



The LincPIN

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CONTENTS

Editorial - page 2

TRILLIUM

by LaVonne Schoneman - page 3
Retirement through the eyes of a Child - page 3

THE LATE EFFECTS OF ME

Can they be distinguished from the Post-polio syndrome?
Dr. E.G. Dowsett MBChB, Dip Bact. - pages 4 to 10

The WHO and who?

Cilla Webster - Founder - Post-Polio Network Z A - page 11 to 13

The Family Culture and Relationship with Disability.
by Margaret Backman, PhD. Clinical Psychologist - page 14

Stress Management for the Mind, Body and Spirit:
the SHARED method

Kathryn P. Fraser, PhD. pages 15 to 17

How do you handle adversity? page 18

Tips For Living With Dysphagia

by Polio Survivor Ellen Riddle - page 18 to 20
Roger Brown from Melbourne Australia writes about voice control - page 20 to 21

The Sunshine Vitamin & Osteoporosis
by member Vivien Holland - page 22

Letter from Sylvia Dymond - page 23
To Wheel or not to Wheel, that is the Question?
by Ellen Riddle - page 23 to 24

Contact Information - page 24

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Editorial by Hilary Hallam

As I return to the UK after an unexpected extended stay in Florida due to the delay in the work on my house I reflect on the *difference* between America and the UK in relation to the problems Polio Survivors are experiencing with the late effects. Obviously America is a huge country and facilities differ not only from State to State but also county to county so the comments are general.

In the UK we have a free National Health Service although we pay for this in advance in our taxes. We can go and see our General Practitioner usually within a few days. We tell them our symptoms and if necessary we are referred to a Consultant. This referral unless its an acute condition, can take months and sometimes over a year. When we get to that appointment we might see the Consultant or his Registrar. We are likely to be referred for tests and it can take weeks, sometimes a few months for the report to be done and sent back to the Consultant. Often a return appointment will not be sent till these results are to hand. If we need an operation or treatment then again we go on a waiting list. It is free but its very long and drawn out and stressful waiting and wondering what is wrong with you. For many of us there have then been further referrals to other Consultants. For some of us to get to an answer has taken 5, 10, 15 and more years from first reporting symptoms to finding out that the polio of our childhood needed to be taken into consideration.

In America, as you travel along some areas of largish towns you see sign after sign for health professionals (and attorneys). You need a doctor and pick up the local Yellow Pages and find that doctors and therapists are further broken down into which part of the body that they deal with. You ring for an appointment and you can be seen usually within a couple of weeks providing they will accept your insurance plan. Medicare, Medicaid, HMO's, Blue Cross there are so many plans, so many terms, so many rules and conditions that even the medical administrators you meet say they have difficulty understanding it all. Employers often offer insurance plans but mostly these stop when you leave or retire. Who you can see and for how long relates directly to what you are able to afford in Insurance. Health professionals can decide which plans they will accept. A large local primary care surgery we rang explained that with no exception you pay them and then reclaim from your insurance plan and they did not accept Medicare which is the Social Security and Retirement Insurance Program. Medicare has set fees that they will pay for each procedure and they pay 80% of that figure. You have to find the 20% or beg who you want to see to accept the 80% as full payment. Often the amount they award for a procedure or item of medical equipment does not cover the cost so its no wonder that some health professionals will not accept it. E.g, Medicare will only pay about \$39 towards that cost of shoes and they only pay for the shoe that fits the brace.

There are some excellent multidisciplinary PPS Clinics, specialists and therapists in most States. However there is still the problem that because the condition is most often not taught at medical schools that many health professionals are unaware of its existence, or 'its not my field'. We receive between six and fifteen requests for help from the States each week from Polio Survivors who have just found the condition exists on the Internet. Most report that the doctors they have seen have not heard of the condition or know little about it and are requesting information on who they can be referred to. So the *difference* for many is the same, it all depends on whether there is a polio and PPS knowledgeable facility near to where you live and can you afford to go there.

We complain about the NHS (and often with justification where chronic neurological conditions are concerned) but we can usually register with our nearest surgery, we don't have to check if they will accept our insurance plan. When we are ill we don't have to decide eat or see the doctor. Each prescription item costs the same, we don't have to ask it's cost to see if we can afford it before we get it filled. Our main problem is 'will we still be alive by the time we get to see a Consultant who is knowledgeable about polio and its late effects'.

Survey. Janice Eary would be grateful for return of these as soon as possible and thanks the now 45+ of you who have returned them. (American and Canadian members will have a copy of the survey with this issue). As I have said in nearly every issue of the newsletter, we need to hear from you, your stories, hints and tips, ideas for future issues. The newsletter is made up from items sent to me and of information that I feel from my daily contact with polio survivors, support group leaders and PPS specialists, that might be helpful to you in trying to manage your symptoms effectively. No two polio survivors are the same, but I often get a phone call or email telling me that something in our newsletter has been tried to great effect. Pen and Phone Pals - Members in your Area. Again I ask if you would like to be put in touch with members who live near to you then please contact Wendy not only to request this **but also to give permission for your details to be passed on.** We cannot divulge information without your permission. Those who have attended our AGM's will agree that meeting other polio survivors and their families and being able to share stories has not only been very helpful but produced lots of rib aching laughter and there is no better medicine than laughter to relieve the stress of PPS.

