

POLIO DEJA VIEW

Central Virginia Post-Polio Support Group

www.cvppsg.org

February 2009 – March 2009

February 7th Meeting

2:00 pm at Children's Hospital, 2924 Brook Road, Richmond

We will have a **general discussion** among the PPSers while Dave VanAken will lead a **Partners Discussion Group** in another room. We try to have these twice a year and it gives the PPSer Partners a chance to share their experiences and challenges. PPSers bring any question or issues you'd like to discuss.

March 7th Meeting

2:00 pm at Children's Hospital, 2924 Brook Road, Richmond

After our Partners Session in February, we will continue by having an open discussion among our members and their "partners" about issues, questions and concerns within the family.

A GUIDE FOR POST-POLIOS

DO'S AND DON'TS plus GENERAL THERAPIES AND THINGS TO AVOID

The following information has been made available with the permission of the *Easter Seal Society of Washington*. The opinions expressed are those of the individual writers, and do not necessarily constitute an endorsement or approval by the *Easter Seal Society* or *Polio Outreach Advisory Council* or the *Lincolnshire Post-Polio Network*. Although it does not imply endorsement, it is provided as a service for those seeking such information. Always consult your doctor before trying anything recommended in this information or any other publication.

What follows is a general, practical guide for post-polios to use, and summarizes the current thinking about post-polio. It will be most valuable if it stimulates you to seek further and more specific information.

- Take time to rest. Nap (if possible) during the day, work fewer hours, and take longer vacations.
- If you are experiencing increasing muscle weakness, exercise only under the supervision of a knowledgeable physician.
- Make sure your food intake is nutritious.
- Be alert to (but not obsessed with) changes in your body, and heed your body's signals.
- Take note of any new symptoms plus clear or gradual changes.
- Get enough exercise to prevent disuse atrophy, but not enough to produce overuse damage.
- Learn how to pace yourself.
- Prevent the secondary complications of weakness, particularly falls; this might entail the use of crutches or a cane, a wheelchair for extended travel, or braces or other adaptive equipment.
- Avoid weight gain. Too much weight only aggravates stress on joints and muscles.
- Consider possible adaptations to your lifestyle, even minor adjustments (changes in hobbies or modes of transportation) can help.
- Do not assume that every physician fully understands post-polio problems. Educate yourself and never hesitate to ask questions.
- Minimize alcohol use, particularly at bedtime. Alcohol inhibits swallowing, interferes with nutrition, and causes falls and accidents.
- Maintain a positive attitude towards your health. Accept change, adapt, and never equate your self-worth with physical disabilities.
- Take common colds very seriously.
- Get bulk-producing fiber in your diet. Avoid stimulant laxatives.
- Medical evaluation of post-polios should include a complete history, physical exam, and appropriate lab studies.
- Muscle strength evaluation should be done by a registered physical therapist or someone familiar with neuromuscular disease. Muscle testing is now advised every year even if there is no obvious change.
- The current recommendation is that all post-polios have a complete medical evaluation covering the three major areas affected by the polio; neuromuscular, circulatory and respiratory.
- Problems with extremities or joint function may require special consultation from physiatrist, orthopaedist, and/or neurologists familiar with skeletal deformities and muscle weakness.
- Experienced physical or occupational therapists can help determine functional losses and how best to adapt.
- Muscle stretching and joint range-of-motion exercises are important where there is muscle weakness.
- Swimming is the best cardiovascular endurance and general conditioning exercise. Water should be warm (at least 90 degrees).
- Discontinue any exercise that causes pain, weakness, or muscle fatigue, including walking.

- Muscles weakened by polio respond poorly to vigorous strengthening programs. Programs such as weight lifting often aggravate the condition.
- Each of you should know your own strength limits or endurance, and avoid going repeatedly to that limit.
- You should avoid narcotics for any reason; aspirin is preferred as an analgesic for muscle or joint pain.
- Occupational therapists can assess extremity function, daily activities, and the need for assistive devices to help achieve the highest level of independence possible.
- Rest is the best known treatment for aching muscles. Moist heat, anti-inflammatory medication, and avoiding exertion are also helpful.
- Physical therapy - heat, massage, joint mobilization, and stretching exercises - can help chronic lower back pain.
- Change of gait pattern, such as using crutches, may be needed to prevent recurrence of lower back pain.
- You **MUST** learn to conserve energy.
- Even though you were once rehabilitated, you must be re-evaluated and taught new techniques to replace those that no longer work.
- Body positioning during sleep is important for post-polios with severe weakness and postural joint deformities.
- Those with marginal respiratory reserve at sea level should be prepared to use respiratory aid when travelling above 3,000 feet.
- Everyone with respiratory insufficiency is advised to get flu vaccination according to Public Service guidelines and recommendations.

Compiled by the Post Polio League.

Did you know?..... Rx Information from Jenny

TAPERING MEDICINES

Patients often don't know which drugs need to be tapered to avoid withdrawal or rebound symptoms. There's no one-size-fits-all approach...but there are some general principles to keep in mind.

