we can be.

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CHOOSING TO FLOURISH: WHAT WORKS FOR ME

Dorothy Woods Smith, PhD, RN, AHN-C, QTTT
Portland, Maine

Holistic Health Strategies

During the era when most of us had polio, the focus was almost entirely on the physical aspects of the disease. The treatment goal was to restore our muscle function to the extent possible, then to find ways to work around the deficits that remained. Although pain was a hallmark of polio there was little or no treatment or medication for pain. Our emotional response to such overwhelming and instantaneous change was typically not addressed. Who comforted us or encouraged us to express our fear or terror, our shock, or the outrage that would have been appropriate? More typically, we were praised if we were brave. "No pain, no gain" was one of many "stiff upper lip" messages. Those aspects of ourselves, our human responses to the sudden and devastating illness, our grief at losing fellow polios, were to be hidden from the outside world. We learned to do that well. How else did we respond? Spiritual beliefs for some were a source of comfort, for others, distress. One post-polio friend from Maine described God as his only friend during seven years in a hospital for crippled children. For another, misfortune was viewed as punishment. Many of us still carry survivor guilt, and wonder on some level why we were singled out to experience this life-altering illness.

As human beings, we are designed to store memories in many ways. Some are triggered by attending a post-polio conference or support group. Other memories are hidden much deeper. One theory is that memory is a hologram, stored not only in our brain, but in every cell in our body. Memories of trauma seem to be stored intact, tucked away so we can get on with our lives. A certain touch can release an old memory, almost like hitting a replay button for a video you didn't know you had kept. We are discovering more about this with holistic energy and body work techniques.

Holistic is one term for body-mind-spirit treatment approaches. Holistic approaches all support and energize our own healing processes. We were born to be healthy, able human beings. The "map" for that is within us, and just as it guided the cells in the womb in the process of becoming us, it guides us in healing throughout our lives. Holistic health practitioners work with us to promote our own self-healing, "doing with" rather than "doing to" us. Although I have academic credentials in this area, I have learned on a deeper level through what my body has experienced. I continue to try to comprehend how these changes can take place despite "evidence" that it would not be possible.

I first learned of post polio syndrome (PPS) in 1984. In 1985 Dr. Augusta Alba diagnosed me with PPS. She sent me to a physical therapist who did trigger point therapy for my pain, and taught me several points I could use on my own. Dr. Alba practices what I would call integrative therapy: observing and guiding, blending the medical model with holistic therapies, realizing that ultimately all healing is self-healing. Being supported by someone like Dr. Alba in itself puts us in a good place for healing! At the same time, I was a graduate student at NYU. There, doing a project on PPS, I met Dr. Dolores Krieger, the nurse professor who was co-developer of Therapeutic Touch (TT). A former polio nurse, Dr. Krieger thought my symptoms might be helped by TT. My body began to inform my whole self by experiencing "impossible" changes, subtly, slowly, but over time noticeable in body, mind and spirit. I continue to use TT as a cornerstone of both my personal and professional life nearly 20 years later.

I learned from the work of Deepok Chopra, M.D., that all of our cells are renewed over a 7 year period, some more frequently than others. In his words: "I now view my body in non-materialistic terms. I realize that 98% of the atoms are replaced once a year. My skin is new once a month. My stomach lining is new every five days. My skeleton changes every three months. I make a new liver every six weeks. Even my DNA at the level of the atoms changes every two months. I am constantly changing my body, even more effortlessly than I change my clothes." At the time I heard this, I was very concerned about the findings that all polio survivors tested in one study showed ongoing denervation – even those without symptoms of PPS. I decided I would try to give each of these forming cells, specifically the replacement nerve cells, the nutrients and the oxygenation associated with deep sleep that they need to be at least as good as those they are replacing. I expect that the more optimistic expectation also contributed to my improved well-being.

Later I trained as a clinical provider with Dr. Herbert Benson, pioneer in studying the benefits of the Relaxation Response (RR) and interned in a chronic pain program based on his work, which required me to be a participant for a full 10-week program. Research-supported health benefits of the RR include lowering of the heart rate, blood pressure, and breathing rate; lowered metabolism; decreased muscle tension and anxiety; and decreased stress-related physical symptoms. Added benefits include improved sleep, improved performance, and greater efficiency; increased concentration and awareness; greater self-acceptance, and less self-criticism and negative thoughts. Again, my learning was truly a body-mind experience! As I regularly practiced the RR, I received more benefits to my own health More efficient use of the muscles I use to breathe translates into fewer demands on my trunk muscles and diaphragm. More oxygen in my blood means more efficiency for my muscles. Greater relaxation of the muscle tissue allows waste products to leave our muscles with greater efficiency. Each small change builds on the others, offsetting the decline, maximizing what exists, creating health a cell at a time. Now, nearly 20 years after the Dx of PPS, I feel better and have greater flexibility and more stamina than I did then. I was not able to change the polio history, but I have tried to change my response to it in a way that is healthy for me. I have added supplements and watch my diet to provide myself with the necessary ingredients for making every new cell as healthy, or healthier, than the one it is replacing in the ongoing process of cell renewal. Myofascial release and craniosacral therapy are part of my ongoing regime. Some things I tried did not help, or took away some of the improvements I had experienced. I had to become a good observer and reporter, and partner with a well-informed and open-minded physician.

I would encourage each of us to find 5 ways we can achieve the relaxation response in our day-to-day lives, and to observe the benefits. There are many practices that can be used to achieve the RR. For us as polio survivors, exercise and breathing to accomplish our daily routine can be pushing the envelope of what is good for us. With everything there is a cross-over point between enough and too much. As post-polios, we tend to do the latter! We need to be creative, and use our adaptation skills to figure out ways to relax. One man in our Maine post-polio group told us about his 20 minute morning exercise routine which involved muscles from head to toe. His body was frail and his breathing needed frequent mechanical help. We were amazed to learn that he did this routine in his bed using imagery, picturing each step of this routine! Research has now confirmed that the brain cannot distinguish between reality and imagery, and that our body responds the same to both. What power this is for us if we take advantage of it!

Music as a means of creating the RR works for many – listening to a tape or CD at bedtime, or enjoying the sound and vibrations of live music Singing can be both relaxing and exhausting! Meditation and guided imagery are healthy options. Laughter is a fun way to release endorphins and increase our sense of well-being. Being at a post-polio health conference includes socialization and just plan fun – a way to collectively achieve the Relaxation Response!

In the group presentation "Choosing to Flourish: What Works for Me", we will take about 15 minutes to experiment with some quick and simple ways to achieve the RR. Using individual "biodots" for feedback, individuals can learn what "minis" may work best for them.

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LONG TERM CARE: BUYING IT AND SECURING IT

Matt McCann
District Sales Manager/ACSIA Long-term care, Inc.
Darien, Illinois

Introduction

Personal background and experience in LTC.

Overview of the long-term care problem in the United States

Review of risk of needing care.

How LTC is funded in the United States

Health insurance
Medicare
Medicaid
Private funds
Long-term care insurance

How does long-term care insurance work?

Policy designs, benefits and costs

Long-term care insurance and Post Polio issues

Insurance companies and underwriting, who they will offer coverage and why, who they will not offer and why

Alternatives to LTC insurance for those uninsurable

Annuity options with LTC benefits

Who to talk to talk about long-term care insurance products

Q&A

SESSION III OPTIONS

1:30 pm – 2:45 pm

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OPTIONS WHEN A POST-POLIO CLINIC IS *NOT* AN OPTION

Carol Vandenakker, MD
Sacramento, California

A. You must start with a good primary care physician.
  1. Keys to finding a good doctor:
    a. Look for a physician you trust and can communicate with.
    b. Identify the best hospitals in your area and try to find a physician on staff there. The best hospitals attract the best doctors.
    c. Get recommendations from trusted sources: hospital referral service, health plan directory, another physician or nurse, friends and neighbors.
    d. Find out if the doctor is Board Certified.
    e. Access your state's web site for information.
    f. Your insurance choice may dictate what physicians you can see.

  2. You will be an "expert patient":
    a. Good and bad connotations.
    b. Provide a brief summary of PPS:
      1) NINDS Post-Polio Syndrome Information Page
      2) March of Dimes Quick Reference and Fact Sheets – Post-Polio Syndrome
      3) Post-Polio Health International – Polio and Post-Polio Fact Sheet or The Late Effects of Polio-An Overview
    c. Do not expect that the doctor will know much about polio.