TRILLIUM

*Trillium
trillium
my hope is in thee
Easter Lily of my
childhood free*

*Never gathered in
glens of green
but plucked in the
"Little Woods" unseen
(from tangled
density I mean)*

*Near my home
where hearts once bled
and Bleeding Hearts
from mossy bed
to maturity grew
instead*

*I gathered you
on Easter Day
remember how we
used to say*

*Three
pure white petals
I could see
an uncorrupted
trinity*

*Beauty,
transient as life
a half-century ago
the years and the
trilliums
where did they go?*

by LaVonne Schoneman Copyright (c) 1991 <Vonnejo@aol.com>

This Easter Poem was written by Polio Survivor LaVonne Shoneman in 1991 after a long illness and in gratitude for being alive and well. LaVonne has won many competitions with her poetry and I hope you enjoy this one that I selected from the choices she offered for this time of the year.

Member Dr. Henry Carter.

I am sorry to inform you that my father, Dr Henry Carter, died on 3rd February. He had been unwell for some time and, following two operations, died peacefully with his family around him. Simon Carter.

Our condolences to Mrs. Carter, Simon and family.

Retirement In A Trailer Park Thru The Eyes of a Child

After a spring break, a teacher asked her young pupils how they spent the holidays. One child wrote the following:

"We always used to spend the holidays with Grandma and Grandpa. They used to live here in a big brick house, but Grandpa got retarded and they moved to Arizona. Now they live in a place with a lot of other retarded people. They live in a tin box and have rocks painted green to look like grass. They ride around on big tricycles and wear name tags because they don't know who they are anymore.

They go to a building called a wrecked center, but they must have got it fixed, because it is all right now. They play games and do exercises there, but they don't do them very well. There is a swimming pool too, but they all jump up and down in it with their hats on. I guess they don't know how to swim.

At their gate, there is a doll house with a little old man sitting in it. He watches all day so nobody can escape. Sometimes they sneak out. Then they go cruising in their golf carts. My Grandma used to bake cookies and stuff, but I guess she forgot how. Nobody there cooks, they just eat out. And they eat the same thing every night, 'Early Birds'. Some of the people can't get past the man in the doll house to go out. So the ones who do get out bring food back to the wrecked center and call it pot luck.

My Grandma says Grandpa's worked all his life to earn his retardment and says I should work hard so I can be retarded some day too. When I earn my retardment I want to be the man in the doll house, then I will let people out so they can visit their grandchildren.

Author Unknown.

THE LATE EFFECTS OF ME

Can they be distinguished from the Post-polio syndrome?

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<http://www.ott.zynet.co.uk/polio/lincolnshire/library/dowsett/lateeffectsmeme.html>

INTRODUCTION:

Few people would dispute that ME (Myalgic encephalomyelitis), an illness which blights the hopes and aspirations of all sufferers, especially the young, is denied equal treatment in respect of diagnostic facilities, medical coverage and welfare provision. Comparable chronic and unpredictably disabling neurological conditions, for example Multiple Sclerosis, which was formerly ascribed to "hysteria" and similarly neglected, now receive government recognition, facilities within the NHS, and more generous research funding - though the potential cost of effective treatment can still arouse bitter debate.

WHAT IS ME?[1,2,3]

a. ONSET:

It is a syndrome (a group of linked symptoms) initiated by one or more of a related group of enteroviruses which circulate annually in the community in summer and autumn in temperate climates, but all the year round in tropical areas.

b. MINOR ILLNESS:

The majority of encounters with these viruses are asymptomatic but some subjects, more commonly teenagers and adults, suffer a seemingly trivial minor illness, usually described as a non specific summer 'flu accompanied by gastrointestinal upset, sore throat and occasionally by generalised glandular enlargement.

c. SECONDARY PHASE:

The minor illness is self limiting in 90% of adults. However, some 5-10% of all age groups exposed, may progress to a more significant episode with severe headaches and vertigo, a stiff neck and back and generalised muscle pain, signifying that the central nervous system has now become involved with a possible progression to viral meningitis and encephalitis[3]. Clinical recovery at this stage is normally possible, but does not preclude further effects of the illness in later years. It has to be remembered that ME is a life-long disability where relapse is always possible.

d. FINAL STAGE[1,2]:

After a variable interval, a multi-system syndrome may develop, involving permanent damage to skeletal or cardiac muscle and to other "end organs" such as the liver, pancreas, endocrine glands and lymphoid tissues, signifying the further development of a lengthy chronic, mainly neurological condition with evidence of metabolic dysfunction in the brain stem. Yet, stabilisation, albeit at a low level, can still be achieved by appropriate management and support. The death rate of 10% occurs almost entirely from end-organ damage within this group (mainly from cardiac or pancreatic failure). It has to be said that suicide in younger patients and in earlier stages of the disability is related to the current climate of disbelief, rejection of welfare support and loss of educational and employment prospects. It is an additional and potentially avoidable factor.

WHAT ARE THE LATE EFFECTS OF ME?