For example, abruptly stopping beta-blockers (metoprolol, etc) or clonidine can cause rebound hypertension. Most beta-blockers should be tapered over 1 to 2 weeks...and clonidine over at least 2 to 4 days.

SSRIs (Paxil, Zoloft, etc) and SNRIs (Effexor) can cause flu-like symptoms, anxiety, tremor, and other symptoms after stopping them suddenly.

Antidepressants should be tapered over 4 weeks...and even slower if needed for Paxil and Effexor.

Benzodiazepines (alprazolam, diazepam, etc) can cause withdrawal and rebound symptoms such as sweating, increased heart rate, tremor, insomnia, anxiety, agitation, nausea, vomiting and hallucinations....especially with chronic use. In general, benzodiazepine doses should be decreased by 25% per week for 2 weeks then about 10% every week...or slower after prolonged use.

Alprazolam dosing should be decreased no faster than 0.5 mg every 3 days... and much slower for patients taking at least 4 mg/day for 3 months.

Lots of other drugs sometimes need to be tapered such as oral corticosteroids. Steroid withdrawal symptoms include flu-like symptoms, hypotension, weight loss and disease flare (e.g., contact dermatitis, lupus, rheumatoid arthritis).

Other meds include antiepileptics (Dilantin, Neurontin, etc), opioids (morphine) (withdrawal symptoms include runny nose, tearing, chills, muscle pain, vomiting, diarrhea, cramps, anxiety, agitation, hostility, insomnia), tramadol, baclofen, tricyclics, (amitriptyline, imipramine) and antipsychotics (Risperdal, Seroquel, etc).

Call if you have any questions!
Jenny Aveson
(804) 730-9498

PAIN RELIEF: Some tips from the collected wisdom of the Internet Polio Mail List

Assembled by Tom Walter

Tom Walter is a Polio Survivor. Up until a few years ago, 30 years or so on from recovering from Polio, he walked unaided with only a slight limp, working and living a normal life. He didn't even know any other people with Polio. He now has difficulty swallowing and breathing and spends most of his days in a wheelchair or propped up in bed. With his laptop computer he collects and dispenses advice and information on post-polio syndrome. Tom, or TominCal as he is known by his email name, is highly regarded and respected as a source of reliable information by the online post-polio community worldwide.

NUMERO UNO -- "*Lifestyle Adjustment*" -- The "sine qua non" without which none of the other tips or aids seem to do much good.

That means reducing physical exertion / activity AND mental stress to the level of one's current capabilities.

Dr. Perry, over 40 years at the polio clinic in Rancho Los Amigos Medical Center in Downey CA USA, says we should exercise normal (if any) muscles normally but not do anything that causes PPS-affected muscles pain, weakness or fatigue that lasts more than 10 minutes.

Assuming the person has been thoroughly checked for any other conditions that could mimic PPS symptoms and be treated -- and that any orthopedic anomalies that could be causing pain have been treated -- here's a partial list of some tips that PPSers have reported seem to work for them, alone or in combination:

1. Moist heat applied to the painful area.
2. Light massage to the painful area.
3. Ice packs applied to the painful area.
4. Chiropractic or osteopathic "adjustment" of neck / back / joints.
5. Acupuncture; and electro-acupuncture to the ear lobe.
6. Herbal dietary supplements such as ginger, pycnogenol, cayenne pepper.
7. Treatment of sleeping difficulties, i.e., insufficient amount of Stage IV sleep.
8. Treatment of breathing difficulties, i.e., insufficient amount of oxygen and or too much carbon dioxide, especially during sleep.
9. Use of assistive and adaptive aids, as necessary, to reduce stress and strain to muscles and joints; assuring that all body parts that require it, e.g., neck, head, back, shoulders, are properly supported at all times.
10. For inflammation of muscles / joints -- use of arthritis-type drugs: NSAIDs (Non-Steroidal Anti-Inflammatory Drugs). Over-the-counter types like Aspirin, Ketoprofen or prescription types like Relafen, Voltaren, Naprosyn.
11. For "nerve" pain -- use of anti-depressant prescription drugs --
 - Elavil (amitriptyline) -- an anti-depressant of the tricyclic type -- is the first choice in drug therapy by some PPS specialist docs for those with PPS pain AND trouble sleeping, at dosages less than would be used for clinical depression. But a lot of us don't tolerate it well.
 - And for those (and also those who DON'T have sleeping problems), one of the SRUB class of anti-depressants (Serotonin ReUptake Blockers) such as Zoloft or Paxil -- also in smaller doses than would be used for clinical depression -- may be of help.
12. Occasional and/or careful use of muscle relaxants such as Quinine or Methocarbamol.

13. Hormone Replacement Therapy, especially for post-menopausal, post-hysterectomy women and others with lower than normal levels of estrogen, testosterone, thyroid. DHEA, Melatonin.

From Henry's Desk by Henry Holland

The Benefits of Western Traditional Medicine

Post-Polio Syndrome (PPS) is a chronic, often progressively debilitating neuromuscular condition that most survivors of paralytic and bulbar polio are experiencing in their later adult years. No precise etiology for PPS has been found; although many theories seem plausible. Many treatment recommendations have been made over the years. These treatments involve conventional medical model approaches and numerous alternative treatments. I have personally heard lectures, seen demonstrations and witnessed some of the alternative treatments. Examples would be magnets, chiropractor, therapeutic massage, acupuncture, the Feldenkrais method, holistic supplements, vitamin therapy, yoga, healing touch, chelation, dream analysis and spiritual approaches. This article is not intended to be critical of any of these approaches except to say that most of them are not verifiable by the scientific method. Modern western traditional medicine is based on the scientific method. Any respected medical or surgical journal will reveal the scientific method in its articles.

The New England Journal of Medicine is of one the most highly respected medical journals in the world. It is published weekly and began in 1812. All original research and clinical research articles in this journal follow the scientific method with a written background on reasons for the particular research or study, methods utilized in the study, which often include double blind studies, the results of the study, and finally the conclusions reached as a result of the study. Jonas Salk and Albert Sabin used this very approach in their research on the development of an effective polio vaccine. A massive double blind study was done with the Salk vaccine on school children in the United States from mid 1954 to April 1955. What did "double blind" mean in this study? It meant that some of the children got the real Salk vaccine and some got a placebo, but the folks who gave and the children who received the vaccine did not know which was which. After the time of the study was over, it was found that the children who really received the Salk vaccine had a much greater protection against polio than those who received placebo. Only those who set up the study were aware of who got what. Thus, the givers of the vaccine or placebo and the children receiving the same were both "blind" as to the real contents of each syringe. This method greatly added to the objectivity of the study and made it more likely that other researchers could repeat it and get the same results. Albert Sabin did the same thing except he used Russian children to conduct his clinical studies. The scientific method is the backbone or the basis of western traditional medicine. This method is used in every accredited

medical/research/teaching center in the United States as well as used by the pharmaceutical industry. The Federal Food and Drug Administration attempts to keep us safe by the same approach.

How has this approach benefited the world? Disease prevention is a major example. The scientific method has provided the world population with numerous effective vaccines. Many of you are aware of this if you have traveled to Africa, Asia, and other continents. Our children are protected from many childhood contagious diseases because of vaccines. The scientific method has brought about many effective pharmaceutical treatments and curative surgical procedures. The skills and instruments to aid in making a correct diagnosis have progressed immensely in terms of technology. Magnetic resonance imaging is a wonderful tool for the early diagnosis of some potentially terrible disorders.

Technological advances are happening almost every day. No physician is 100% correct in making a diagnosis and recommending a treatment, but the rational scientific approach has helped us more than any other approach. I challenge the reader to name any known disease entity that has been uncovered, diagnosed, and successfully treated as a result of any other method than the scientific method.

How does the placebo effect influence the effectiveness of various therapies? What is the placebo effect? The Wikipedia Internet Encyclopedia defines placebo as follows:

"A placebo is a substance or procedure a patient accepts as medicine or therapy, but which has no verifiable therapeutic activity. The placebo effect (or placebo response) is a therapeutic effect following administration of a placebo, or more generally: is the psychosocial effect of medical treatment. Effective on 30% of humans and only for some conditions, it is also known as the non-specific effect or subject-expectancy effect."

Thus, one could question whether the reported or experienced therapeutic effect of alternative therapies may be largely due to the placebo effect. In double blind drug studies a drug can be evaluated for its therapeutic effect if it has a positive effect beyond the effect of placebo (beyond 30%). In therapies or treatments that are not verified by the scientific method, the placebo effect may be quite significant or it may be less significant. Particularly in chronic medical conditions such as fibromyalgia, degenerative arthritis, tension headache and PPS, the placebo effect may be more significant. Surgical procedures are also judged more effective only if they result in a better result with less risk than previously accepted surgical treatments.

Western physicians are trained by this method to this day. Every college student who would like to go to medical school must do well in the premedical required courses, do well on the standardized Medical College Admission Test (MedCAT), and get accepted to at least one accredited medical school. Then this same student must be highly motivated, energetic and intelligent enough to learn an immense amount of subject

matter in the first two years of medical school. During the last two years this student must learn an equally difficult amount of clinical material by means of lectures by practitioners, making hospital rounds, and serving on clinical rotations in the hospital or community facilities. Then after all of this the testing never seems to end. There is the state board of medicine exam, the national board of medicine exam, the specialty board exam and endless continuing education requirements in order to maintain one's license. The challenge is to never become complacent, but to continue to learn more.

I for one believe that the traditional western approach to the study and practice of medicine in utilizing the process of research, diagnosis, treatment and prevention of disease has and will continue to be the leader in the progress toward a healthy life for more and more people throughout the world. Admittedly there is much to fix in the delivery of health care to everyone, but the scientific methods of the past continue to be effective.