  3. Do NOT overwhelm a new physician.
    a. Let the physician get to know you and evaluate your overall medical condition and health issues.
    b. Do not go in with a shopping list of equipment needs or a stack of disability forms.
    c. Be familiar with the summaries and provide the **one** most appropriate for your needs.
    d. Give the doctor a chance to learn about you and PPS.

  4. The first step to managing symptoms of Post-Polio Syndrome is optimizing health. (Any good doctor can help you with this step.)
    a. Other conditions must be diagnosed and treated. "Diagnosis of exclusion"
    b. Monitoring for osteoporosis (strong limb/weak limb), hypertension, anemia, sleep apnea, thyroid dysfunction
    c. Aging changes should be discussed.
    d. Health promotion through:
      1) Nutrition – calories and weight control
      2) Exercise – stretching, strengthening and aerobic conditioning (see Guidelines for polio survivors)

        3) Stress management – psychosocial, emotional health

B. Symptoms should dictate diagnostic testing and/or referrals. A variety of specialists may be able to identify and treat problems. You may find one of your specialists most receptive to your needs.

1. Pain may be classified into different categories:
    a. Post-polio muscle pain – caused by overuse of weak muscles
        1) Occurs in polio muscles
        2) Similar to pain of acute polio
        3) Associated with cramps, twitching, crawling sensation
        4) Increased at end of day
        5) Aggravated by activity, stress, cold

        Specialists: PM&R, Orthopedics, Neurology- YOURSELF!
        Treatment: Protection of muscles, activity modification, pacing

    b. Soft tissue pain
        1) Injury or inflammation of muscles, tendons, ligaments, bursae
        2) Common examples: rotator cuff tendonitis, "tennis elbow", bursitis of the hip
        3) Often affects the "strong" limb
        4) Related to body mechanics

        Specialists: Orthopedics, PM&R, Rheumatology
        Treatment: Correct/adapt body mechanics, protect affected areas, rest, ice, NSAIDS, injections, therapy

    c. Joint pain from degenerative changes
        1) Affects joints in strong limbs due to normal or excessive "wear and tear"
        2) Joints in polio - affected limbs may have force changes resulting in ligament tears, joint deformity
        3) Joints with mild degeneration may be symptomatic because of abnormal body mechanics

        Specialists: Orthopedics, PM&R, Rheumatology
        Treatment: Bracing, assistive devices, therapy, medications

    d. Spine pain
        1) May be in spine or referred into extremities
        2) Increased scoliosis increases risk of spine problems
        3) Spinal stenosis may mimic PPS

        Specialists: Orthopedic Spine, PM&R
        Treatment: Therapy, injections, bracing, surgery

    e. Nerve pain
        1) Severe pain often associated with sensory changes or shooting/electrical symptoms
        2) May result from diffuse disease or localized nerve compression (carpal tunnel syndrome)

        Specialists: Neurology, PM&R, Orthopedics
        Treatment: Activity modification, splints, therapy, medications, injections, surgery

    f. Bone pain
        1) Osteoporosis with small compression fractures
        2) Traumatic fractures/bruising

        Specialists: Endocrinology, Orthopedics
        Treatment: Treatment of osteoporosis, immobilization of fracture, bone stimulation

2. Fatigue
    a. Evaluation of causes/aggravating factors
        1) Sleep pattern
        2) Other medical illnesses: thyroid, CAD, obesity, anemia
        3) Deconditioning
        4) Depression
        5) Overuse
        6) PPS

3. New weakness
    a. Evaluation of possible causes:
        1) New superimposed neurologic condition
        2) Disuse atrophy/ deconditioning
        3) Weight gain
        4) Medical condition
    4) PPS

Specialists: Most of the assessment can be done by the primary MD, with assistance from PM&R, neurology, and possibly psychologist, sleep specialist, physical therapist

Treatment: Treat all contributing factors, appropriate pacing, limited exercise program, protecting weak limb

4. Respiratory/Pulmonary problems
    a. Decreased muscle strength from polio causes restrictive lung disease similar to that seen with other neuromuscular diseases.
    b. Polio survivors may have obstructive disease as well, especially with h/o smoking or allergies.

Specialist: Pulmonologist, referral to local muscular dystrophy clinic pulmonary specialist may be most helpful.

5. Swallowing difficulties
    a. Should be assessed by a speech therapist and appropriate studies ordered as indicated

C. Basic principles of treatment:

1. Identify goals
    a. Improve body mechanics
    b. Correct or minimize postural and gait changes
    c. Protect weak muscles and joints
    d. Adjust the workload on muscles and joints to match their capacity
    e. Control inflammation (sign of poor body mechanics)
    f. Control muscle spasm (sign of overstress of muscle)
    g. Alleviate nerve impingements
    h. Promote healthy lifestyle modifications
2. Determine appropriate treatment modalities:
    a. Behavior modification/pacing
    b. Physical therapy (provide resources)
    c. Occupational therapy
    d. Bracing
    e. Assistive devices
    f. Weight loss
    g. Joint/spine injections

    h. Medications
    i. Psychological counseling

3. Educate those who work with you
    a. Provide resources (not stacks of printed material)
    b. Let your feelings and needs be known without becoming overbearing or too demanding
    c. Treatment plan should result from discussion between you and your h health care provider - not one or the other giving orders!

If unable to find satisfactory treatment locally, I recommend a visit to a post-polio clinic for assessment and recommendations.

Post-polio Fact Sheets Available on the Internet
http://www.ninds.nih.gov/disorders/post_polio/detail_polio_pr.htm
http://www.marchofdimes.com/printableArticles/14332_1284.asp?printable=true
http://www.post-polio.org/ipn/fact.html
http://www.post-polio.org/ipn/lep.html

PRINCIPLES OF BRACING FOR POLIO SURVIVORS

Complete physical assessment is essential to determine the best bracing options for an individual.

Braces should be used for specific management of a selected problem.

There should be a specific goal of treatment, i.e. decrease pain, improve stability, prevent falls, or protect joints and weak muscles.

Joint movement should be allowed whenever possible and appropriate.

The brace should be a light as possible.

The brace must be comfortable and functional- or you won't use it!

Our goal is to continue safe, independent mobility as long as possible.

Factors that must be considered in prescription:
    Patient weight
    Activity level
    Strength of other extremities
    Ability to use assistive devices
    Ability to don/doff brace
    Edema
    Sensory loss (i.e. diabetic neuropathy)
    Skin problems
    Home/work environment (uneven surfaces)

The orthotist fitting and fabricating the brace should be board certified and preferably have experience with polio survivors- they are different (and more difficult) than most other types of patients. Orthotist must be receptive to the patient's wishes and ideas, communicative, patient and willing to make adjustments.

The physician should be able to communicate with the orthotist if there are any questions or concerns about my prescription. It is easier to discuss changes before the brace is made than have to make adjustments later.

Don't pay for the brace until it fits right and you can use it!

EXERCISE GUIDELINES FOR POLIO SURVIVORS

Exercise is defined as planned, structured, and repetitive body movement. Physical activity is movement occurring during daily activities.

A therapeutic exercise program is designed for health benefit- generally to reduce pain, increase strength, increase endurance and increase the ability to do daily activities.

Not all polio weakness is due to overuse, often lack of exercise and physical activity leads to muscle wasting and cardiovascular deconditioning.

Research supports a carefully designed therapeutic exercise program for most polio survivors to enhance optimal health and function. The program should be individualized and modified if problems arise.

Important principles to follow are:

1. Start very slowly. Often 3-5 minutes is all that can be tolerated initially if muscles have not been exercised for a period of time.

2. Interval exercise, short bouts of exercise alternating with rest periods, can be very effective.

3. Progression should be slow, especially in polio- affected muscles.

4. Intensity should be low to moderate.

5. The plan should include a rotation of different types of exercise such as stretching, cardiovascular (aerobic) conditioning, strengthening, and range of motion exercises.

6. Pacing should be incorporated into the program with at least one day of rest between strengthening exercise sessions.

7. Aquatic exercise is often ideal as the buoyancy of the water help to support weak muscles and unweight joints while providing mild resistance to muscles. Remember it is easy to overdo in the pool because it is so much easier to move!!

8. Be aware that signs of overuse can occur 24-48 hours after too strenuous exercise or an overly active day. **Symptoms of overuse indicate a need to decrease the amount of exercise or decrease the frequency of activity.** The symptoms to watch for are: muscle cramps and spasms, muscle twitching, muscle pain and extreme fatigue.

REMEMBER THAT YOU <u>CAN</u> EXERCISE SAFELY AND IMPROVE YOUR CONDITION IF YOU APPROACH IT WITH PATIENCE AND CONSISTENCY!!

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EXPRESSING SEXUALITY: WHAT WORKS FOR ME

Linda L. Bieniek, CEAP
La Grange, Illinois

"We still need to be caressed and held and fondled. We still need to love and be loved. We still need to have the physical and emotional releases that sex provides ... one part of a relationship, and one part of your own sexuality, is having sexual feelings ..."
- Klein and Kroll, *Enabling Romance*

Many of us have survived serious health problems and have worked hard to accept our limitations. We have contributed to our families, jobs, professions, communities, and worthwhile causes in society. Yet, as we age and our health conditions change, we may encounter new challenges in expressing our sexuality and giving and receiving sexual pleasure.

Sexuality often is equated with sex, particularly intercourse. Actually, sexuality is a form of expression that encompasses our beliefs, feelings, behaviors, libido, values, self-esteem, body image, and body language. Our sexuality allows us to communicate our passions, values, and sensitivities and provides us with opportunities for experiencing active and fulfilling sex lives.

Research shows that sexual satisfaction in relationships is closely related to satisfaction with self (sexual esteem) and with one's partner. When partners are compatible and supportive, sexual satisfaction is more likely regardless of physical limitations. Non-disabled partners report that sexual fulfillment is more important than intercourse and that a person can have an orgasm without having intercourse. What they seek most is emotional closeness, mutual trust, affection, and a willingness to explore a variety of sexual expressions. (Esmail et al) This paper offers a collection of ideas and exercises about expressing your sexuality that you may want to explore.

Polio Survivors, Ventilator Users, and Others with Disabilities Share What Works for Them

Breathing

"I got tense whenever my wife and I start to be sexual. She insisted we get some help. We went to a workshop on "Intimacy" and I learned about deep breathing. It has helped me relax and experience erotic feelings, not just going through the motions when making love."

"Breathing is intricately connected to sexuality. I've learned to be conscious of how my breathing changes as I become sexually excited, and to let the BiPAP support my breathing rather than fight against it. Sometimes, as I get close to orgasm, I realize I am holding my breath in an attempt to "bring it on" faster. This can make me uncomfortable and out of breath, or make the BiPAP trigger a breath when I'm not ready, either way causing an unwelcome interruption. So now, I try to deepen my breath instead of stopping it when I am approaching climax. It takes a little longer to get there, but when I do come, it's more intense and longer-lasting."

"Adaptive equipment, including ventilators and their attachments, can sometimes get in the way when you're being intimate. But if you approach it creatively, the equipment and tubing and stuff can also enhance sexuality. Sometimes I have used silk scarves, feathers, body paint, etc. to help integrate the tubes and/or mask into the sexual activity. By treating the equipment and attachments as part of the play, they eventually feel less like foreign objects, and more like sex accessories!"

"Using a trach with mechanical ventilation supports me in expressing my sexuality. The trach pumps air into my neck. This means my face is available, and I don't need to fear suffocation."

Positioning/Environment

"In the movies, the woman can jump on the guy's lap and do all these gymnastic moves, but I have to get him to put me in bed. That reduces the spontaneity, but it doesn't take out the thrill."

"I've had to work hard at asking for what I need in intimate relationships. If I don't, I get distracted and down on myself afterwards. Sometimes I need the temperature adjusted or to hear more tender words to get my juices flowing."

"I cannot be on the bottom when making love. I am best when I am sitting upright on top so I can breathe more easily. When the man also has had respiratory issues, this has been more of a challenge. The spoon position has worked at times. In the end, our ability to find comfortable positions and ways of making love has boiled down to the level of trust and sincere affection. My body is very intuitive and will not open up when a relationship isn't grounded in deep feelings."

"The point is not to 'perform,' but to have fun. I might have sex in ways that are very different that what you see in R-rated movies, but if it brings pleasure to me and my partner, then it's good sex!"

"This lack of sensation does interfere with my enjoyment but the transfer of sensation to different parts of my body means I enjoy different areas than those where you'd normally expect to gain pleasure – my neck is really sensitive."

Self- Esteem

"I used to think that no one wanted me, but now I've realized that it comes back to my self-esteem. I've realized, since I met my current partner, that I have rejected potential partners rather than the other way around."

"Presenting a positive, confident self-image helps me look approachable. (if you need, get grooming assistance before you leave your domicile). I am willing to (and do) make eye contact with people I encounter -- that's confidence! And I smile -- especially if I find the other person attractive! That's a great start even if I haven't said a word! If the opportunity for conversation presents itself, I start one. I carry a card with my name and e-mail or phone number, in case the environment isn't conducive to a conversation. ....I am looking for friendship first. Without friendship and trust solidified, I don't think it's emotionally healthy for me to go beyond that since I'm looking for a serious relationship. Good communication is crucial."

"I realize that even as a ventilator-dependent quadriplegic, I still have a lot to offer to a potential relationship, especially in terms of friendship."

"I feel that it can be too easy to blame everything on my disability. I'm beginning to realize that other factors come into play, that very few people ... have 'perfect bodies' -- and that I may be rejected for quite separate reasons other than my body. This realization has cheered me up immensely and prompted me to look at my beliefs with a therapist. This has opened up a whole new world in my relationships."

"The only reason why I went into an intimate relationship with this person was that I felt trust again, and that this person was caring enough that I could address disability issues with him. When I found myself discussing my disability, the guy didn't run."

"My new marriage has taught me that the fears I had about my manhood and sexuality as a disabled person were empty ones. Although I miss the conventional sex most people experience, I've learned to cherish what I still have. We may make love differently, but it's just as rewarding, satisfying, and meaningful to us as a couple."

"Working through my shame and remorse about my past sexual relationships helped me the most. I wasn't able to get into a healthy relationship until I did. I had to forgive myself for getting into potentially dangerous situations with men I didn't know well. I was sexually starving and somehow I needed to prove I was a woman. Now, that I am clear about when physical contact is safe for me and the kind of relationship I want, I feel a lot better about myself and my judgment."

"I reject shame. I am who I am, sexy and attractive, WITH (not despite) my disability and everything that goes with it -- including my BiPAP and all its accessories and sounds. If I happen to be wearing my Nasal-Aire with my machine pumping away on the back of my wheelchair, and I decide I want to flirt -- I just do it! I don't hold back out of embarrassment. I use my eyes, my words, my machine-modulated voice (those breathing pauses can be sexy!), and my energy to try to make an erotic connection."

Connections with Self and Others

"The best sex comes from open communication and the willingness to be silly, to forget about the inconveniences the disability creates. I'm always open about my disability and willing to talk about it...I've read a lot of books on sex and sexuality, so I've been able to develop my own sexual techniques that I've tailored to my abilities."

"I'm not afraid to experiment, to try new things, and to tailor my sex life to my personal needs and desires. Living with a disability has taught me the value of adaptability and finding different ways to do things when the conventional ways don't fit me. It's also taught me that how something works for me is more important than how it might look to others. In trying different positions, activities, whatever -- I go with what works -- even if other people might judge it too kinky OR too vanilla."

"I found it hard to form relationships in my 20's because of society's attitudes about I beauty and my father's attitudes. I was also very shy. I overcame this when I advertised for a partner who shared my interests and was willing to adapt to my lifestyle."

"Since I tire easily, my husband brings home take-out dinners so I can save my energy to be sexually expressive! ... with aging parents, work schedules, etc we schedule at least one weekend a month concentrating on each other... sometimes we just spend time talking. We watch "educational" shows about sex and intimacy on Discovery Channel, etc, and I often read articles/books. We still flirt with each other, too. .."

"After years of soul-searching, I came to realize that most of my romantic failures came from my latent doubts about myself as a disabled person, and the fears I had about my own sexuality."

"Though I still have physical problems, I've had professional counseling that has helped me tremendously in finding out who I am and what I want out of life and relationships. Occasionally, I still experience episodes of anger and sadness over my disability, but I am much more satisfied with how I am in intimate relationships."

"Most important to my sexual development has been FINDING COMMUNITY. As I was growing up, and even in college, I knew very few people with significant disabilities. Adults and my own peers respected my intellect and accomplishments, yet they could not see me as a whole human being with a sexual nature. I received the unspoken message that my body was not my friend -- that it needed tending and maintenance, but not excitement and pleasure. In adulthood, when I found and got involved in the disability community, I finally got to know people who could see me as a sexual person. It also has been important to me to be part of lesbian communities, where I could find recognition, reflection, response and outlet for my sexual desires."

Are You Up To Taking a Quiz?

If you're interested in discovering more about yourself, you may want to see if you relate to any of the options listed and what else may come to your mind.

How do you express your sexuality?

- Through sensuality---how I speak, dress, and react to touch, smell, etc.
- By the ways I communicate my needs, desires, values and interest in others
- By viewing myself as a sexual person, continually discovering more about myself
- Through my ability to give and receive emotional closeness, trust, and support
- Through my ability to experience my sexuality in satisfying and pleasurable ways

What is important to you about your sexuality?

- Feeling more alive
- Feeling like a man/woman
- Enjoying myself or how my body feels
- Getting noticed by someone special
- Feeling energetic afterwards
- Feeling good about myself
- Feeling healthier
- Feeling less ____________
- Others

How do you want to express your sexuality?

- Being more romantic with my spouse/partner
- Exploring more ways of making love
- Being more sexually active
- Touching and receiving affection more often
- Taking more risks in disclosing my feelings to someone special
- Dressing more attractively and playfully
- Investing in understanding more about myself
- Initiating conversations with men/women I find attractive
- Sharing more gratitude and caring feelings
- Others

What helps you to express your sexuality? *(Think of times when you did.)*

- Receiving encouragement from others
- Encouraging myself with positive self-talk
- Listening to certain music
- Receiving affection from my partner
- Trusting the other person's interest in me.
- A stimulating book or discussion
- Massaging each other
- Feeling well-rested
- Experiencing playfulness, teasing, good humor
- Hearing compliments from someone special
- Watching a romantic or erotic movie
- Eating a candlelight dinner
- Soaking in a hot tub together
- Others

What are obstacles to expressing your sexuality?

- Experiencing pain or fear of pain and discomfort
- Dealing with the effects of medications

- Feeling depressed, lacking sexual feelings
- Using a ventilator
- Lacking trust in another
- Lacking of confidence in my ability to be intimate
- Fearing my inability to "get aroused" or get an erection
- No longer find my spouse/partner sexually attractive
- Lacking of energy and/or time
- Fearing conflict, getting hurt or rejection
- Fearing exposure—uncertainty about responses to my disclosures
- Fearing abandonment
- Fearing too many expectations, feeling overwhelmed or feeling trapped
- Grieving over a former relationship(s)
- Having difficulty speaking up for myself or setting limits with others
- Avoiding unresolved issues from my past
- Others

More Tips for Letting the Feelings Flow

SELF-CARE

- Arrange for sexual activities at times when you are most energetic.
- Take a nap beforehand. Take breaks and get re-energized.
- Avoid alcohol because it depresses your breathing, reduces sexual arousal, and numbs feelings.
- Consult physician(s). Find out the level of sexual activity that is safe if cardiac or respiratory problems exist.
- Ask your health provider for advice about safely adjusting your ventilator settings to help in reaching sexual climax (e.g., frequency, tidal volume).

COMMUNICATION

- Express tender messages of desire and longing.
- Convey gratitude, acceptance, and openness. Incorporate humor, as appropriate.
- Ask for what you want. Find out what satisfies your partner, what he/she wants?

ENVIRONMENT

- Remove respiratory irritants to improve air quality. Use an air filter, humidifier.
- Adjust the temperature to a comfortable setting. Open windows or use air conditioning to provide adequate air for comfort and breathing while making love.
- Choose lighting that enhances the mood of your environment.
- Use color, patterns, texture and accessories to stimulate the senses.

SENSUAL AMBIANCE

- Incorporate undressing, bathing or showering (e.g., in candlelight with music playing) and positioning as part of the lovemaking experience.
- Use vibrators and playful sexual toys to enhance giving and receiving pleasure.
- Add comfort and ease using pillows. Use oils or gels to increase lubrication.
- Share romantic or erotic poetry, music, literature, or films to evoke feelings.
- Cover distractions (tubing) with erotic fabric to enhance comfort and senses.

TOUCH

- Explore oral stimulation by using one's tongue to stimulate tender spots on the hand, cheek, armpit or knee.
- Explore touching and petting: find the most sensitive, stimulating parts.
- Stroke with one's lips, tongue, cheeks, and little finger--any part that is mobile.
- Massage feet, hands or other areas to relax and stimulate your partner.

POSITIONING

- Explore what makes it easiest to breathe? Relieves pain? Lying on one's side on two pillows? Use fabric that makes it easiest to move and arouses the senses.
- Use the spoon position: woman lies parallel to the man with man's chest facing her back. He enters her vagina from the rear with her guidance to take pressure off the chest wall or rib cage. Lying with legs crossed over a partner's can be erotic.
- Lessen pressure on painful joints by using the L-shape position: lie facing each other with your trunks at right angles and legs intertwined.
- Use an upright kneeling position, if muscle strength and flexibility exists, to take pressure off an ostomy bag or ventilator tubing or to reduce breathing difficulties.

Is It Safe?

Boundaries: ability to set limits and protect one's safety and well-being.

Opinions differ about what is "healthy" sex. Many people consider any sexual contact between two "consenting adults" as ok. Aside from the risks of sexually transmitted diseases or pregnancy, sexual contact can result in physical, emotional or psychological harm. Although an individual may desire and agree to sexual contact with another adult, a person who is lonely or lacks adequate sources of healthy intimacy and/or sexual expression is at greater risk of entering exploitive, controlling, or abusive relationships. This applies to individuals in unhealthy marriages or relationships as well.

Internet and dating services offer opportunities for meeting people. They also provide an outlet for predators to prey on vulnerable individuals. Some predators exploit individuals to satisfy their power and control needs through voyeurism and sexual fetishes. Others may initially act generous or helpful, and later become controlling or abusive. (Olkin) Regardless of a person's physical condition, physical and emotional harm may occur when a predator seeks sexual contact as a way to achieve power, control, self-gratification, revenge, or grandiosity (e.g., feeling above the law).

Exploitive relationships also can occur when "power differentials" exist. A person in authority has a far greater ability to seduce and negatively impact another person in cases of medical professionals with patients, teachers with students, clergy with parishioners, managers with employees, and counselors/therapists with clients. Resources on "professional boundaries" provide greater insight into these situations.

When considering sexual involvement with another person or the quality of an existing relationship, the following questions can reveal factors about the safety and risks of the situation. This is especially important when evidence of a person's sincerity, integrity or psychological stability is lacking.

- Are your sexual activities safe for your overall health and well-being?
- Do you feel safe with your partner? Do you have any concerns?
- How has your relationship with this person affected you emotionally?
- How do your sexual behaviors reflect your values? Any mismatches?
- How does your partner's behavior respect or disrespect your needs?
- Is your partner trustworthy and dependable? Or unpredictable?
- How do you feel after you are sexually active with this person? Respected, comforted, nurtured, or having greater understanding, trust, and closeness?
- Are you both free to choose what you will do?
- Are you afraid of disappointing your partner or of his/her responses?
- Are you each able to honestly express your feelings, needs, desires?

RESOURCES: www.advocateweb.org for professional boundary info
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Forks in the Road ...

In the *Post-Polio Health* article "From the Inside Out" a man described his use of psychotherapy for a sexual dilemma. In the process, he discovered unconscious feelings about past polio experiences that were impacting his sexuality. He mentioned using a therapeutic approach known as EMDR. Eye Movement Desensitization Reprocessing (EMDR) is one of several treatment options that can help us heal from traumatic experiences. Other modalities also are useful for shifting our limiting beliefs and our ability to let go of resentments and other harmful feelings.

If we are interested in resolving obstacles to our sexuality, or want to enhance the pleasure we experience, a first step is identifying and clarifying what we want to change or improve. In our pursuits, approaching ourselves with deep compassion and the curiosity of a private detective will make the process easier and add to its success. Making changes requires a great deal of courage and the strength to reach out for support -- a challenge for many of us. Once we understand our options, we each can decide what is best for us to do or not to do.

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www.sexualhealth.com section on Disability and Chronic Health Conditions

http://respiratory-care.advanceweb.com search Sexuality article by Barbara Rodgers

Workshops, Training Programs, Conferences, Books, Tapes:

Internal Family Systems Model: **Center for Self Leadership,** P.C. P.O. Box 3969, Oak Park, IL 60303 (708) 383-2659 IFSCSL@aol.com, www.selfleadership.org

Sexual Trauma Programs:

http://www.riveroakshospital.com/newsite/programs.htm

http://www.tworivershospital.com/services/mandj_general.htm

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Interfaces: New, Tried & True, and Custom

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1 **Assess and Communicate:** Assess the patient's respiratory, medical, physical & psychological conditions & limitations

- May include Pulmonary Function Tests (sitting up & lying down), Maximum Inspiratory Capacity oxygen saturation, end tidal CO2, arterial blood gas results
- Interview the patient, family and caretakers to determine history, preferences, physical limitations, claustrophobia and motivation
- Interview should include key questions that will help guide the interface selection

2 **Interface Fitting Process:** Assess the way they breathe, the type of nose bridge, nose length, nose width and nostril diameter to determine the type and size of interface to use

- **Breathing Types**: Nose breathers, nose breathers that leak out of their mouth or mouth breathers
- **Nose Bridge Analysis**: Ranges from flat bridge to a prominent high bridge. Historically this was the weak link in nasal mask fitting; poor fit resulted in leaks to the eyes or serious nose bridge ulcers
- **Nose Length**:
  - For Nasal Masks: measure from the top of the nose bridge to under the nose
  - For Full Face Mask: measure from the top of the nose bridge to under the lower lip or under the chin for masks that fit under the chin
- **For Nostril Interface**: determine nostril size

3 **Interfaces & Mask Categories**

- **Nostril Style Interfaces**: Fits into the nostril. Best suited to:
  - Nose Breathers or Nose Breathers/Mouth Leakers if used with a Chin Strap
  - Those with prominent nose bridges
  - Patients who require lower pressures, unless a heated humidifier is used
  - For the claustrophobic
  - **Favorites with patients:**
    - ResMed Swift: very lightweight, easy to take on & off, clear line of vision
    - Puritan Bennett Breeze: easy to take on & off, no straps on face
- <u>Nasal Mask</u>: Fits around the nose. Best suited to:
  - Nose Breathers or Nose Breathers/Mouth Leakers if used with a Chin Strap
  - Those who aren't comfortable with the Nostril Style Interface or want to avoid their nostrils stretching
  - **Favorites with patients**
    - ResMed UltraMirage. Also comes non-vented for volume vent users
    - ResMed Activa: very leak resistant
    - Respironics Comfort Gel: Comes in a Petite size for very small noses
    - Puritan Bennett DreamSeal: No straps on face but doesn't seal as well as with straps
    - Fisher & Paykel FlexiFit HC407

        - Many more models on the market
- **Full Face Masks**: Fits around the nose & mouth. Best suited to:
    - Nose Breathers or Nose Breathers/Mouth Leakers
    - Those people who are unable to keep their mouth closed
    - Those people who are uncomfortable with the nasal interface/chinstrap combination
    - **Favorites with patients:**
        - ResMed UltraMirage Full Face Mask: Fits below lower lip. Best fitting
        - Fisher & Paykel FlexiFit Full Face Mask: Fits below chin
        - Respironics Total Face Mask: Fits over entire face. Need to lie on back
- **Oral Interfaces**: Fits in the mouth. **Favorites:**
    - Respironics Angled: Small mouthpieces for Sip & Puff for daytime use
    - Fisher & Paykel Oracle: Has a seal that fits over the mouth for night time use

4 **Headgear Types & Features:**
- Strap Style Headgears: Range from 2 to 5 point connections. Sized & secured with Velcro, buckles, clips. Stretchy models easier to take mask on & off w/o securing clips
- Rigid Style Headgears: For Puritan Bennett Breeze & DreamSeal. Easy to take on & off. Fits like headphones rotated 90 degrees
- CPAP Pro: Nasal pillows that are secured with a boil and bite formed dental retainer instead of a headgear
- Interchangeable or Proprietary: Some interchangeable, some are made just for a certain type interface

5 **Chin Straps**: Encourages patients to keep their mouth/lips closed. Goal is a "stiff lower lip". Does not keep mouth completely sealed

Other Comfort Considerations
- Ease of Securing the Mask
- Clear Line of Vision to see or use glasses
- Quick Tubing Disconnect
- Volume Vent Application: Most interfaces are designed for CPAP & bilevel PAP. May need to modify or obstruct exhalation ports

The Interface Fitting: Matching the Interface to the Patient
- Need to be done by a skilled, experienced Respiratory Therapist
- Need a comprehensive selection of interfaces, in a variety of sizes, from various manufacturers to choose from
- Try on lying in the position patient sleep in
- May need more than one model to rotate or use one type in the day and another at night

Follow-up
- You can't really tell until you try it and sleep with it. It may need to be changed or "fine tuned"
- Build a trusting, long-term relationship with a customer service focused provider

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COLLABORATION WITH PHI AND WITH EACH OTHER

Beth Kowall, Greenfield, Wisconsin
Joan L. Headley, Saint Louis, Missouri

Collaboration: **a working together;** the act of working together with one or more people in order to achieve something.

During the first half of the session representatives of Support Groups/Organizations will discuss collaboration with Post-Polio Health International, whose mission is to *enhance the lives and independence of polio survivors and home ventilator users through education, advocacy, research and networking.*

The second part of the session will be dedicated to a continuation of Thursday's session. The group will address the list of "Challenges" generated during the Thursday session so representatives will leave the conference with options they can try with their group/organization.

Join us for this discussion even if you couldn't attend the Thursday evening session. Past leaders are invited to come and share their expertise at both support group sessions.

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BREATHING TRAINING: DEVELOPING A USER FRIENDLY BODY

Betsy Thomason, RRT, Breathing Trainer
Whippany, New Jersey

From: Betsy's *BreathPlay™ Journal*, September 10, 2004 (www.fitnessOutdoors.com)

I became a respiratory therapist to be a better breathing trainer. The story starts in 1987 when my friend, occupational therapist Ann Lane Mavromatis, was dying of breast cancer. Over the years, she had taught many hikers, including myself, how to get up mountains without huffing and puffing. On her deathbed, she asked me to carry on her work. Later that year, I took a weeklong workshop with Ian Jackson and became hooked on BreathPlay™, the efficient, fun breathing system he developed with an athletic model.

I began using BreathPlay™ during my daily walk, and then started teaching workshops in my New Jersey community. I felt frustrated because the medical community did not show interest in

BreathPlay™. A respiratory department director suggested that I go back to school. Because of insurance issues, he said, only licensed professionals could practice in a hospital. Being an elementary school teacher was not good enough.

So I enrolled in my local community college and embarked on the most challenging studies of my life. I could not rest on the laurels of being a breathing trainer. I had to do a major attitude change and become a respiratory therapist.

After graduating with an associate's degree in 1992, I imposed a two-year hospital-based respiratory internship upon myself. Now that I had RRT after my name, I wanted the full range of experience to go along with it. During those two years, I made a major discovery. I could teach vented ICU patients to. I'd watch the patients overhead monitors as blood pressures would moderate as would heart and respiratory rates. The patients actually learned to interact with the vent. The only problem was that the pulmonary medical director thought I was nuts.

Two years later, I found a job in pulmonary rehabilitation. This is just where I wanted to be teaching mostly old ex-smokers with COPD how to live life to its fullest. BreathPlay™ was an essential part of the curriculum. BreathPlay™ enabled my student patients to coordinate their activities with their source of energy. BreathPlay™ also allowed me to interact regularly with my patients to learn what they were discovering about their own breathing patterns. The pulse oximeter demonstrated the results. Saturations improved and endurance expanded with BreathPlay™ use.

Today, I am involved in home care. Most of my clients have neuromuscular diseases and use some form of non-invasive ventilatory support. BreathPlay™ training is part of their care plan. BreathPlay™ is not just about breathing. It promotes a positive mind/body relationship and gives the user a sense of body control. Over the years I have discovered that even people with little muscle function can do BreathPlay™ because a grunt is as good as a pursed lip out breath.

My work as a respiratory therapist will continue to include teaching BreathPlay™ to clients and promoting its use to the respiratory therapy community. Now, I believe I'm a better respiratory therapist because I am a BreathPlay™ trainer.

From: Betsy's *BreathPlay™ Journal*, January 9, 2003 (www.fitnessOutdoors.com)

BreathPlay™ and People Affected by Polio

Polio is a paralytic viral disease that affected people in the United States mostly in the 1950s, before there was a vaccine. Today, the people who survived are in their fifties and sixties with varying degrees of physical dysfunction. Now as adults, they are experiencing unanticipated expansion of physical difficulties. The symptoms, which include breathing difficulties (often manifested as difficulty sleeping, headaches, low energy, daytime sleepiness, and often ignored), and mobility issues, are called post-polio syndrome.

(There is a worldwide effort, spearheaded by the United Nations and Rotary International, to eradicate polio on the planet through vaccination.)

I have dared to teach BreathPlay™ to several people with post-polio syndrome. I say dared because it is a common, unspoken belief in the rehabilitation community that people with paralysis can't use their belly muscles. In my work in respiratory homecare with people with paralysis caused by many different diseases, I have found only one or two who truly do not have conscious control of their belly muscles. Usually the problem with belly muscles arises from disuse, a cultural phenomenon.

So let me tell you about three people who had polio as children. Sam is a practicing neurologist who is in his late 60s. Mary Jane is also in her sixties, the mother of three and grandmother as well. Linda, now in her late forties, the mother of two teenage sons, experienced a polio exacerbation a few years ago that ended her career as a social worker.

Sam is a short, very thin man - his legs are like sticks - with severe kyphoscoliosis (front-to- back and side-to-side spinal curvature), and highly functional. He walks with a cane and wears an AFO (ankle foot orthotic -a plastic splint for the lower leg). Nothing stands in his way. He told me about doing deep breathing exercises for 15 minutes upon waking and before bed at night. He had been doing this focused breathing for a few years when I first met him, and had also started swimming 4-5 times a week. (Prior to this exercise routine, he was using Canadian crutches - the ones that attach to the arms - for mobility.) I asked him about the medical prohibition on exercise for folks with post-polio. "Nonsense," he said. "And, there's no such thing as post-polio syndrome."

Because BreathPlay™ enhances body awareness; it is the perfect tool to prevent overuse of muscles that are already weakened by polio. Gentle exercise is essential to keep muscles and connective tissues from contracting and creating deformities. Sam was eager and excited to refine his breathing. He latched on to BreathPlay™ and raves about how it makes his workout easier. (BreathPlay™ reduces the effort of breathing.) BreathPlay™ also helps him with balance and energy output and conservation when he sails his 22-foot sailboat.

Mary Jane, short and extremely thin, experienced respiratory distress three years ago. She was hospitalized, intubated and placed on a ventilator. The doctors wanted to trach her (cut a hole in her throat for a breathing tube). She was NOT interested. Her family did some research and found Dr. John Bach at the University of Medicine and Dentistry in Newark, New Jersey. Dr. Bach is aggressive about helping people with neuromuscular conditions fight the system that wants to perform tracheotomies. So Mary Jane discharged herself from one hospital and went to UMDNJ Hospital.

Today, Mary Jane is as active as any grandma, maybe more so. She exercises on a treadmill 4 - 5 times a week using BreathPlay™, and travels to visit her grandkids in Texas and Ireland. She uses a portable ventilator for sleep and BreathPlay™ during the day when she's active, and for relaxation. I taught her how to use BreathPlay™ when rolling dough for Christmas cookies! BreathPlay™ is a tool for her to use to stay mindful of her body and its needs, and even to appreciate its capabilities.

Linda, a tall, thin woman, is very close to her breathing. By that I mean that she is aware of almost every breath her body takes. Her unconscious breathing is very high in her chest and neck, which means that she is spending too much energy in the breathing process. She uses a ventilator for sleep and often during the day. Folks with no breathing issues, who can ignore their breathing with no ill effect, use 3- 5% of their energy for breathing. Linda probably spends 30% of her total energy just to get air to enter her body. So BreathPlay™ is really important for her, to reduce her work of breathing.

For Linda this is a complex process, not as easy as for Sam and Mary Jane, because BreathPlay™ needs to be learned by the muscles, and Linda's muscles have learned some bad habits. (This is the body's attempt to compensate for dysfunction.) Rather than trying to undo old breathing patterns, I encouraged Linda to think of BreathPlay™ as something new. It's easier to learn something new than to undo old habits. So we began BreathPlay™ing, rather than breathing. Linda's stomach muscles needed some assistance, so Linda placed her hands on her belly and would gently press during the outbreath and release for the inbreath, thus allowing her belly to expand and invite air in. Practicing BreathPlay™ several times a day in a quiet place for 3 -5 minutes or more, is essential for teaching muscles, which are smart, but slow learners. Everyone, no matter what his/her physical condition, benefits from learning BreathPlay™ in a quiet place, before using BreathPlay™ with activity. While Linda walks on a treadmill (using the vent) most days for 20 minutes, her challenge is to use BreathPlay™ throughout the day with routine activities of daily living. BreathPlay™ is a tool to help Linda lower her breathing range from 25 - 30 times per minute to 10 - 20. The net result will be more energy for homemaking and hobbies, a happier body, and perhaps a longer life, if you believe as the Chinese do that we each are given a certain number of breaths for our lifetime.

Join me for the Breathing Workshop: Developing User-Friendly Body. Learn pursed-lip belly breathing; to focus on exhalation; to exhale on exertion; to use images/imagination, etc.

Betsy Thomason, RRT, Breathing Trainer
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ACUTE, POSTOPERATIVE PAIN

Selma Harrison Calmes, MD
Sylmar, California

Why try to prevent and treat postoperative pain? After all, you had an operation – it's supposed to hurt! This old attitude is changing today as the result of numerous influences. The new attitude evolving is that we are not supposed to have any pain at all. In reality, it is very difficult to achieve this new goal of no pain at all, which may not even be realistic – or good for you. But postop pain can usually be made much better with some relatively easy techniques.

This talk will review briefly why postoperative pain (abbreviated as "postop" from now on) should be treated, what can be done for acute postop pain and the role of post-polio changes in possible management. Chronic pain in polio patients will be discussed by Dr. Julian Lo, and then there will be time for audience questions and discussion. Pain management is a very complex area, polio issues are a small part of a big picture, and it may not be possible to cover all issues, given the time allocated for the session.

In the past, cultural factors determined who got pain relief for operations. When anesthesia was first introduced in 1846, men having operations often did not receive anesthesia. Undergoing the pain of an operation was thought to help in achieving "manliness." Similarly, poor people did not deserve pain relief. Women and children, thought then to be "weaker" than men, needed protection from pain during an operation, as did wealthy people, and these groups always received anesthesia, if it was available. It took until the last quarter of the 19th century before most patients had pain relief during surgery.

Such cultural factors still play a role today in the area of postop pain. The most common example is nurses from other countries not realizing a patient has pain or not treating it if the patient requests pain medication. A more difficult example is surgeons. Throughout the U.S., they are the main treaters of postop pain. Unless they have had an operation themselves, they have little concept of the severity of postop pain, how to treat it and the importance of treating it.

These old concepts are slowly changing in the U.S. These changes have been stimulated by patients' families, who have experienced the long, painful death of a loved one and asked why can't we do a better job of treating pain; scientific documentation of the harmful physiologic effects of pain; and the attention of hospital accrediting agencies, such as the Joint Commission on the Accreditation of Healthcare Organizations (JCAHO), to this problem. New organizations interested in pain management, training programs in pain management and the ability to become Board-certified in this area, and validated measuring tools for pain also contribute to this transition in thinking. As an anesthesiologist working daily with recovering postop patients, I can tell you we are still not where we need to be in all staff accepting that pain, especially postop pain, needs to be relieved if possible.

Competing factors working against this new concept, in addition to cultural issues, include lack of adequate numbers of pain-trained physicians and RNs, a nation-wide shortage of anesthesiologists, the high cost of providing an acute pain service, lack of interest (this is not a flashy, techie area!), and reimbursement issues. Pain providers are financially rewarded for invasive procedures and not for drug management, which would often be adequate, and less risky than invasive procedures, at times.

What about post-polio's role in postop pain? It does seem that post-polios often have more pain than other patients. Many of us have experienced, for example, very severe pain with a simple stub of a toe. See the pain pathway illustration and illustration of a spinal cord on the next page. Pain signals travel up (and down) the spinal cord, and I postulate that pain signals are modified (probably enhanced, or "wound-up") because of inflammatory changes in the spinal cord from the original polio infection of the cord. There is no experimental evidence (as far as I am aware) to support this concept; it is a theoretical idea only. But, we do know in other patients that pain signals are often modified (usually increased by "wind-up") in the spinal cord.

What is available for acute, postop pain management? Planning for a particular patient should be done at the initial pre-anesthesia visit. Multiple interventions should be planned, as a mix of approaches generally leads to greater efficacy and fewer side effects.

1. IV OPIATES: This is what most postop patients get, because they are effective. These are drugs like morphine, and they work directly on the pain receptors in the brain and spinal cord to relieve pain. They have some side effects such as nausea, urinary retention and depressed respiration.

Typically, they are given only when a patient requests pain relief. The RN then has to get a key to the narcotic box, sign out and prepare the medicine and then go to the patient to administer it. This process often takes a long time, and it also results in an "up and down" blood level of the drug, not a constant therapeutic level. High blood levels (reached soon after the medicine is given) can cause side effects such as airway obstruction and low blood levels (as the medicine is wearing off) give inadequate pain relief. Patient Controlled Analgesia (PCA) systems, which were developed by anesthesiologists in the late 1960s, can deliver a constant blood level, and boluses are possible when the patient determines they need more pain relief. These machines solve the "up and down" problem and the RN time problem. PCA can be started in the recovery room, soon after surgery is over.

Morphine or Demerol are typical drugs used for PCA. (Demerol is used less and less because it has more side effects.) Other long-acting narcotics can be delivered in this system. Many hospitals today have PCA available, floor RNs are pretty well trained on it and, in general, PCA is very safe and effective.

Intramuscular (IM) opioids should not be used because onset of pain relief is too long, and they are often ineffective. An anti-inflammatory drug Toradol (ketorolac) is popular for its additive effects to opioids for pain relief but has many contraindications. It is an anti-inflammatory drug (a NSAID like Viox) and is given IM or IV. It acts on the initiation of the pain signals at the site of the painful stimulus, in this case a surgical incision.

2. TECHNIQUES THAT ARE PART OF THE ANESTHESIA PLAN:

a. Injection of local anesthesia at the surgical site(s): This is done by the surgeon, usually before the surgery begins, so it helps decrease the pain stimulus from the incision site during surgery and thus decreases the amount of other anesthesia needed. If a long-acting local anesthetic (usually bupivicaine or marcaine) is used, pain relief can be as long as 48 hrs. This forms the background, or basal, pain relief technique. It is not always possible to inject local anesthesia at a surgical site, usually because of infection. Because the injection takes time to do, it is often difficult to convince surgeons to take this simple but important step.

b. IV injection of a long-acting narcotic toward the end of surgery: This is done to cover the initial pain as a patient wakes up from general anesthesia. The usual drug is morphine; some use longer-acting drugs. A possible problem is that this would delay awakening, but cautious dosing, with additional small doses as it becomes clear where the patient is in the awakening process, can solve this problem. For short operations, the long-acting narcotic can be given even before anesthesia starts, as a pre-medication, planning on a postop effect also.

c. Regional anesthesia, with additional drugs/techniques to prolong its pain relief: Regional anesthesia includes spinal, epidural and various blocks of the arms, hands, legs, feet and peripheral nerves. Not all operations can be done with regional anesthesia; but if this is possible, it can serve as a background technique for postop pain relief. First, a long-acting local anesthetic could be used, to give pain relief for 24 to even 48 hrs. A good example of this would be an axillary block or supraclavicular block of the arm done with the long-acting local anesthetic marcaine (bupivicaine, mentioned previously).

Another possibility is to add narcotics to the local anesthetics injected into the spinal canal or epidural space. These narcotic drugs migrate into the spinal cord and actually enter it to "sit" on narcotic receptors in the spinal cord, giving long-acting pain relief. If many days of pain are expected, a small plastic catheter can be placed in the epidural space and a continuous infusion, or bolus injection, of either local anesthetics, narcotics or a mixture of both, can be given. This gives excellent pain relief and is how "labor epidurals" are given for obstetric patients. This is a manpower-intensive technique, however, and many hospitals don't have adequate manpower to manage these – you can't just walk away from them and think the technique will work perfectly.

No matter which pain relief technique is used for a postop patient, certain "system" pieces must be in place: The RNs should ask you frequently how much pain you're having and what the pain is like. The timing of questioning varies from the recovery room to the floor. If you report significant pain, you should expect that the RN will give additional pain medicine, and then re-assess the pain to see how effective that medicine in that dose was. (Other techniques such as ice packs can be tried in certain circumstances.) These two requirements are from the JCAHO and MUST be met by every hospital that is accredited. The RN is also to record your pain level, the intervention used and the response to the intervention. Unfortunately, there are many difficulties getting these requirements established consistently, especially the re-assessment part.

Unusual circumstances may interfere with efforts to get good postop pain relief. For example, low blood pressure (hypotension) or breathing (ventilation) problems may occur postoperatively for various reasons and interfere with our ability to "push" narcotics to the needed level. Finally, surgical misadventures can lead to new pain postop. The most common example I see is unrecognized postop bleeding in a laparotomy patient, and blood is accumulating inside the abdomen. This is typically painful. If the usual pain relief techniques don't seem to be working well, the patient needs to be re-evaluated to determine all possible causes of pain. Return to the OR might be needed instead of additional morphine.

3. POLIO AND POSTOP PAIN MANAGEMENT: Postop pain management depends greatly on narcotics such as morphine. Many post polio patients have obstructive sleep apnea. Narcotics may increase the apnea episodes and increase the risk of death. (Deaths have occurred in "normal" postop patients with sleep apnea.) The solution is, first, try to rely on other pain relief techniques – generous local anesthesia, Toradol, etc – and, second, to put the patient where they can be directly observed (an ICU) for 24-48 hours postop.

Ventilation is often marginal in post polio patients also, and the respiratory depression from narcotics can cause further problems. The solutions are to, first, identify ahead of time post-polio patients with limited respiratory reserve; next, make an appropriate plan (try to use local or regional anesthesia and avoid narcotics, if possible), admit the patient to an ICU postop and be ready to support ventilation as needed. Artificial ventilation might be done for several days, and pain management could then be adequate since the risk of respiratory depression is taken away. During weaning from ventilation, if that is possible, pain medication would have to be cut back, of course.

Finally, technical issues can be prominent for post-polio patients. For example, we might want to place an epidural catheter for several days of postop pain relief after a major operation, but the patient's severe scoliosis makes this very difficult or even impossible. New technology (ultrasound identification of the epidural space) may help with this problem.

In summary, with proper planning, good and safe postop pain relief can usually be achieved in post-polio patients. However, many systems issues still make this difficult for some patients.

Figure 1: Cross-section of a spinal cord in a polio patient in 1870. Shows the scarring from inflammation due to the original polio infection. This scarring could be a cause of "wind-up" of pain signals in post-polio patients. SOURCE: Paul JA. *A History of Poliomyelitis.* (Yale U. Press, New Haven) 1971. pg 56.

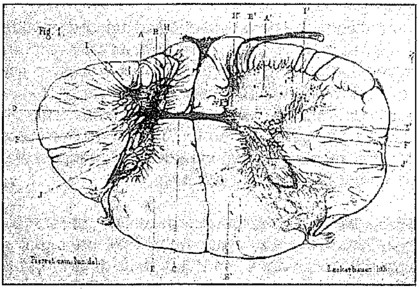
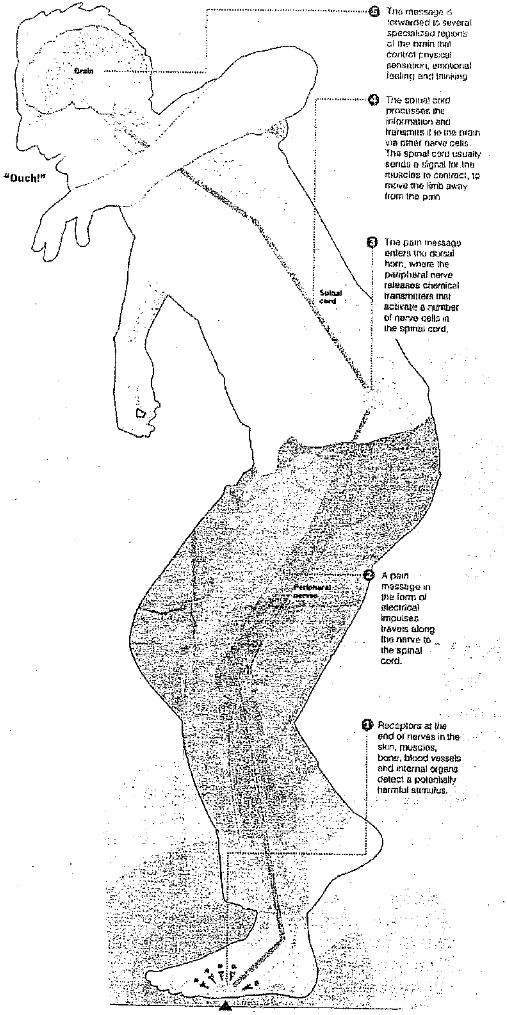


Figure 2: PAIN PATHWAYS: SOURCE: NY Times, Feb 15, 2005. p F1.



⑤ The message is forwarded to several specialized regions of the brain that control physical sensation, emotional feeling and thinking

④ The spinal cord processes the information and transmits it to the brain via other nerve cells. The spinal cord usually sends a signal for the muscles to contract, to move the limb away from the pain

③ The pain message enters the dorsal horn, where the peripheral nerve releases chemical transmitters that activate a number of nerve cells in the spinal cord.

② A pain message in the form of electrical impulses travels along the nerve to the spinal cord.

① Receptors at the end of nerves in the skin, muscles, bone, blood vessels and internal organs detect a potentially harmful stimulus.

Selma Harrison Calmes, MD
Olive View-UCLA Medical Center, Sylmar, CA 91342

SESSION IV (Plenary)

2:45 pm – 4:15 pm

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TRANSLATING GOOD IDEAS INTO PRACTICE: WHAT ABOUT TOMORROW?

Kristi L. Kirschner, MD
Chicago, Illinois

"The isolation ward was well named: I have never been so alone in my life as in that bed, where I was confined for the next three weeks, feverish and contagious; where I would learn, thoroughly, the lesson of self-reliance. It was an education that would sustain me for the rest of my life- and cut me off from others so that, even today, I have to work to remember that what I learned so well was wrong, or incomplete. And somewhere deep inside I turned tough as old leather for ten or fifteen years ..."

(*Mee, Charles L. A Nearly Normal Life. Boston: Little Brown and Co. 1999,* p. 16)

We have heard from presenters at this meeting about all sorts of health and wellness options: exercise, emotional health, ventilator management, and numerous preventive health care strategies to name a few. Many of us will leave the meeting, initially energized and ready to embrace these strategies and make some real lifestyle changes. And just like New Year's Resolutions, for many of us these lifestyle changes will be relegated to the dustbin within a few months. Which brings us to the question: Why is change so hard? What are the barriers that prevent us from embracing and translating good ideas into greater holistic health and well-being?

These are the questions I hope to tackle in my talk today. I will break my remarks into three sections:

1. **What are the "good ideas' that we need to take seriously?**
2. **What are the barriers to embracing these good ideas and these lifestyle changes?**
3. **What resources and supports are available to help empower us to choose paths of great health and well-being?**

1. What are the "good ideas" that we need to take seriously?

"Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity." -WHO Constitution

- Aging is inevitable for all of us
- Life expectancy for pwd's has lengthened greatly in the last half century though people with pps age faster—ie., have medical and functional problems at an earlier age.
- Some common symptoms with pps
  1. Fatigue, 2. weakness, 3. pain! Particularly joint and muscle pain (overuse/ joint instability/ degeneration), 4.cold intolerance, 5.new respiratory and bulbar dysfunction, 6.Depression and anxiety (16-23%). 7.Decreased concentration, memory attention, etc.

- Preventive healthcare needs may include:
    1. see md if having new symptoms—may or may not be pps!
    2. pulmonary function test (if vital capacity <50% need to screen for chronic respiratory failure)
    3. weak cough—prone to infection (peak expiratory cough flow < 3.0 L
    4. swallowing evaluation if bulbar symptoms
    5. immunizations—influenza and pneumococcal
    6. coughalators/ vests/ etc.
    7. osteopenia/ osteoporosis evaluations (21% of aging polio survivors had a fracture—more common in affected limbs)
    8. energy conservation strategies
    9. Role of exercise-- judicious
    10. Pain management
    11. Other preventive health care issues
    12. Emotional health (more on this later!)

2. What are the barriers to embracing these good ideas and these lifestyle changes?

There are multiple barriers that prevent people with post-polio syndrome from practicing good health habits and adapting to their changing bodies. The barriers are both external (imposed by circumstances outside the person) and internal (physical and psychological issues) Let's examine these issues in more detail:

External Barriers:
1. Physical environment
    a. accessible doctors offices and exercise facilities
    b. accessible equipment—exam tables, mammogram machines, wheelchair scales, etc.
    c. adequate transportation
    d. accessible and affordable housing
2. Attitudes of public and healthcare providers—focus on disability and not whole person, lack of knowledge
3. Financial pressures
4. Access to healthful food choices/ nutrition counseling

Internal Barriers:
1. Fatigue
2. Pain
3. Increasing impairment
4. Motivation and concentration
5. Psychological issues
    a. post-traumatic stress
    b. Anxiety
    c. fear of "giving in"
    d. shame
    e. lack of trust in others

3. What resources and supports are available to help empower us to choose paths of great health and wellbeing?

a. Self-education
b. Lifestyle changes — back to the basics! Small changes over time
c. Partnership with healthcare providers
d. Nurture social support and networks of interdependence

e. Manage stress!
f. Seek formal psychological support services as needed
g. Focus on building in your "nurture activities" – time for spirituality, appreciation of the arts, time with family and friends, indulge in creating new interests, etc
h. Self awareness and acceptance of our bodies which all have limits

Some on-line health resources:

Andrew Weil, MD. (integrative medicine) www.DrWeil.com

RealAge www.Health@RealAge.com

Weightwatchers online program www.Weightwatchers.com

National Center on Physical Activity and Disability www.ncpad.org

WebMD resources webmd.com

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THE RESEARCH FUND

The one million survivors of poliomyelitis in the United States, and the 12 million worldwide, know there are consequences of living and aging with a disability. They also know that funding for research into their problems is limited.

Post-Polio Health International (formerly Gazette International Networking Institute) established The Research Fund (formerly The GINI Research Fund) in 1995 dedicated to "seeking scientific information leading to eventual amelioration of the consequences of poliomyelitis and/or neuromuscular respiratory diseases."

Q: What research will PHI support?
A: The grants will help support researchers, scientists, and clinicians worldwide to investigate the cause(s), treatment, and management of post-poliomyelitis and neuromuscular respiratory disease.

As it approves grants, PHI will foster new innovative research – both basic science and clinical – that will result in improved quality of life for people with disabilities, as well as support valid ongoing research.

Q: How will funding decisions be made?
A: A panel made up of peers and people with disabilities will review all grant applications that meet established requirements for respiratory research or post-poliomyelitis research. This panel's recommendations will be reviewed by the PHI's Board of Directors, who will make the final funding decisions.

Q: How can contributions be made?
A: Post-Polio Health International is a not-for-profit 501(c)(3); Federal ID No. 34-0961952. Tax-deductible contributions can be made online (www.post-polio.org) or sent to Post-Polio Health International (PHI), 4207 Lindell Boulevard, #110, Saint Louis, Missouri 63108-2915 USA

Checks should be made payable to "Post-Polio Health International" (US dollars only). PHI also accepts VISA, MasterCard, and Discover.

The Research Fund now with a corpus of $420,000 awarded its first grant from the interest in the fall of 2000.

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  ☐ Or, donate this complimentary subscription to person selected by Post-Polio Health International.
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Send to:

POST-POLIO HEALTH INTERNATIONAL
4207 Lindell Blvd., #110
Saint Louis, MO 63108-2915 USA
314-534-5070 fax

CONF

Note Cards Available!

Post-Polio Health International remembers the survivors of polio...

To commemorate the 50th anniversary of the development of the Salk vaccine, Post-Polio Health International chose to honor those for whom the vaccine was too late. Since its inception in 1958, the organization has focused its resources and efforts on improving the health and independence of polio survivors and ventilator users and is committed to continuing this practice.

Artist Deborah Goodwin and polio survivor Mickie McGraw teamed up to create a visual reminder that millions of polio survivors are citizens of the world community who are in need of information, advocacy and research. (The artwork is in shades of blue and yellow with green accents.)

> *The nautilus shell represents an external stillness and static mobility. Contained and protected within is a rich and active life force that radiates outward from the central creation point of its spiral to reach beyond the limits of its boundaries.*
>
> *The butterfly depicts the ephemeral, unique beauty of each life that begins encased within a cocoon and emerges in its time, transformed, to color the world and give wings to the future.*
>
> *Together they celebrate our human potential to transcend limitations. They commemorate the 50th anniversary of the development of the Salk polio vaccine, which forever changed our lives and our future.*

To help PHI remind the world of this anniversary, and to support our work, order your set of 10 note cards for $13.50 (s&h included).

Send the form below to PHI, 4207 Lindell Blvd. #110, Saint Louis, MO 63108 (314-534-5070 fax) or order online at www.post-polio.org/order-card.html.

Please send _____ sets of the 50th Anniversary Commemorative Note Cards.

For larger orders or international orders, please contact 314-534-0475 or info@post-polio.org.

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☐ Please send an invoice.

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