Most doctors with substantial experience of examining these patients would agree that the outlook for any individual is unpredictable. Case records need to be kept up to date for prolonged periods because patients who have remained clinically stable over 40 years or more and have worked normally for most of their lives are still subject to significant late effects. These include: overwhelming fatigue both physical and mental; cognitive

disturbances; muscular and joint pain; muscular weakness and wasting; difficulty with breathing; episodes of hypothermia and low blood pressure; problems with swallowing and voice production as well as sudden attacks of breathlessness while sleeping. The similarities of these symptoms to those complained of by sufferers from the Post-polio syndrome, is striking and requires further explanation.

WHICH GROUP OF ME SUFFERERS ARE CHIEFLY AT RISK OF THE LATE EFFECTS?[4]

The majority of ME patients contract their illness in the 3rd and 4th decade (50%) with secondary peak at puberty (18%). The incidence at the extremes of age (below 10 years and above 50 years) has, until recently, been low (about 10% in each group). Epidemiological surveys made between 1988 and 1998, in 2 Essex hospital clinics dedicated to ME, indicate that the percentage of patients over 50 years of age attending with new illness has risen from 6% in 1988 to 16% in 1995 and 18% in 1998. Some patients indeed, present with paralysis. Others have a vague past history of illness in childhood. Some years of "weakness" or "growing pains"; recovery, but always poor at sport; possibly a stable work record for 25 years or more, followed by a decline in walking ability; unusual fatigue after simple tasks; problems with climbing stairs, dressing and with short term memory. The current age range of these patients is from 40-92 years, so it is not easy to dismiss their symptoms as due solely to "ageing". Their social and medical problems are especially severe, as they share all the difficulties of access to remedial and support services complained of by other disabled people in the same age group. However, in the UK, there is almost nowhere to refer patients with suspected post-polio symptoms as the medical profession has largely forgotten or never experienced the many manifestations of that disease. Successful immunisation against only 3 polio viruses among some 69 enteroviruses currently in circulation is deemed to have solved all problems!

WHAT IS THE POST-POLIO SYNDROME?[5,6,7]

Poliomyelitis is an acute enteroviral infection with a wide range of clinical manifestations and multi-organ involvement (a fact which was frequently overlooked by physicians dealing with large numbers of dangerously paralysed patients, between 1940 and 1950). 95% of people who contract the infection remain symptom free or suffer only a trivial non-specific respiratory or gastrointestinal illness as in ME.

Some 5% of those contracting the minor illness develop muscle weakness or paralysis before more serious or fatal complications supervene. The diagnostic distinction between "paralytic" and "non-paralytic polio" was entirely arbitrary in the days of the big epidemics. In fact, the category of "non-paralytic polio" contained many patients with mild or temporary paralysis and with encephalitis, which occurs in patients reaching the later stages of this illness. Modern studies indicate that overt paralysis in these patients depends entirely on the percentage of spinal nerve cells destroyed. For damage to be visible as weakness or paralysis at least 50%-60% of the nerves controlling muscular action must be damaged or destroyed. Thus, patients with less damage who may only have had a minor illness, and some who were asymptomatic can still present many years later with a classic Post-polio syndrome.

Recent publication[6,8] of this information (originally derived from studies made in 1955) has resulted in a re-definition of the post-polio syndrome and will certainly include many patients currently seen in ME clinics.

SUGGESTED NEW CRITERIA FOR THE DIAGNOSIS AND ASSESSMENT OF THE POST-POLIO SYNDROME[7].

- a. A history of remote paralytic or non-paralytic polio, or findings on history, physical examination or laboratory and other technical studies compatible with damage to the central nervous system in earlier life.
- b. A period of recovery.
- c. A period of stable functioning for 10-50 years.
- d. New symptoms for which no other explanation can be found.

Many patients and research workers point out that the assessment of sufferers will now have to become more holistic, that standard electrical tests of muscle function (EMG) will have to be more widespread (and repeated), and that manual muscle testing must refer to repetitive activity and daily tasks rather than a single examination on the couch[16].

IS IT POSSIBLE THAT MANY PATIENTS DIAGNOSED AS HAVING ME ARE SUFFERERS FROM AN ILLNESS CLINICALLY IDENTICAL TO "NON-PARALYTIC" POLIO?[6,8]

Yes, undoubtedly! This is an important question with fundamental implications for further research into the diagnosis, treatment and prevention of both disabilities.

Modern research published currently in a dedicated supplement of the American Journal of Physical and Medical Rehabilitation by the Editor and 3 leading research teams[6,8], indicates that part of the current difficulty in obtaining a clear diagnosis of the post-polio syndrome lies in the error of dividing acute poliomyelitis into "paralytic", "non-paralytic", "abortive" and "sub clinical" categories. It has to be recognised that there is a wide range of nerve damage in every patient. The Post-polio syndrome may therefore include:

- a. Patients whose nervous system damage was not clinically obvious at the time of diagnosis.
- b. Those who had minimal paralysis for a short period and were misdiagnosed as non-paralytic polio.
- c. Those patients suffering from infection due to non polio enteroviruses with potential to cause nervous system damage and the "Post polio" syndrome, equal to that of polio viruses e.g. Coxsackie viruses A9, A7; Coxsackie B viruses 1-6; ECHO virus 9; Enteroviruses 70, 71 - all of which have been implicated in outbreaks of ME or epidemics clinically identical to paralytic poliomyelitis.
- d. Patients with symptoms clinically identical to the Post-polio syndrome whose nerve damage arises from some other cause, for example, local muscle problems due to metabolic dysfunction, the effects of persistent virus infection, immune reaction to fragments of viral genetic material etc.

It is essential that patients with clinical symptoms suggestive of Post-polio syndrome should be referred to a Physician to exclude other nervous diseases (e.g., Motor Neurone Disease), and especially those which are treatable.

IS IT NECESSARY TO DIFFERENTIATE BETWEEN THE LATE EFFECTS OF ME AND THE POST-POLIO SYNDROME?[8,9,10]

Not really, even if it were useful or practicable to do so at present, as the two conditions are clinically identical and similar in respect of neuroanatomical, neuroendocrine, neuropsychological electroencephalographic and other techniques, including brain imaging and molecular biology, as indicated by a remarkable series of research papers published by Bruno and colleagues over the past 20 years.

WHAT IS THE EVIDENCE THAT THE LATE EFFECTS OF ME AND THE POST-POLIO SYNDROME CAN BE CAUSED BY ENTEROVIRUSES OTHER THAN POLIO VIRUSES 1-3?

- a. [11] In 1948, the year in which polio viruses were first cultured, specimens from 2 children with clinical poliomyelitis, yielded a non-polio enterovirus, (eponymously called Coxsackie after the neighbourhood in which they lived). This finding opened a Pandora's box of some 70 previously undiscovered enteroviruses of which 14 strains were later found to have neurogenic potential equal to that of polio viruses.
- b. [12] From the late 1940s, studies in the USA indicated that outbreaks of major or minor enteroviral illness (e.g. Paralytic or non-paralytic and non specific "summer 'flu") could be caused by varying proportions of virulent and non virulent polio viruses combined with other neurogenic enteroviruses, for example in Akron and Cincinnati [Table 1], Ohio (1947) Delaware and Connecticut (1949).
- c. [13] In the UK, an outbreak of poliomyelitis affecting an Edinburgh housing estate from August 1961-February 1962 (a period when polio immunisation with the Salk (injectable) vaccine had recently been introduced) provided evidence that a "mosaic" of enteroviruses, including Polio type 3, Coxsackie viruses B2 and B4, Echo viruses 5 and 15 could act in combination to enhance virulence in individual patients, to block the spread of polio virus type 3

and to interfere with vaccine efficiency. Each virus type appeared sequentially until the arrival of Echo virus 5 in November which ended the outbreak by the following February (as indicated by serial sampling of the local school sewer). It has to be remembered that a sudden change in the virulence and spread of enteroviruses in the 20th century has been due to alterations in human hygienic behaviour rather than to viral mutations.

**TABLE 1. 1947 OUTBREAK OF SUMMER 'FLU, CINCINNATI, USA [12]
HOW MAY SYMPTOMS OF THE LATE EFFECTS OF ME AND POLIO BE EXPLAINED?[9,10]**

It has to be accepted that some degree of encephalitis has occurred in all these cases and that the areas chiefly affected include the upper spinal motor and sensory nerve roots and the spinal nerve networks traversing the adjacent brain stem (a nerve centre controlling all vital bodily functions which is always damaged). The most troublesome symptoms of both conditions are progressive muscle weakness, fatigue and pain, and the commonest cause of relapse over use of repaired nerve networks and an inappropriate response to physical or mental stress in combination with the increasing effect of normal aging.

FATIGUE:

This is almost always central and due to damage affecting the Reticular activating system (which keeps the brain awake and alert as well as maintaining some control over muscular activity). Fatigue is characteristically intermittent, but profound and incapacitating and related even to minor activity.

[14]MUSCLE WEAKNESS AND WASTING:

This may have a central cause (as above) or a local origin due to loss of motor units controlling individual muscles

DIAGNOSIS	CASE No	CSF Cell Count	Virulence of Polio Virus	3 Laboratory Tests for Coxsackie Virus (Non Polio Enterovirus)			Summary of Laboratory Findings.
Summer Flu	1	0	Polio HV	-	-	-	High virulence polio virus only
Summer Flu	2	40*	Non paralytic polio LV	-	-	-	Low virulence polio virus and infection of CSF
Summer Flu	3	3	“	+	+	+	Low virulence polio virus & coxsackie virus
Summer Flu	4	150*	“	+	+	+	Infection of CSF & low virulence polio virus & Coxsackie virus
Non Paralytic Polio	5	734*	Polio HV	-	-	-	Only high virulence polio virus & infections of CSF
Non Paralytic Polio	6	27	Polio HV	-	-	-	Only high virulence polio virus
Non Paralytic Polio	7	70*	-	-	-	-	Only Coxsackie virus & infection of CSF
Paralytic polio	8	107*	Polio HV	-	-	-	Only high virulence polio virus and infection of CSF

KEY * Raised cell count in cerebro-spinal fluid indicates infection in the central nervous system
 Polio HV - Polio type one, virulent.
 Polio LV - Possibly polio type two, low virulence (non paralytic)
 Coxsackie is a neurovirulent, non polio enterovirus

(including the breakdown of repair to these over time). Metabolic, immune or ongoing viral injury to muscle fibres, are other possibilities where infection persists.

PAIN:

This is a severe symptom which is difficult to treat and is usually due to dysfunction of the thalamus, an important sensory relay station in the brain stem. Failure to produce natural painkillers (e.g. endorphins and enkephalins), may be an additional factor.

INAPPROPRIATE REACTION TO PHYSICAL OR MENTAL STRESS:

This also arises from injury to the brain stem which normally controls the production of cortisol (a steroid required for stress control) via the hypothalamus, pituitary and adrenal glands. In the absence of an efficient response, even minor stress can cause catastrophic collapse in these patients. NB. Because of the many and varied symptoms arising from encephalitic damage to the brain, all symptoms reported, however bizarre they may seem, must be taken as possible evidence of organic disease.

MANAGEMENT:

Despite promising reports from the USA of anti-enteroviral agents[18], and of Dopamine receptor agonists[9] (to correct some deficiencies in neurotransmission) no specific medical treatment is yet available in the UK and the main principles of management rely upon conservation of energy, reduction of stress, and simplification of manual tasks at home or at work. These objectives cannot possibly be achieved without financial and social support, aids to mobility, house conversions and suitable rehabilitation facilities. In the USA it is claimed that (with counselling, if necessary, for those who find such adjustments to life style difficult) 91% of patients will stabilise in view of the fact that, at this stage, the disability is only slowly progressive. Patients have to be cautious about drugs, especially those acting on the central nervous system including psycho-active preparations and alcohol. In general, these patients need less anaesthetic but higher doses of pain killers than usual and more time to convalesce from surgery. There are now many new options for muscle problems including modern orthoses and corrective surgery.

COMMENT.[15]

a. There has been little government interest or support for patients suffering from the late effects of ME or from the post-polio syndrome. It is generally expected that survivors of polio will gradually disappear because of successful immunisation of the UK population 40 years ago. However the fact that "Post-polio", by any other name, can arise from currently circulating enteroviruses has not been taken into account. The Chief Medical Officer's Working Party on ME (set up in 1999 and funded privately by the Linbury Trust) has made it clear that its remit is only with management, and that all discussion about the cause, epidemiology and social benefit requirements of these patients is ruled out. It seems that it will be difficult to advise on rational management in the absence of such vital information.

b. The potential size and cost of the problem. This is impossible to assess in the UK because no official epidemiological surveys have been made. However, increasing numbers of patient support groups and individual research workers have been making their own calculations. In the case of ME, prevalence appears to range from 300/100,000 to 500/100,000 in occupations at high risk of infection[2], but no information is yet available about the number likely to suffer late effects (except that it may have trebled in the last 10 years)[4].

The number likely to be affected by the post-polio syndrome has been calculated as between 200-270/100,000 currently[7], but no account has been taken of survivors from non-paralytic polio which could easily double that figure. Possible costing for ME support has been based on 3 times the cost of maintenance for multiple sclerosis on the supposition that ME is 3 times as common[4]. The only costs that we can be sure of are those derived from the failure of appropriate management, and of inappropriate assessments which waste vast sums of money and medical time while allowing patients to deteriorate unnecessarily.[16]

c. Some Immediate Steps that Could Be Taken[7,17,18,19,20]. These patients could be referred to NHS rehabilitation clinics and welfare facilities as for any other chronic neurological disease but physiotherapy must include exercise suitable for patients with some damaged muscle fibres

which have been overused while others are normal and liable to deconditioning[7]. Separate "ME" and "Post-polio Clinics" are more expensive and often inaccessible. We should be educating doctors and paramedics now about the very common and seriously disabling effects of neglect[7]. Rapid diagnostic tests for enteroviruses, anti-enteroviral drugs and possible vaccines are already in preparation here, or in use (in the USA) to deal with the tremendous burden of circulating enteroviral infections, (for example, leading to febrile respiratory infections, viral meningitis and myocarditis, let alone unnecessary admissions to hospital and inappropriate prescription of antibiotics in children)[17,18]. These methods could well be employed for the benefit of young people in the UK and to prevent the rising tide of ME in schools - the commonest cause of long term absence and subsequent educational deficit![19,20]

d. Research workers must be encouraged and appropriately funded to work in this field. However they should first be directed to papers published before 1988, the time at which all specialised experience about poliomyelitis and associated infections seem to have vanished mysteriously! [11,12,13]

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The WHO and who?

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Reading the claims by the World Health Organization makes me very nervous. Who is going to help them? There is an incredible volume of work entailed in ensuring the planet is polio free by the year 2000.

People inundate me with URL's advising that polio is going to be eradicated by the year 2002. I receive gleeful e-mails rejoicing at the fact that South Africa, Africa, India and in fact the whole world is going to be free from polio by that incredible year 2002.

Lets look at some facts. You never hear the wild life societies or game reserve officials telling you that they're going to eradicate TB in buffalo or any such comment relating to an animal, because they know the hard work involved in tagging the affected lions, buffalo or whichever animal it is. These animals are monitored consistently. Records are kept and the health and the progress of these animals are scrupulously, studied and kept on file.

To successfully eradicate polio in a third world country at all let alone by the year 2002 you would have to do the following:-

- ❖ Eradicate poverty.
- ❖ Continually educate parents regarding the need for polio vaccinations and ensure that the rural areas are reached.
- ❖ Plan a successful and ongoing education campaign for the illiterate.
- ❖ Do an aerial view photograph of all the areas where you intend doing inoculations.

<p>My face in the mirror, Isn't wrinkled or drawn, My house isn't dirty, The cobwebs are gone. My garden looks lovely, And so does my lawn, I think I might never Put my glasses back on.</p> <p>Sent by Jo Kelly <kelly10@aol.com>. While making rounds, a doctor points out an X-ray</p>	<p>to a group of medical students.</p> <p>"As you can see," she says, "the patient limps because of lost muscles due to Polio. His left fibula and tibia are radically arched. Michael, what would you do in a case like this?"</p> <p>"Well," ponders the student, "I suppose I'd limp too."</p> <p>Sent by Marsha in Texas <marsha@CCMS.NET></p>
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- ❖ Visit each home indicated in the aerial photograph and go to the village and note each child living in these homes.
- ❖ Confirm whether or not any of the children are HIV positive and/or have full-blown Aids.
- ❖ Check also for children suffering from malnutrition.
- ❖ Check constantly for missing homes as a result of ethnic fighting or war.
- ❖ Check constantly for new homes that have been built in the various villages in order that the children from these homes can be added to the existing aerial photograph of the village.
- ❖ Confirm whether or not there are any new cases amongst the children in the villages of HIV/Aids: Due to the constant raping of women and children this is a very real problem.
- ❖ You cannot possibly inoculate any children who are HIV positive and/or have full blown Aids. The manufacturers of the vaccine specify that you do not inoculate anyone with immune systems problems.
- ❖ All immune system diseases in children, including malnutrition, are not the conditions under which Albert Sabin would ever have done a clinical trial let alone give carte blanche approval for the “live” vaccination to be done on such children. If you go ahead and vaccinate any child who has an immune system problem or suffers from malnutrition you are guilty of putting this child at risk of becoming a polio victim.
- ❖ You would have to note the record cards of each child, i.e. their first vaccination, second, third, etc. In South Africa a newborn baby receives a “live” polio drop within the first 24 hours of its life. (This is not possible currently if, due to economics, a child is born in a hut in a rural area.)
- ❖ The fact that South Africa “appears” not to have polio cases is because the Ministry of Health cannot give you records from as far back as 1989. I, among others, have sought true figures on numerous occasions.
- ❖ The residents of the various villages need to know in advance that you are going to be entering their villages, towns, etc. to avoid suspicion and superstition.
- ❖ Take staff with you who know the chiefs of the various villages in the rural area and educate them on keeping records of who has been vaccinated, needs to be vaccinated and who has been raped and/or who is suspected of being HIV positive or having full blown Aids.
- ❖ Make your records open to the public to ensure that proper information is available to all interested members of the public and the government responsible for health records.
- ❖ Always inform parents that their children are being vaccinated with the ‘live’ virus so that they can be constantly aware when changing nappies or finding sores, and, if they themselves have open wounds on their hands are provided with the means to be protected from the exposure of the ‘live’ virus which can be found in the faeces.
- ❖ Be cautious before inoculating a child: Be responsible enough to bear in mind that because the ‘live’ virus is the only cost-effective way to inoculate the masses, and that a child with an open wound could effectively become another polio statistic.
- ❖ Do not ever overlook the health of the children and final eradication of polio in a quest to be able to show the world that polio has been eradicated.
- ❖ Every single person living in an area where new and dangerous strains of Tuberculosis and Malaria have surfaced, and, where Aids is wiping out whole generations, are only too aware that the false impression of the eradication of polio will end up being equally as dangerous as the aforementioned new strains of old diseases and/or viruses.

The ‘live’ vaccine is still used in England, South Africa and other third world countries because it is more cost effective. Israel currently uses both forms of the virus. American legislation has been passed to rule out the use of the ‘live’ virus. There are those who still care about adhering to the manufacturer’s instructions when vaccinating children against polio and of course there are those who don’t.

We South Africans live in a country where incidences of polio are no longer recorded and neither is the Health Department enforcing the fact that it is a notifiable disease. If this country cannot afford the required HIV/Aids treatment, how can we possibly expect polio and the eradication of same to be treated any differently?

The stark reality is that there is no money for the correct vaccine procedures.

Recently I was approached by a Namibian publishing house to assist them as they had been contracted to print a booklet, at the request of the Namibian government on infectious diseases, and, when the representative from the publishing house took the book for verification and final approval the health department instructed them to remove the section on polio because the World Health Organization had

advised that polio had been eradicated from the face of the earth. False information can ruin the lives of innocent people.

Whether or not people fail to vaccinate under the correct conditions and/or circumstances is of vital importance to the inhabitants of the planet. In fact, unless the rules of and problems of using the 'live' virus correctly are strictly adhered we have no hope whatsoever of ever eradicating polio from the face of the earth.

Don't be taken in by propaganda. Read up on polio and become an informed parent, teacher, nurse, doctor or counsellor. It is to this end that I am humbled to share with you the following true story sent to me by a South African living in England. This family is a victim of the ignorance and lack of control of the 'live' vaccine.

"I am a South African who with my English wife and three young children moved to the United Kingdom in July 1997. In November 1997 our fourth child was born in the UK. He was well and healthy and all was fine. He was breastfed. Shortly after his birth he developed a perennial abscess on his left buttock. This cleared after a few days and then he developed a second abscess on his right buttock. At 8 weeks he was taken for his vaccinations and the abscess was shown to the health visitor, the nurse who was to do the vaccines and then she called a doctor. He looked at the abscess, squeezed it and took a swab for analysis and prescribed an antibiotic. We were told, when questioning if the vaccines should be given, that it would be fine as the abscess was one end and the vaccines were the other. Four days later the abscess had become so enlarged and uncomfortable that it was decided to lance it and drain it. The wound was then packed as best as it could be but each time he had a bowel movement the wound was filled with his stools.

A week later he developed a high fever and became irritable. He was diagnosed as having possible meningitis and hospitalized. Two days later the paralysis set in and all movement was lost. His breathing was maintained although it was very weak. His sucking was also only just maintained.

Even his voice was lost.

It is now two years later and he remains severely paralyzed. He cannot sit up and can only grip with his right hand. His shoulder muscles are very weak and he has very little and erratic movement in his right leg. His head control is good and he is a very bright little chap but physically he is severely handicapped. He has a special seating chair and a prone standing frame to enable him to be stood upright to assist in his bodily functions.

I hope our story will help prevent other children from having their lives affected by the vaccine.

The big questions are why did they not know this would happen and why was the vaccine not postponed? Why is the live virus used when the dead one is proven to be just as effective.?"

In third world countries like South Africa the 'live' virus is cheaper which enables more people to be reached and vaccinated. You cannot possibly ignore the economics of using Sabin's vaccine: Neither can you ignore the necessity to use it wisely and properly.

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NEWSBITES - a service on our WebSite of Polio Related News Items from around the World. Here is just **one** of the recent entries. Subscribe to What's New Updates to receive email notification.

©NEW YORK TIMES ON THE WEB - MARCH 29th 2001 Filed at 4.00p.m. Eastern Time.

WHO says Polio Strain Eradicated.

##ATLANTA (AP) -- One of three strains of polio has apparently been wiped out -- a milestone in the global effort to eradicate the paralyzing disease.

The World Health Organization said Thursday that the global network of laboratories that tracks the disease reported no new cases of Type 2 polio in 2000. The last recorded cases were in India in 1999.

The Americas were declared polio-free in 1994, and the disease has been eliminated in Europe. Still, more than 2,800 cases were confirmed last year in Southeast Asia, Africa and the Mediterranean, where war, poverty and other problems have hurt efforts to vaccinate children.

**Continuing report on
Florida East Coast Post-Polio Support Group
Late Effects of Polio - Overview 2000
December 8th - 10th 2000
Daytona Beach, Florida.**

**The Family Culture and
Relationship with Disability.
by Margaret Backman, PhD. Clinical Psychologist.**

Family members have fears and frustrations.

- They cannot change the situation.
- They are seeing the other doing too much being in pain.
- They can't do what they would like to be doing themselves.
- They are also experiencing the losses; what we used to do together and loss of control.

We, the person with the disabilities are

- Afraid of what the future holds
- Afraid physically that our needs will place such demands on family and friends that they will grow weary and resentful and withdraw. We will be a burden.
- We fear being judged by our appearance.

How family members are sometimes experienced;

- Overprotective
- Taking over (helping us too much)
- Paternalistic (Too much empathy)
- Avoid talking about issues
- Ignore
- Forget
- Anger

Message to the Other.

Person with Disability.	Family Member
When I say I am tired I mean it, Do not over estimate what I can do.	Consider me too.
Co-operate when I need something, sometimes I need to put myself first.	When you can see that I am busy, give me time to finish what I am doing.
Complement me once in a while.	Thank me once in a while.

**Significant Others
Getting a Balance in your Life.**

1. Plan for possible changes. Confront fears

2. and develop a 'just in case' attitude.
2. Be flexible and adaptable. Find new interests compatible with your new life style as needed.
3. Take time for yourself.
4. Have outside interests.
5. Develop a support network for socialising and for having more help.
6. Communicate - talk to each other.
7. Do what you can to 'stay healthy physically and mentally'.
8. Consider counselling or psychotherapy to help you.
 - come to a comfortable stage of acceptance.
 - integrate new and changing roles.
 - improve communication, i.e. learn how to express feels and needs.
 - reduce chaos in the family or with friends
 - learn how to deal with others' fears and personalities and needs.

**Margaret E. Backman PhD.
Columbia University and
New York University Medical Centre
has written a book called:**

**The Psychology of the Physically Ill Patient.
A Clinician's Guide.**

published by Plenum Publishing Corporation.
Priced at \$59.00 at the time of the Conference.

Mental health professionals are becoming increasingly involved with medically ill patients, particularly in helping patients to cope with the psychological repercussions of severe chronic illness. 'The pendulum has begun to swing.. to the interrelationship of body and mind,' says author Margaret Backman. 'Quality of life is again becoming a critical consideration to treatment'.

Drawing on her own clinical experiences as well as studies of psychological factors in medical illness, Bachman examines the psychological and social worlds of physical ill patients. She discusses understanding the physically ill patient, therapy, practical, and philosophical considerations of the therapist, empirical and theoretical approaches to psychological interventions, and case studies of patients with specific illnesses. Useful as a reference or resource book for the independent practitioners as well as institutions.

**Stress Management
for the Mind, Body and Spirit:
the SHARED method
reprinted slightly modified with permission
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What is Stress?

Demands on the mind, body and spirit are greater than you can cope with. You might feel overwhelmed, exhausted, confused, depressed, irritable, and like giving up. Previous coping mechanisms might no longer be working. You might turn to things that are mentally, physically, and spiritually unhealthy for you. You have lost your ability to comfort yourself.

Some stress signals are:-

- Irritation
- Frustration
- Hostility
- Restlessness
- Sleep problems
- Lack of concentration
- Emotional outbursts
- Aggressive behavior
- Biting nails
- Clenching jaw
- Grinding teeth
- Back Pain
- Stomach problems
- Muscles aches
- Change in sexual functioning.

and Physical Symptoms

- Ulcers,
- Irritable bowel syndrome
- Migraine Headaches
- Asthma
- Allergies
- Skin disorders (excema, acne, psoriasis)
- Poor immune system.

Stress Management: the SHARED Method.

SHARED is an acronym that provides an easy way for us to remember some of the major areas of our lives which can be used to promote good health and stress management. It stands for Sleep, Humour, Affirmations, Recreation and Relaxation, Exercise and Diet. Note the many different ways you can bring stress relief, peace and harmony into your life and ask yourself.: Have I 'SHARED' LATELY?????

SLEEP

Many people are sleep deprived without even knowing it. Everyone has a different sleep requirement, the average being seven to eight hours per night. If you feel chronically stressed or fatigued, you may not be getting enough sleep.

If you have difficulty sleeping, here are some tips:

- 1 Go to bed at the same time every night.
- 2 Don't do anything else in bed but sleep so your body gets conditioned.
- 3 Have a relaxing routine, e.g. read a little or have a soothing drink, that you go through each night before going to bed.
- 4 Listen to a calming relaxation tape 15 to 30 minutes before your bedtime.
- 5 Do something energetic in the early evening to help you feel more tired by bedtime.
- 6 Take a warm bath shortly before going to bed to relax yourself.

HUMOR

There's nothing quite like a good belly laugh to get you going sometimes. Humor is a great stress reliever mentally because it helps us to cope, gives us a sense of control, and helps us to keep a balanced perspective. One of the most compassionate things we can do for ourselves is to take our imperfections less seriously by finding humor in the situation. Some doctors believe that laughter also has the physical benefits of giving your cardiovascular and respiratory systems a healthy little workout.

Unfortunately, not all of us can laugh at just any situation. Embarrassment, anger, worry, pain and fear of rejection are all emotions that can limit humorous thoughts and feelings. Just remember that wherever you are, whatever you are doing, it is *always* okay to be good to yourself. You may not be able to laugh out loud right away, but you can certainly save up some inner smiles for future use. Finding some sparks of humor in the most desperate of times can sometimes give you the boost you need to make it through. Do be kind to others, as well as yourself. And don't use humor to avoid your other emotions, but rather to relieve them.

AFFIRMATIONS/POSITIVE SELF-STATEMENTS.

Whether out loud, or in our thoughts, we all talk to ourselves all the time. We are always commenting on the things that go on in our lives, and believe it or not this has a lot to do with the way we feel about things. Without realizing it, we tend to

'catastrophize', 'awfulize', and 'shoulda, woulda, coulda' ourselves into a very stressed out state of mind. Using positive self-statements is a way to counteract those negative self-statements. Positive self-talk is also a way to build up confidence and boost our spirits when we need it. In the long run, you can really change the way you feel about yourself and help yourself become more assertive and better at achieving your goals.

Take an inventory of your self-statements and try to figure out where the negative ones come from. Next, challenge yourself as to whether they are true or not, or if you might just be being too hard on yourself. Then try to come up with a positive statement that counteracts the negative statement. Positive self-statements should be written in a positive rather than negative way (i.e. I will, rather than I will not) should be written in the present tense, and should have an 'I' statement in there. Try using about three of these every morning when you are facing a difficult task, and see how changing your thoughts can change your feelings.

[Source: The Anxiety and Phobia Workshop

- I respect and believe in myself apart from others' opinions.
- I love and accept myself the way I am.
- I accept the natural ups and downs of life.
- Circumstances are what they are, but I can choose my attitude towards them.
- Life has its challenges and its satisfactions - I enjoy the adventure of life. Every challenge that comes along is an opportunity to learn and grow.
- I am setting the priorities and making time for what is important.]

RECREATION/RELAXATION.

Recreation and relaxation are about adding leisure time to your life. