



The LincPIN

The **Lincolnshire Post-Polio Information Newsletter**
Volume 3 - Issue 11 - July 2002

WebSite - <http://www.lincolnshirepostpolio.org.uk>

ANNUAL GENERAL MEETING

SATURDAY 28TH SEPTEMBER 2002

New Venue
The Memorial Hall, North Hykeham, Lincoln

AGM COMMENCES AT 11.00 A.M. Members and Carers.

All Welcome from 12.45 onwards to the
BUFFET SALAD LUNCH - Cost £3.50.

3 AFTERNOON SPEAKERS - Commencing at 2.00 p.m.
[Titles and speakers to be confirmed in AGM mailing mid August.]

A GREAT LADY'S CENTURY OF ALCHEMY

She was
a great lady
Britain's Queen Mum
(Elizabeth) epitome
of grace and dignity
beloved for a century
of
pomp and pageantry
white roses
signal
the end of her
rein of majesty
and this great lady's
century of alchemy.

LaVonne Schoneman
Polio Survivor
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Lincolnshire Post-Polio Network - UK Registered Charity 1064177
Donations large and small towards our work are always welcome.

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Next LincPIN Newsletter - October 2002

Articles for publication by September 25th - Publication date approx. 5.10.2002

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Editorial by Hilary Hallam

EGM - The changes to the Constitution were agreed at the EGM. A copy of the new Constitution is enclosed with this newsletter.

AGM - Information on this years AGM is on the front page. Please note the change of venue due to no caretaker being available to open our normal venue. However although not as ideal this is nearer to the IBIS Hotel. The Memorial Hall is on the A1434 [from Lincoln to Newark] opposite the North Kesteven Sports Centre. It is on the north side of the road about 100 yards west of the traffic light junction with Station Road and Moor Lane. **AGM Papers** - The full AGM will be finalised and posted to you mid August.

IBIS Hotel - Ten rooms have been pencilled in for the nights of Friday 27th and Saturday 28th September for LincsPPN members. Please contact the hotel directly on 01522 698333 stating that you are a member of the LincsPPN. I have asked that all rooms are together if at all possible. The prices are £29.95 per room per night, continental breakfast from the breakfast bar is extra per person. The IBIS do provide a small bar menu. Next door there is the Pride of Lincoln with full menu all day, and Frankie and Bennies Italian restaurant. The hotel are happy to order Take-Aways. We will be meeting socially in the hotel bar each evening. Laughter guaranteed.

Speakers - Dr. Elizabeth Dowsett has kindly agreed to speak again. We hope to have two other local medical/nhs speakers but due to new appointments we have been unable to confirm this to go out with this newsletter. The information on name and title of talk will be in the AGM Papers.

AGM Question Time - Whether or not you are able to attend we would like to receive questions for Question Time. These can be on any pps issue. All questions and answers will be printed in the newsletter following the AGM. Please will you send any questions in writing as soon as possible.

Lincolnshire Post-Polio Network Treasurer. - We welcome Lincoln based Life Member Jennie Paulger for agreeing to be co-opted to the Committee and taking on the post of Treasurer from 1st August 2002. <jennie.paulger@lincolnshirepostpolio.org.uk>

POST - All post including membership renewals, enquiries, etc to the main address till further notice.

NEW LINCOLNSHIRE APPOINTMENTS - We are pleased to be able to tell you that the new Rehabilitation Consultant for Lincolnshire will be Dr. Prasad - replacing Dr. Elizabeth McClemon - and he will be starting in September. We have also just been notified that Lincolnshire will shortly have its first resident neurologist, a Dr. Bowen.

MULTI-DISCIPLINARY REHABILITATION CLINIC - BURSLEM - STOKE ON TRENT - DR. Ali Arshad is now the Rehabilitation Consultant at the Haywood Hospital, Burslem, Stoke on Trent, North Staffordshire. Dr. Arshad, his registrar Dr. Alex Ball and team of Physio, Occupational and Speech Therapists would be happy to see any polio survivors living in the area.

PHYSIOTHERAPY STUDENT NEEDS YOUR HELP. Hannah Long a Physio Student in Brighton whose father has had polio is researching what its like to Live with Post Polio Syndrome. Full letter page 14.

STATISTICS AND ASSESSMENTS - Following the Neurological Alliance June meeting [where they launched their 'Levelling Up' document] at the Glaxo Neurological Centre in Liverpool where I was able to continue discussing these subjects in person - I heard from Nikki Joule the Neurological Alliance Policy Officer [see page 15 for Press Release].

'**Statistics** - The Neurological Alliance are setting up a group to look at this including some of the professional organisations, possible meeting in September. **Manual Muscle Testing and other Assessments.** The issue of Manual Muscle Testing (and other assessments) and their appropriateness in assessing symptoms reported by the person with the condition. These are important issues that you raise and, following the announcement of the scope of the NSF last week and the opportunity this gives us to reorganise services from the users' point of view, we intend to take this up with those working on the NSF. We will also sound out professional colleagues for their views on muscle testing and other assessments.'

Local Neurological Alliances - neuro support groups coming together to influence local medical providers to improve the level of service they currently offer. In the past as single conditions we were told 'there are not enough of you'. Representing an estimated 60,000 people living in Lincolnshire means we are being listened to and change is and will continue to happen. Representatives of local groups meet regionally and nationally sharing information and best practice.

Lincolnshire Neurological Alliance - there will be a coffee morning in mid September at a Lincoln venue open to members of all neurological support groups to bring them up to date with what is happening locally and to attract new members. Information on date and venue will be sent with the AGM Papers.

Cardiovascular Issues of Polio Survivors

Remarks at GINI's
Eighth International Post-Polio and Independent
Living Conference June 2000.

Rupert D. Mayuga, MD,
Assistant Professor of
Clinical Medicine/Cardiology,
Northwestern University Medical School,
Chicago, Illinois.

Cardiovascular disease (CVD) is the leading cause of death in both men and women in the United States. One of every 2.4 deaths is attributable to CVD. However, the incidence of CVD individuals with post-polio syndrome is not known.

CVD is often a 'silent' disease without significant symptoms until its life-threatening or catastrophic sequelae appear suddenly. All too often, the first manifestation of CVD is sudden death, stroke, or heart attack. The need to identify individuals at increased risk early enough to alter its catastrophic course cannot be overemphasized.

Q - Are there reasons to suspect that polio survivors who are experiencing post-polio problems might be at increased risk for CVD?

Yes, certain features such as generalized fatigue, generalized and specific muscle weakness and joint and/or muscle pain may result in physical inactivity - deconditioning, obesity, and dyslipidemia. Polio survivors with respiratory difficulties may develop hypoxemia (low levels of oxygen). Any of these circumstances - deconditioning, obesity, dyslipidemia, and hypoxemia - can increase the risk for cardiovascular disease.

Furthermore, most polio survivors are at an age when CVD becomes increasingly more likely.

Q - What are the common signs and symptoms of CVD?

CVD signs.

Enlarged heart.
Swelling of the ankles or legs
Unusual/excess weight gain
Wounds that do not heal.

CVD Symptoms.

Chest discomfort
(pain, pressure, squeezing, heaviness etc) especially if brought on by exertion and relieved by rest.
Shortness of breath with minimal exertion or upon lying down
Palpitation or irregular heart beats
Severe dizziness or loss of consciousness
Sudden weakness or paralysis of one part of the body
Sudden slurring of speech or loss of vision

Frequent nocturnal urination
Unusual and progressive fatigue
Leg pain/discomfort with walking.

A WORD OF CAUTION. The symptoms of CVD overlap with common symptoms of post-polio syndrome. This presents a problem because individuals diagnosed with the syndrome may not recognize cardiovascular symptoms and think that these may just be a progression or altered manifestation of the post-polio symptoms. The resulting delay in diagnosis can be costly.

Q - What tests should I have if I experience some of the above symptoms?

One study, of practical importance to polio survivors, evaluated the cardiovascular autonomic function of individuals who had polio (Borg 1988) and concluded that there was no significant dysfunction of autonomic nerves despite the presence of progressive muscle atrophy.

This finding becomes important when one considers that many current methods for assessing cardiovascular function and fitness include evaluation of parameters - such as heart rate, blood pressure, heart rate variability, valsalva response, etc. - all of which require an intact autonomic system. The study results suggest that polio survivors in general can use any of a number of standardized tests for cardiovascular risk assessment such as the exercise stress test without a decrease in test sensitivity, provided that due consideration of the presence of muscular dysfunction is made.

For example, an arm ergometer may be used instead of a treadmill as the method of providing the exercise in individuals with lower extremity weakness. There are also non-exercise types of cardiovascular stress testing such as pharmacologic, vasodilator perfusion stress tests (dipyridamole or adenosine stress tests) used in conjunction with nuclear imaging, or a dobutamine stress echo test. These are the preferred tests for those who cannot perform significant exercise.

Also, make certain that blood pressure, cholesterol/lipid profile, fasting blood sugar (FBS), body weight, and an ECG are included in your annual physical examination. A chest x-ray would also be useful periodically to determine heart size and the status of the lungs. More frequent testing as well as additional specific tests (stress tests, echocardiograms, coronary angiograms, etc.) may be needed.

Although there appears to be no large scale studies evaluating whether individuals experiencing post-polio syndrome are at increased risk for CVD, it is probably safe to assume that there may be increased risk in certain individuals who have the traditional risk factors mentioned above. A study of 64 post-polio individuals (Agre 1990) found that 66% of the men and 25% of the women had hyperlipidemia (high

lipid concentration) with men also having low HDL (the 'good' cholesterol. These findings underscore the need to actively screen for dyslipidemia and/or hypercholesterolemia (excess cholesterol in the blood: less than 200 total cholesterol is desirable). In addition, deconditioning and obesity was found to be strongly associated with the presence of dyslipidemia. Therefore, it is important to address these issues.

Q - Since CVD is described as a 'silent' disease without significant symptoms, what are some of the risk factors that are of major importance to everyone with or without a history of polio?

Risk factors include cigarette smoking, hypertension (high blood pressure), elevated LDL cholesterol (the 'bad' cholesterol: less than 100 is optimal), diabetes, male gender, post-menopausal women, family history of premature coronary heart disease, the presence of peripheral arterial occlusive disease, and, last but not least, obesity and physical inactivity.

The presence of multiple risk factors results in more than just additive risk.

Q - How can I avoid physical deconditioning and becoming over-weight?

In individuals with identified post polio symptoms consistent with cardiovascular deconditioning, there has been some hesitation in prescribing an exercise program to improve conditioning because of fears that traditional exercise regimens may lead to further loss of muscle from overuse. The prospect of safely and effectively training PPS subjects was evaluated by a number of investigators. All investigators found that a carefully designed exercise program, which avoided excessive muscle fatigue was able to provide positive results.

Consult your health care professional for appropriate recommendations. In general, exercise has to be started very gradually and at a lower level individually tailored to each individual's physical status and needs. Care should be taken not to over-exercise. Nutritional counselling is also a useful resource.

**“If we don't know the disease,
we don't know that we are at increased risk,
and we might not do anything about it.”**

Rupert D. Mayuga, MD.

**SIGNS AND SYMPTOMS
OF A HEART ATTACK
OR IMPENDING HEART ATTACK:**

Continuous chest and/or throat discomfort/pressure/pain/heaviness lasting more than 15 minutes even with rest and even after sublingual nitroglycerin. This may be associated with shortness of breath, sweating, dizziness, and palpitations. Discomfort may radiate to the left arm or jaw.

**Immediately
proceed to the nearest emergency room
[Casualty Department]
or call paramedics 911
{999 in UK}**

If you have no severe allergies to aspirin, chew one tablet of regular 325mg aspirin. This can help immediately by preventing or delaying further accumulation of blood clot in the arteries of the heart. In the emergency room, you can be given powerful clot dissolving medications or, if the facilities are available, emergency coronary angioplasty (a means of re-opening a blocked artery using a small balloon at the tip of a catheter) can be performed. These procedures can prevent an impending heart attack or reduce the size of a heart attack that has already started, thus reducing significantly the risk of dying as well as the risk of future complications.

Remember, emergency coronary angioplasty is only effective if the blocked artery causing the heart attack can be opened within the first few (preferably less than three) hours of the onset of chest discomfort.

Do not delay in getting to the ER [CASUALTY]

Weird Things You Would Never Know!!

Butterflies taste with their feet.
A duck's quack doesn't echo, and no one knows why.
Elephants are the only animals that can't jump.
It's possible to lead a cow upstairs...
but not downstairs.
A snail can sleep for three years.
No word in the English language
rhymes with "MONTH".
TYPEWRITER is the longest word that can be made
using the letters only on one row of the keyboard.
A crocodile cannot stick its tongue out.
The cigarette lighter was invented before the match.



Fatigue, Heart Palpitations, Skipped Beats, Low Blood Pressure.

Richard L Bruno,

Reprint from New Mobility Magazine

Richard L Bruno is chairperson of the International Post-Polio Task Force and director of the Post-Polio Institute at Englewood Hospital and Medical Centre, New Jersey, USA.

Question. I had polio with weakness in my left leg. I recovered and carried on a normal life until the early 1990's when I started to have fatigue, heart palpitations, skipped beats and low blood pressure, especially after I eat. Should my doctor be considering any tie-in with Polio?

Answer. Oh yes! Fifty years ago polio pioneer David Bodin discovered that every polio survivor had some poliovirus damage to neurons in the brain stem, the so-called 'bulb' of the brain. When brain stem damage was severe, the diagnosis was 'bulbar' polio - when brain stem breathing-control neurons stopped working. But the most common symptom of 'bulbar' polio was trouble swallowing, not trouble breathing. Some 'bulbar' polio patients also had severe difficulty controlling their blood pressure and heart rate.

The damaged brain stem neurons that are responsible for these symptoms control the vagus nerve, which carries commands from the brain stem to activate muscles in your throat, esophagus, stomach and intestines. It also controls your heart rate. But the vagus nerve is a two-way street, since it 'listens' to activity in the gut and sends that information back up to the brain stem neurons.

Vagus damage that disrupts the normal functioning of the gut may explain our Post-Polio Survey findings that swallowing difficulty, diarrhea, colitis, ulcers and constipation are as much as six times more common in polio survivors than in non disabled individuals. And the symptoms you describe may result from poliovirus damage to the vagus as well as to brain stem blood pressure and heart rate control neurons.

We have a growing number of post-polio patients who feel exhausted after a meal. When their stomachs fill with food, the vagus is apparently over stimulated and triggers a drop in blood pressure, causing feelings of fatigue and sometimes palpitations. Polio survivors have also been reporting another problem: food sticking in the upper esophagus. We think this is due to the vagus not stimulating esophagus muscles to move the food downward. When food gets stuck irritation triggers a painful esophagus muscle spasm that also stimulates the vagus nerve, causing blood pressure to drop and the

heart to race or to slow.

Although blood pressure drops, our patients don't faint, a finding consistent with our 1995 Post Polio Survey discovery that polio survivors do not faint any more frequently than non disabled folk. However, the survey did find that those who had fainted only once in their lifetimes reported significantly more daily fatigue than those who had never fainted. This suggests that damage to brain stem blood pressure control and vagus neurons may be coupled with poliovirus damage to bulbar 'brain activating systems' neurons, those which our laboratory research suggests are responsible for post-polio brain fatigue.

The relationship between fatigue, brain stem damage and low blood pressure links polio survivors to another bunch of very tired folk - those with chronic fatigue syndrome. About one quarter of CFS patients have fatigue that is associated with low blood pressure or increased heart rate. Some CFS patients report fatigue when a hot shower or hot room causes blood pressure to drop, as do about one third of polio survivors. Other CFS patients have blue feet, just like our patients 'polio feet', suggesting that blood pooling in the legs contributes to low blood pressure.

Polio survivors should have a doctor take their blood pressure and heart rate lying, sitting and - if possible - standing. Anyone having fatigue associated with drop in blood pressure or a slowed or racing heart needs to see a cardiologist who treats low blood pressure. Compression stockings - which push blood back towards the heart - and medications that increase the fluid in our blood or stop blood from pooling in the legs, can be helpful. If fatigue follows eating, try consuming frequent, small, higher protein meals - they can prevent the stomach from getting too full and stimulating the vagus.

Polio survivors having trouble swallowing should see an ear, nose and throat doctor. Eating smaller bites of softer foods and washing down each bite can prevent food from sticking in the esophagus. For those who still have a sticking problem, a low dose of the muscle relaxant Klonopin taken 30 minutes before eating can prevent muscle spasm and help food slide down.

A Follow-up on the Dangers of Oxygen

by E.A. Oppenheimer, MD

Physicians usually see two types of pulmonary impairments. The most common is Chronic Obstructive Pulmonary Disease (COPD), i.e. emphysema, asthma, chronic bronchitis, etc. COPD is a condition where the lungs or airways are damaged but the respiratory muscles function normally. The second is hypoventilation (underventilation) due to neuromuscular disease, i.e. polio, Muscular Dystrophy, ALS [Motor Neuron Disease] etc. In neuromuscular hypoventilation the lungs are healthy, but weakened respiratory muscles impair the movement of air in and out of the lungs.

With COPD the problem is with oxygen exchange. The damaged lung tissues interfere with the transfer of inhaled oxygen into the bloodstream. The problem with post-polio and other neuromuscular diseases is the inability to move air (oxygen) effectively. Since COPD is so common, many physicians are used to treating a low oxygen saturation (even when there is an elevated CO₂) with oxygen, not considering the possibility that the problem is truly hypoventilation rather than COPD. Although modern blood gas equipment often automatically calculates the alveolar gas equation, many MDs and RTs no longer think in these terms and don't remember when or how to use this information.

Both COPD and hypoventilation due to neuromuscular disease result in a decrease of arterial oxygen levels as the problems get worse. If the doctor or respiratory therapist uses the "alveolar gas equation" to check the arterial blood gas (ABG) data in COPD patients it will show a wide alveolar to arterial oxygen difference due to the lung damage (ventilation:perfusion mismatch). But in post-polio hypoventilation the alveolar to arterial oxygen gradient is normal -- the calculation using the alveolar gas equation shows that all of the drop in oxygen is due to underventilation, due to the increased alveolar CO₂. This is often referred to as CO₂ retention.

Most physicians know that you need to be careful with oxygen administration in COPD. Too much can turn off respiratory drive and result in death. The body recognizes the higher oxygen level and tells the breathing muscles to slow down or breathe shallower. It's as if the nervous system is saying, "You've got plenty of oxygen. Slow down. You don't need that much." But COPD patients need some oxygen supplementation because of their problems with oxygen transfer. Dr. Peter Gay (Pulmonary

physician at the Mayo Clinic) published a review of similar problems when oxygen is given to people with neuromuscular disease. Already weakened respiratory muscles will be getting the wrong signals. The respiratory drive will turn off and death can result.

If COPD patients are given assisted ventilation without oxygen, the low oxygen problem persists. If a post-polio patient with low oxygen saturation is given mechanical ventilation, the oxygen level returns to normal without adding oxygen. This is because the post polio problem is underventilation. These patients respond to assisted ventilation alone.

So why give the wrong treatment and risk a bad outcome? The answer is: You shouldn't! You should use mechanical ventilation to correct the underventilation, and avoid mixing up treatment of post-polio and COPD!

Post-Polio Breathing and Sleep Problems

by Judith R. Fischer, Joan L. Headley

New breathing and sleep problems in aging polio survivors can be insidious and often not recognized by either polio survivors themselves or their health care professionals. Polio survivors who were in an iron lung or barely escaped one during the acute phase should be aware of potential problems and educate themselves in order to avoid acute respiratory failure. Polio survivors who did not need ventilatory assistance during the acute phase may also be at risk for respiratory failure, and should likewise be aware of problems with breathing and sleep.

Simply stated, the major problem for polio survivors is hypoventilation (commonly referred to as underventilation). Not enough air reaches the lungs, producing an imbalance in the gas exchange in the blood: too little oxygen, too much carbon dioxide (CO₂) or hypercapnia.

Hypoventilation is caused by one or a combination of the following: chest wall deformities such as scoliosis, respiratory muscle weakness due to the poliomyelitis, and sleep apnea (an interruption of breathing during sleep) which can be central, obstructive, or mixed and occurs in the general population as well.

Other factors contributing to a polio survivor's problems are a history of smoking, obesity, lung disease, and diminished vital capacity (VC). As aging occurs in anyone, vital capacity (VC) diminishes, but this decrease in VC is more serious in an aging polio survivor with limited musculature remaining to produce adequate ventilation.

Many polio survivors had impairment of the diaphragmatic and intercostal muscles, and the normal changes due to aging may cause them to lose VC at a greater rate, thus exacerbating the development of hypoventilation.

Signs and symptoms include: fatigue, daytime sleepiness, morning headaches, need to sleep sitting up, sleep disturbances (including dreams of being smothered, nightmares, restless sleep, interrupted sleep), snoring, poor concentration and impaired intellectual function, shortness of breath on exertion, claustrophobia and/or feeling that the air in the room is somehow bad, anxiety, difficulty in speaking for more than a short time, quiet speech with fewer words per breath, use of accessory muscles to breathe, and a weak cough with increased susceptibility to respiratory infections and pneumonias.

Polio survivors experiencing more than one of the above signs and symptoms should seek a respiratory evaluation by a pulmonologist, preferably one experienced in chronic neuromuscular disorders. (If your pulmonologist is unfamiliar with post-polio, you may wish to provide copies of pertinent literature, or offer to connect him or her with a physician in the I.V.U.N. Network.)

Pulmonary function tests should include at least: VC, air flow, MIF (maximum inspiratory force) and MEF maximum expiratory force), and ABG (arterial blood gases). A sleep study should also be considered. However, strong anecdotal evidence from polio survivors indicates that a sleep study may miss detection of hypoventilation. A sleep study is designed to detect sleep disturbances such as sleep apnea; it does not measure CO₂.

Management of breathing and sleep problems can be achieved largely through the use of nocturnal noninvasive ventilation in the form of mouth intermittent positive pressure ventilation, nasal intermittent positive pressure ventilation (a variety of commercial and custom nasal/face masks are available - see References) and negative pressure body ventilators. However, polio survivors may find themselves gradually extending periods of ventilator use. In some cases, as a last resort, invasive tracheostomy positive pressure may be necessary.

Medical literature regarding the management of breathing problems often includes a warning about the use of oxygen therapy. Respiratory failure in polio survivors is usually due to hypoventilation which can be aggravated by the short and long term use of oxygen. When the brain senses an excess concentration of CO₂ in the blood it instructs the body to increase breathing, ridding it of the CO₂ and increasing

the oxygen.

When oxygen is supplied, the mechanism in the brain detecting the CO₂ eventually turns off. Hypercapnia is best treated with assisted ventilation. Polio survivors with different problems, such as COPD or pneumonia may benefit from short term oxygen therapy under careful supervision.

Thanks to Edward A. Oppenheimer, MD and John R. Bach, MD, for reviewing this article.

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Post-Polio Sleep and Breathing Problems: Assisted Breathing Aids By Judith R. Fischer, Editor, IVUN News

People with neuromuscular disease such as post-polio often need help with breathing because the respiratory muscles are weakened or paralyzed. Often the chest wall is stiff and inelastic, and if scoliosis is present, the work of breathing may be further compromised. The inability to produce a good cough can lead to an increased incidence of respiratory tract infections and pneumonias. Sleep apnea may also occur.

Underventilation is not uncommon and assisted breathing through mechanical ventilation can help people prevent respiratory failure.

Oxygen is not the preferred treatment for underventilation and may exacerbate the condition. The following descriptive terms may be helpful.

CPAP - Continuous Positive Airway Pressure: Air flows continuously into the airways via the nose with use of a nasal mask. CPAP keeps the airways open, but does NOT assist inspiratory muscle activity directly NOR does it assist gas exchange in the lungs. John Bach, MD, describes it as "breathing with one's head out of the window of a car going 60 mph." Higher pressures make exhaling uncomfortable and difficult. CPAP is primarily used to treat obstructive sleep apnea, and thus is normally used only at night during sleep. CPAP units are not ventilators.

BiPAP - Bi-level Positive Airway Pressure: BiPAP refers to both a method of breathing and a machine. BiPAP units also continuously deliver air, but the inspiratory pressure can be adjusted separately from the expiratory pressure. BiPAP units are also used with a face or nasal mask or

nasal pillows, and like CPAP, used mainly at night. (Like CPAP, BiPAP is not for 24-hour use.) However, BiPAP can only deliver a certain amount of pressure that may not be enough for people with respiratory insufficiency and underventilation. BiPAP is registered to Respiroics, Inc. There are many other bi-level positive airway pressure support devices on the market, but the only one that can be truly called BiPAP is from Respiroics.

Ventilators - Volume: Volume ventilators deliver a pre-set volume of air via nasal/face mask, nasal pillows, or tracheostomy tubes. These machines can deliver much more air than BiPAP units, and thus enable deeper breaths for improved coughing and air stacking. They may be necessary for people with poor lung elasticity and stiff chest walls, when BiPAP is not enough. Volume ventilators, though larger, heavier, and more expensive than bi-level units, are quieter, have more alarm features, and can be used for 24 hours. The most commonly used volume ventilators in the U.S. are the LP6 Plus, LP10, and new Achieva TM from Mallinckrodt, and the PLV-100 and PLV-102 from Respiroics.

Ventilators - Next Generation: A new generation of ventilator technology has produced the LVTM series from Pulmonetic Systems, Inc., and the UniVent-A9 Eagle-A9 from IMPACT Instrumentation. These new ventilators are compressorless and run by turbines. They are very small - about the size of a laptop computer - and lightweight, about 13 lbs., but more expensive.

What is an interface? In reference to assisted breathing equipment, an interface is what connects the tubing from the ventilator or CPAP/bi-level unit to the person using it, either through nasal or facial masks, tracheostomy, lipseal, or mouthpiece.

Oxygen therapy - A useful analogy (from Lisa S. Krivickas, MD, Spaulding Rehabilitation Hospital) in regard to people with respiratory failure from neuromuscular disease is that the lungs are like a deflated balloon that is not strong enough to inflate. To inflate the balloon, mechanical assistance to force air into the balloon is needed. Blowing oxygen across the mouth of the balloon (the equivalent of using supplementary oxygen delivered by nasal cannula) will do nothing to inflate the balloon.

Assisted Coughing - Manually assisted coughing involves another person administering a thrust to the chest and abdomen of the individual with neuromuscular disease immediately after that individual takes a big breath. Mechanically assisted coughing can be performed with the In-Exsufflator Cough Machine (J H Emerson Co.,

Cambridge, Massachusetts). The In-Exsufflator applies positive pressure to provide a deep breath in, then shifts rapidly to negative pressure to create a high flow out, as with a normal cough. A newer model of the In-Exsufflator will be unveiled in 2000.

References:

Bach, J.R. (1999) Guide to the evaluation and management of neuromuscular disease. Philadelphia, PA: Hanley & Belfus, Inc.

Fischer, J.R. & Headley, J.L. (1995) Post-polio breathing and sleep problems. IVUN News, 11 (4), 2. Oppenheimer, E.A. (2000) Oxygen is NOT for hypoventilation in neuromuscular disease. IVUN News, 14 (1), 4.

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RELAXATION METHOD.

In my relaxation method, you also go to the river -- or in my case a babbling brook, and you place your worries and problems on the autumn leaves that are floating in the water -- you put the ones you want to let go of on the leaves that are headed straight downstream to the sea, and the ones you just want a rest from, on the leaves that are headed toward a little whirlpool located just down the stream near the bank. That way you can pick those up to deal with when you feel rested, refreshed and strong enough to deal with them again.

Pam <Pampsyphd@aol.com>

Why do some patients respond to drugs while others do not? Why does one person feel no toxic effect while another has a life-threatening reaction?

The difference is due to their genetic makeup, according to a presentation at the conference of the American Physiological Society in San Francisco. The genes of the first person may be coded to tell the body to quickly and efficiently absorb drugs and eliminate them as soon as possible. By contrast, the genetic commands of the other may instruct the body to slowly absorb and release its ingestibles, thus causing lingering and toxic effects according to Allen Roses, M.D., the Worldwide Director of Genetics at GlaxoSmithKline Inc.

He is responsible for the company's development of "pharmacogenetics," the utilization of a person's DNA to create medications that best respond to their genetic makeup. Pharmacogenetics is expected to replace the current "one size fits all" approach to medications. Many predict that medications will soon be prescribed based on the unique combination of safety, toxicity and efficacy most compatible with the patient's genetic uniqueness.

Answered by Life Member Jann Hartman.

Question: My doctor says I need to lose weight, how can I lose weight when I have PPS?

Herbal Medicines

A Clinical Review reported by Richard Daggett.

Reprinted with permission from
February 2002 newsletter of the
Rancho Los Amigos Post-Polio Support Group.

More and more people are using herbal supplements. Most are using them as therapies for various medical conditions, or in the belief that there is some therapeutic or life enhancing value in their use. This may, or may not, be the case. We are often bombarded with hearsay evidence, but there are few unbiased studies available.

The January 2002 issue of *Annals of Internal Medicine* has a very thorough review of several commonly used herbs, with a risk-benefit profile of each. As part of the journal's complimentary and alternative medicine series they looked at Gingko, St. John's Wort, Ginseng, Echinacea, Saw Palmetto and Kava.

The authors searched electronic literature, asked experts in the field for their assessments, and located as many articles on herbs as they could. All systematic reviews of randomized clinical trials in humans were included. They used standardized guidelines to estimate the quality of the reviews. Each review was put through a screening process. They rated the objectives of each study, the data sources, the methodologies, inclusion and exclusion criteria, and various other factors. Each review was rated 'good', 'adequate', or 'poor'. This report summarizes the results of their findings on each herb.

Ginkou (Gingko biloba). Gingko has the longest history of use. It has been a common herb in Asia for centuries. It has been used for a multitude of ailments, including trauma, deafness, vertigo, impotence, and asthma. In clinical practice it is used mostly for memory impairment, dementia, tinnitus (ringing in the ear), and intermittent claudication (limp). Gingko's action is based upon its ability to increase fluidity of blood.

The authors assessed 40 studies of gingko for 'cerebral insufficiency', which they described as memory impairment but not dementia. They concluded that there is encouraging data, but the evidence for gingko as a memory enhancement is not convincing. No compelling data exists that would prove gingko has any positive impact on normal cognitive function.

There was, however, good evidence that gingko was significantly better than a placebo in

delaying clinical cognitive deterioration in dementia. Although many of the studies were flawed, the overall results suggested that the use of gingko might be relevant for dementia.

Gingko might also benefit tinnitus. Some results showed a statistically significant effect on the perceived loudness of the ringing. But, here again, the studies appeared to be flawed, and the therapeutic value of gingko on tinnitus is uncertain.

Tests using gingko for claudication showed that its effects is moderate, but might be clinically relevant. The gingko recipients were able to walk farther without pain than the control groups.

The adverse effects of gingko when used alone are usually mild, but the risks increase significantly if used with other drugs, especially anticoagulants. Serious bleeding had been reported.

St. John's Wort - (*Hypericum perforatum*)

Historically, St. John's Wort has been used for bronchitis, burns, cancer, enuresis, gastritis, haemorrhoids, insect bites, insomnia, and a host of other ailments. It is now used almost exclusively as an antidepressant. Its action seems to lie in selective inhibition of serotonin and dopamine in the central nervous system.

The authors studied a large number of clinical trials, and evaluated the quality of each. The average quality of these trials was assessed as good, and most showed the efficacy of St. John's Wort in mild to moderate depression. They determined that St. John's Wort is more effective than placebo and is similar in effectiveness to low-dose tricyclic antidepressants.

Taken alone, St. John's Wort appears to be very safe, and it is in some respects superior to conventional antidepressants. The only potential side effect is sensitivity to sunlight, and manic depression in predisposed patients. Both of these are extremely rare.

As with gingko, the risks increase when St. John's Wort is combined with other drugs. St. John's Wort can decrease the effectiveness of a wide range of prescription drugs. These include anti-coagulants, oral contraceptives, and antiviral agents. Clinically serious consequences may occur.

Ginseng (*Panax ginseng*)

There are so many types of ginseng, i.e. Siberian or Russian, Chinese or Korean,

Japanese and American etc. that it is difficult to find a standardized formula. Ginseng has been used as a sedative, hypnotic, aphrodisiac, antidepressant and diuretic. It is said to improve stamina, concentration, and well-being.

The authors found few high-quality, double-blind, placebo-controlled clinical trials using ginseng. There were many studies, but few with proven worth. Most used healthy volunteers rather than patient samples. They concluded that there was no compelling evidence on the efficacy of ginseng on any of the above conditions, and both animal and human studies do not support ginseng as an aid to physical performance.

The authors did, however, find one large study where the population consumed fresh Korean ginseng as part of their regular diet. It appeared that this regimen significantly reduced the risk of some forms of cancer. They cautioned that there was no proven causal relationship, but the results clearly showed that further study was warranted.

Another study indicated that 3 grams of American ginseng lessened glycemic fluctuations following meals. The effect was seen in non-diabetic persons and those with type 2 diabetes. They cautioned that American ginseng should be taken with a meal to prevent hypoglycemia in non-diabetic individuals. And ginseng has several serious adverse effects, ranging from insomnia, diarrhea, vaginal bleeding and severe headaches.

Echinacea (Echinacea species)

Echinacea products contain many potentially active ingredients, but no single active constituent has been found. It appears that some ingredients may stimulate the immune system, provide local anesthesia, and have anti-inflammatory, hormonal, and antiviral properties. In the past, echinacea has been used for wound healing, abscesses, burns and eczema. The most common usage today is for upper respiratory tract infections.

The authors found that the quality of clinical trials varied greatly. A few had value and a few were suspect. There is some evidence that echinacea may have a beneficial effect in preventing upper respiratory tract infection, but the trial data was weak and inconclusive.

There seems to be few adverse effects to Echinacea, consisting mostly of allergic reactions. Some of these can be serious however. Other reported adverse reactions include hepatitis, asthma, nausea, and anaphylaxis. Further studies are urged because of echinacea products to be unsatisfactory.

Saw Palmetto (Serena repens)

This herb traditionally used to treat genitourinary problems, increase sperm production, breast size, enhance libido, and as a diuretic. It is currently most used to treat benign prostatic hyperplasia. Why it works is not fully known, but experiments have shown an antiandrogen effect, and it may inhibit the dihydrotestosterone, the form metabolized by the body. It may also inhibit estrogen receptors in the prostate.

Several studies were reviewed for this article. Most were deemed to be 'good on average'. Most were placebo controlled, and some used a combination of saw palmetto and other herbs or saw palmetto with finasteride, a commonly prescribed prescription drug for benign prostatic hyperplasia.

The results of most studies indicated the superiority of saw palmetto over a placebo in terms of peak urine flow and nocturia. The results also indicate that saw palmetto might be as effective as finasteride.

Most of these studies were short-term and the long-term benefits have not been proved. Given this caveat, saw palmetto has shown few adverse effects, and the authors quote from a 6-month, randomized controlled trial that confirmed saw palmetto as 'a safe and highly desirable option' for men with moderately symptomatic benign prostatic hyperplasia'.

Kava (Piper methysticum)

Kava is used in the South Pacific as a recreational drink. It has been used experimentally to lessen seizures and to treat psychotic episodes. It is most often used for its anxiolytic effects.

A review of past trials indicates that Kava, when used at recommended dosages, resulted in a reduction of anxiety using a standardized anxiety scale. One study compared Kava with the prescription drug oxazepam and found that they were equally effective in the short-term.

Serious side effects have been reported, but this seems to be rare. Several cases of liver damage were recently reported with Kava self-medication. Long-term use of Kava is associated with flaky, dry, and yellowish skin, ataxia, hair loss and partial loss of hearing. Most of these are reversible when use is discontinued. As with all herbals, the risks increase when used in combination with other drugs, or in some cases, with other herbals.

All of the herbs studied had problems of quality, purity, and standardized extracts. Some are

associated with positive risk-benefit profiles. Ginkgo, St. John's Wort, and saw palmetto appear to have benefit when used for the conditions discussed. The evidence for ginseng, echinacea, and Kava is less compelling.

The authors comment that 'Generally speaking, trials of herbal medicine products have been too few, too small, and too short. The lack of long-term studies is especially unfortunate. Benign prostatic hyperplasia, for instance, clearly requires long-term therapy, but trials of saw palmetto to date are mostly short term (4 to 48 weeks). Thus the clinician is caught between encouraging results of randomized clinical trials and the relative lack of controlled long term data. The latter information is needed to make responsible therapeutic decisions. Patients suffering from Fibromyalgia used to be told that it was all in their head. Not any more.

Fibromyalgia is a mysterious illness with a long name and a bad reputation. For years, patients who went to their doctors complaining of inexplicable pain, stiffness and fatigue were told that they were depressed or stressed out and their symptoms were psychosomatic. More recently, fibromyalgia has been linked to chronic fatigue syndrome and the after effects of Lyme Disease, which is some medical circles in enough to give any ailment a bad name.

But the reputation is undeserved. Fibromyalgia is a real medical syndrome that is being taken more seriously these days, thanks to a study out of the University of Alabama that has found what may be the underlying causes: reduced blood flow to the parts of the brain that process pain and twice the normal level of a brain chemical called

HURTING ALL OVER

substance P, which helps nervous system cells send pain messages to the brain. Not only do patients now have scientific support to prove they're not crazy but doctors also have a reason to take their complaints seriously.

The complaints are serious indeed, from swelling, tingling, numbness and stiffness in the soft tissues (muscles, tendons, ligaments) to achy, throbbing pain that is worse in the morning, intensifies again at night and has been known to drive sufferers to suicide. Fatigue is a common complaint (reported in as many as 9 out of 10 cases), caused perhaps by disturbances in the deep sleep phase the body needs to get properly refreshed at night. Patients have told me that they feel so heavy in the morning they can hardly get out of bed and that they often find it difficult to concentrate on even minor tasks. For reasons

that are not known, women get fibromyalgia seven times as often as men, but the ailment can strike anyone at any age.

Doctors are at a disadvantage in diagnosing fibromyalgia because many of its symptoms are shared by other illnesses. Compounding the problem is the fact that even with these recent findings, there are still no definitive fibromyalgia markers. X-rays and blood tests can be used only to rule out other illnesses.

To facilitate diagnosis, the American College of Rheumatology established a procedure for examining 18 points on a patient's body. If the muscles feel very sore when pressed in 11 of these 18 points, a tentative diagnosis of fibromyalgia can be made.

Although there is no known cure, there are treatments that work. In fact, many patients have managed the disease successfully with a combination of simple exercises and medication. Heat treatments, massage and regular stretching have been of benefit, as have such aerobic exercises as cycling and jogging. Thought many patients say these exercises only worsen the pain, working through the discomfort can eventually bring relief.

Tricyclic antidepressants such as amitriptyline and cyclobenzaprine are sometimes prescribed to improve sleep and relax muscles. Some patients opt for temporary pain relief via local anesthetic or steroid injections. There's no single regimen that helps everyone. Just keep trying until you find one that works for you. And don't let anyone tell you it's all in your mind.

Dr. Ian <ianmedical@aol.com> is a correspondent for NBC's Today show. For more on fibromyalgia see arthritis.org. Time, February 19, 2001.

Reprinted from Second Time Around, May 2002, Publication of Boca Area Post Polio Group, Boca Raton, Florida.

Lincolnshire Post Polio Library article

Fibromyalgia Is Common in a Postpoliomyelitis Clinic

**Daria A. Trojan, MD, MSc,
Neil R. Cashman, MD
The Archives of Neurology June 1995
Volume 52 620-624**

**From the Department of Neurology
and Neurosurgery
Montreal Neurological Institute and Hospital
McGill University, Montreal, Quebec.**

Abstract

Objective: To determine prospectively the occurrence and clinical characteristics of fibromyalgia in patients serially presenting to a postpolio clinic. Fibromyalgia may mimic some of the symptoms of postpoliomyelitis syndrome, a disorder characterized by new weakness, fatigue, and pain decades after paralytic poliomyelitis.

Design: Case series.

Setting: A university-affiliated hospital clinic.

Patients: One hundred five patients were evaluated with a standardized history and physical examination during an 18-month period. Ten patients were excluded because of the absence of past paralytic poliomyelitis.

Interventions: Patients with fibromyalgia were treated with low-dose, night-time amitriptyline hydrochloride or other conservative measures.

Main Outcome Measures: Patients with fibromyalgia had diffuse pain and 11 or more of 18 specific tender points on examination (American College of Rheumatology criteria, 1990). Patients with borderline fibromyalgia had muscle pain and five to 10 tender points on physical examination.

Results: Ten (10.5%) of 95 postpolio patients met the criteria for fibromyalgia, and another 10 patients had borderline fibromyalgia. All patients with fibromyalgia complained of new weakness, fatigue, and pain. Patients with fibromyalgia were more likely than patients without fibromyalgia to be female (80% vs 40%, $P < .04$) and to complain of generalized fatigue (100% vs 71%, $P = .057$), but were not distinguishable in terms of age at presentation to clinic, age at polio, length of time since polio, physical activity, weakness at polio, motor strength scores on examination, and the presence of new weakness, muscle fatigue, or joint pain. Approximately 50% of patients in both the fibromyalgia and borderline fibromyalgia groups responded to low-dose, night-time amitriptyline therapy.

Conclusions: (1) Fibromyalgia occurs frequently in a postpolio clinic. (2) Fibromyalgia can mimic some symptoms of postpoliomyelitis syndrome. (3) Fibromyalgia in postpolio patients can respond to specific treatment.

End Abstract

Accepted for publication June 23rd 1994.

Lincolnshire Fibromyalgia Support Group report that one third of their members have had polio in their earlier lives.

**Lincolnshire Fibromyalgia Support Group.
Lorraine Money**

18 College Park, Horncastle, LN9 6RE
01507 524 037
Mon-Fri 11-12; 2-4

<http://www.astspace.demon.co.uk/genealogy/fibromyalgia.html>

Fibromyalgia Association UK

P O Box 206, Stourbridge, DY9 8YL
Fax: 0870 752 5118

Email: fmduk@hotmail.com

National Helpline

Tel: 0870 220 1232

Mon-Fri 10.00a.m - 4.00p.m.

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

**Do you have your bedroom window open at night
even in winter!?
A ceiling fan on low - moving air - has helped us.**

PHARMACOGENETICS EXPLAINED

First off, just losing weight isn't the answer to all our problems with PPS. While less weight is better for our bodies, starving ourselves starves our Polio bodies as well. And, they can ill afford it. Don't ever go below 1,000 calories or you won't be providing the basic nutrition your body needs. Most dieters lose weight, but most are not able to maintain it, and often gain weight ending up heavier than before. This yo-yo dieting is not good for your body. A slow weight loss is much more sustainable, and healthier.

For weight management, try a group like Weight Watchers or an exchange-type dietary plan like this one from the American Dietetic Association:
<http://www.eatright.com/catalogue/cat.php?CatNum=0764>

This is a 32 page booklet that emphasizes weight management through healthful eating, regular activity, and lifestyle changes. There is a small fee for the booklet and postage. You may be able to get a copy from a health care provider or nutritionist. Anyone who is in the morbidly obese category needs to be seeing a doctor who specialized in this life threatening condition.

Jann Hartman, BS, Nutrition Educator,
Baltimore, Maryland, USA.

Nutritional Questions

More PPS Nutrition
(basics and links to other WebSites):
<http://www.geocities.com/arojann.geo/ppsnutrition.html>

University of Brighton
School of Healthcare Professionals
Division of Physiotherapy
Information Sheet - Living with Post Polio Syndrome

Dear Participant,

I am a third year Physiotherapy student, studying at the University of Brighton. I will be carrying out a research project looking at how the survivors of polio live with the late effects of polio. I plan to interview six people with post polio syndrome. I am writing to ask if you would be willing to participate in my research project.

I am particularly interested in this area of research as my father had polio in the 1950's. Also because I know research and knowledge of post-polio syndrome are both relatively sparse.

I will be conducting interviews, which if you agree to participate, will take place in your own home. [South east of England, Kent to Sussex] I hope to look at

how you cope with the late effects of polio you are experiencing and in what ways you may have adapted your lifestyle. The interviews will be audiotape recorded with your permission. The information will then be transcribed and analysed. All information you provide will be kept confidential throughout and after the research project.

I hope to gain a deeper insight into post-polio syndrome and help other health professionals to expand their knowledge through my research project.

Many thanks for your time
Yours sincerely, Hannah Long
19 Geneva Avenue, Gillingham, Kent, ME8 6EJ
Email:
hannahbanana000@hotmail.com

Hannah will only be interviewing six people but would be pleased to hear from any members who would like to write/email telling her how they Live with PPS.

National Service Framework

**DEPARTMENT OF HEALTH
WEDNESDAY 12TH JUNE 2002.**

HIGHER STANDARDS TO IMPROVE SERVICES FOR PEOPLE WITH LONG TERM CONDITIONS

Health Minister, Jacqui Smith announced today at the College of Occupational Therapists "Making Waves" Conference that the NSF for Long-term conditions will have a particular focus on the needs of people with neurological conditions and brain and spinal injury, and also address some of the common issues faced by people living with long term conditions.

Speaking at the Conference, Jacqui Smith said:

"This NSF will enable us to tackle unacceptable variations in the quality of care across the country for people with neurological conditions and brain and spinal injury.

"We know that people need help not only in the context of managing their medical condition, but also in the light of their social, educational, employment and family lives. Their views and those of their family and carers are really important in helping to improve their independence and quality of life.

"These are challenging times ahead but occupational therapists have a key role to play in developing and implementing the NSF over the next 10 years. Your expertise in working with patients across health and social care boundaries will be invaluable to this work."

The NSF will build on the NHS Plan principles: aiming to provide good quality, joined-up health and social services along the whole of the patient pathway, with users and carers at the centre of the re-designed services.

The NSF will have a particular focus on services and support for people of working age. For example:

- ◆ User-centred, interdisciplinary health and social care assessment and support including rapid referral for diagnosis;
- ◆ Specialist, community and vocational rehabilitation services;
- ◆ Community equipment services;
- ◆ Help with a range of common symptoms

including pain and movement disorders;

- ◆ Information and support for carers and families;
- ◆ Support and services that help people with long term conditions fulfil their own responsibilities as partners, parents and carers; and
- ◆ Developing the concept of the Expert Patient.

The NSF project team has met with and received a number of submissions from key stakeholders including voluntary organisations, clinicians and health and social care professionals regarding their aspirations for this NSF. We are working closely with the Neurological Alliance and the Long-term Medical Conditions Alliance on the development of this NSF.

Notes to Editors:

1. The NSF was announced by the Secretary of state, Alan Milburn in February last year. The NSF will include services for people with epilepsy, multiple sclerosis, Parkinson's disease, motor neurone disease and brain and spinal injury. Current plans are to publish the NSF in 2004 with a 10-year implementation period from 2005.
1. Further information on National Service Frameworks can be found at www.doh.uk/nsf.index.htm
1. For media enquiries please contact the Department of Health media centre Tel 020 7210 5315/5231/5375

[ENDS]

NEUROLOGICAL ALLIANCE
Contact information on Page 19

Cambridgeshire Neurological Alliance - This is now in the pre launch stage in Peterborough. Anyone interested should contact Di Newman of MEET. A coffee morning held last week brought forward members from some local groups to form a committee. Next open meeting is planned for September.

So you think you are a Polio Survivor?

A Holiday Quiz by Millie Malone.

You may not know this, but many people wish they were polio survivors. I'm sure you have read the surveys pointing out that a higher percentage of us polio survivors are married, have a college education and have important, high paying, high profile jobs than those unfortunate non-polio people. So of course there are those who would like to join our elite group.

The following quiz is designed to winnow out the polio survivors, wannabes and impostors. Answer honestly, writing down the answers on paper as you go. No cheating and don't even use a pencil with an eraser. You must use ink.

1. There is a spot of water on your kitchen floor.
Do you....
 - a. Get the mop and wipe it up.
 - b. Call your child/spouse/service dog to come and wipe it up.
 - c. Use the seat of your pants to wipe it up, seeing as how you have already slipped on it and are on the floor on your backside.
2. You need the mixing bowl that you store on the uppermost shelf of your cupboard.
Do you.
 - a. Climb on a kitchen chair, stretch to the limit of your reach and get it down.
 - b. Call your child/spouse/service dog to climb up and get it for you.
 - c. Buy a new bowl after climbing on the kitchen chair, stretching to the limit of your reach, straining all the muscles in your arm and dropping it (hopefully not on the dog).
3. You are comfortably ensconced in your recliner, feet up, a teensy bit of a drool escaping from your mouth. The phone rings. Do you
 - a. Gracefully reach over and pick it up, answering in a civil tone.
 - b. Ask your child/spouse/service dog to answer the phone.
 - c. Jump straight up three feet in the air, turn a triple somersault whilst grabbing the phone and land in the recliner your heart beating wildly.
4. You have gone to the grocery store, the cleaners, the post office and library,

- arriving home with your tongue hanging out and your legs in spasm. Do you
- a. Make about seven trips to and from the car carrying everything in to the house.
 - b. Call your child/spouse/service dog to come and get the things out of your car.
 - c. Load everything up in your arms, use your teeth to carry the strap of your handbag, put the handles of the plastic grocery bags over your wrists and walk in agony into the house with this load, proud that you have saved yourself many trips.
5. Your church is having a bake sale. They have asked you to bring 12 dozen cookies.
Do you...
 - a. Mix up a quadruple batch of cookies sitting at the kitchen table, put the dough in the refrigerator and have your grandchildren help you bake them after school.
 - b. Call your child/spouse/service dog and give them a blank cheque to go buy 12 dozen cookies at the bakery.
 - c. Arrange to set up and run the bake sale by yourself, make 24 dozen cookies and assorted cakes, take as many pain pills as you feel you can safely get away with and then sleep for three days afterwards.
 6. You need new curtains in your bedroom. You buy a lovely pair that you are sure will make the bedroom look like a picture from House Beautiful. Do you...
 - a. Get the stepstool, take down the old curtains and put up the new ones.
 - b. Ask your child/spouse/service dog to take down the old curtains and hang up the new ones.
 - c. Slip off your shoes and brace, climb on the bed, stretch towards the window, fall off the bed, break your 'good' leg and spend the next 18 months in the bed staring at the old grubby curtains.
 7. Your favourite charity asks you to donate two days a week to helping in their day-care centre. Do you...
 - a. Tell them 'yes' and then show up only if you are not exhausted.
 - b. Ask your child/spouse/service dog if they are interested in a really fun volunteer job.
 - c. Start to form your mouth into a 'No' but hear it come out 'nnnnnOK' - even though you know you are not able to do the job and resent being asked - go to the day-care centre twice as often as you agreed to, take as many pain pills as you feel you can safely get away with and

then sleep through the days you dont go. British or Americans.

8. The holidays are looming. You have always had the family over for dinner. This year do you...
- Tell them that it is time they took over and had the family dinner at their house.
 - Ask your child/spouse/service dog to do the actual work while you supervise.
 - Do all the shopping, cleaning, cooking and serving while in excruciating pain, take as many pain pills as you can get away with and spend the next few days in bed planning the New Years Day Dinner.

Scoring.

If you answered 'a' to any of the questions you aren't even disabled, you faker you, let alone a polio survivor! Get your car out of that handicapped parking space!

If you answered 'b' You're a polio survivor but you cheated! Don't even try to deny it! You've read about what you should be doing to treat your post-polio syndrome, knew those were the right things to do and probably don't do a single one of them. Frankly, we are ashamed of you.

If you answered 'c' Congratulations. You are a bona fida polio survivor and entitled to all the rights and privileges therein unto appertaining (my that sounds fancy) and you know well that you shouldn't be doing any of those things!

Millie Malone is a polio survivor and an avid writer and traveller and swears that if there is an 'AAA' type personality then she's it. She has also met a wonderful man called Jaan and despite living over a thousand miles away have arranged to get married at the 5th Post Polio Internet Reunion in Branson Missouri, June 2003.

This article appeared in New Mobility Magazine.

Diets and Dying

The Japanese eat very little fat and suffer fewer heart attacks than the British or Americans. The French eat a lot of fat and also suffer fewer heart attacks than the British or Americans.

The Japanese drink very little red wine and suffer fewer heart attacks than the British or Americans.

The Italians drink excessive amounts of red wine and also suffer fewer heart attacks than the

CONCLUSION: Eat and drink what you like. Speaking English is apparently what kills you.

Getting Patient Information.

"Is that Mount Sinai Hospital? Could I please speak with the person who gives the information about the patients. I don't just want the doing better or worse answer, I would like all the information."

"The voice on the other end said, 'Would you please hold the line that is a very unusual request'."

Then a very authoritative voice came on and said, "Are you the lady who is calling about one of the patients"

"Yes please. I would like to know the information on Sarah Finkel in Room 302."

He said, "Finkel... Finkel.. Let me see. Farber, Feinberg - Finkel. Oh yes Mrs. Finkel is going very well. In fact she has had two full meals, her doctor says if she continues improving as she is, he is going to send her home Tuesday at 12 o'clock."

The woman said, "Thank God! That's Wonderful! She's going home at twelve o'clock! I am so happy to hear that. Wonderful News!"

The guy on the other end says, "From your enthusiasm, I take it you must be one of the close family."

"What close family? I'm Sarah Finkel!!! My doctor don't tell me nothing."

Dear LincPIN,

Just briefly I would like to explain how I came up on the Lincolnshire Post-Polio Network WebSite and Hilary Hallam.

I contracted Polio in Africa in 1960 and it affected my right leg. After several years I began to wear a full-length calliper and some really ugly shoes!! After arriving in England in 1972 I completed my studies, worked for the MAFF for 8 months and was over the moon when I got a position with an International American Bank where I worked my way up to Senior Manager. After 18 years with them and having travelled extensively in Europe for them, on a trip to Madrid I was horrified to see that the building I was working in had no lifts. I could not walk away from this stressful project and ended up putting a lot of strain on my muscles and cursing the bank for not advising me of the flights of stairs. They had always been aware of my disability and my issues with stairs. All I managed that week, unlike other trips, was to work during the day and crash in my hotel room afterwards. After arriving back from Madrid I confronted my Manager who simply ignored me. I experienced tremendous exhaustion and could not shake this even after taking a long weekend away from work, which I thought would do the trick! Instead my body came to a standstill and I could not get out of bed one morning. Thus began my long struggle with Post Polio, which was diagnosed a few months later at St. Thomas'. I have not been able to work since then and have had several changes to my personal life too.

A couple of years after the Madrid trip I began legal proceedings against my employers. At one point it appeared the case would collapse because there was no evidence that PPS existed. This eventually led me to search the web and initially I sent emails to Australia and Canada. Hearing nothing from them I searched some more and came across the LincsPPN and to my amazement all the information contained therein. I sent an email outlining my predicament and Hilary sent me one back asking me to call her after 8pm [after Eastenders!!!!] and we talked for nearly two hours. Hilary had had a similar experience and I took on board her experiences and was on my guard not to spend too much money on this case [I did not qualify for Legal Aid and my lawyers would not take the case as no win no fee].

Hilary has been a source of knowledge when I would make frantic phone calls asking for this that and the other. I really appreciate all the support Hilary.

Finally last August the other side offered to give me some money to make me go away but it took them until February to put this offer in writing. They thought that we had run out of time but it backfired on them. Two weeks ago the Judge got involved and although I had signed the Consent Form accepting their offer the Judge ordered my employers to pay all my costs.. there is some justice!! So finally I have received some money and await the rest.

It has been a long and stressful saga but at least the other side know that I refused to be intimidated and scared with all their antics although several times I wanted to just walk away!

Yash Airth. Berkshire. <airths@yahoo.com>

Do I come here often?

We've all had temporary lapses - I've been up a ladder with a hammer and asked my wife for 'one of those pointy things for knocking in the wall' - getting another nail is rarely a problem but how many of us know this sort of exchange

I have a number of friends at work that I've known for a number of years. Amongst them a deaf lady with a hearing dog, who's **very** pregnant and a Welsh lady, of similar age and colouring, who is rather, shall we say...rather *plump*?

One day I casually strolled up to one of them waiting for the lift, failing to bring her name to mind for a moment (or possibly longer), I opened the conversation with 'what have you done with Sophie (the dog)'. I can only say that the momentary look of puzzlement was preferable to the look that followed !

I suppose we all have moments like this, mostly they're harmless (my Welsh friend, who shall remain nameless, **is** talking to me again) and, yes, they can be embarrassing - but only if I forget to laugh!

I'm only a beginner at this, age 45, polio at 1yr and just recently seeing some symptoms of pps but it strikes me that the most lightweight orthotic may be a sense of humour!

Tired of being tired ? Speaking as, like most of us, an ex workaholic (and if I didn't knock myself out at work I'd knock myself out at home, gardening, DIY, martial arts, weight training, etc. etc. sound familiar?) I actually quite like taking a lie down when I'm tired these days – feels like the most natural thing in the world. Does it feel good to close my eyes? – oh yes !.

It's not even that bad that this happens more and more often (5 yrs ago – never, 2 yrs ago – lunchtimes, now lunchtimes and when I get home from work) What bugs me is the seemingly physical retribution of doing anything these days. A bit of light gardening one day and I can't keep up with the family the next (why won't those legs just go as fast as I tell them to?) Wash the car and then take my youngest son (age 4) to bed and I just can't hold up that third children's story to read!! At that it's not the actual tiredness that makes me anxious, it's the implication that I'll end up using a chair even though I can still walk well [actually, if I scuff the floor with my left foot one more time] – just so that I can still think, stay awake, hold up that book, or whatever, the following day. That's going to really **brass me off!!**

Typical type A, polio survivor attitude! I'll admit I've got a problem when I **really** have to, so I grudgingly let people know I've got some problems and got a bed put in a medical room at work. (very understanding employer) but I'll be damned if I'll use a walking stick though and double damned if I'll get back in a chair.....yet!

As you can see, the next most effective aid for me (after a sense of humour) would be a large dose of flexibility and a side order of humility! (I suspect that most polio survivors are the same and have got 'PRIDE' written through the middle of them like a stick of Blackpool rock!)

So, what message do I have so far for those of you out there who may be like me? – What we've got is definitely not in the mind but a lot of the solution may be! We have to learn to listen to our bodies and use our 'type A'ness to keep reassessing our situation and taking sensible action – Ditch the PRIDE (yes, in capital letters!) and remember to laugh !

I hope that some of you can understand and sympathise with some of what I've written and that this will help you in your approach to our situation.

Yours (still practising the rueful smile)
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CHECK OUT YOUR LOGIC

This is an unusual paragraph. I'm curious how quickly you can find out what is so unusual about it? It looks so plain you would think nothing was wrong with it! In fact, nothing is wrong with it! It is unusual though. Study it, and think about it, but you still may not find anything odd. But if you work at it a bit, you might find out what it is! Try to do so without any coaching!

What is it? Look at bottom of page 20.



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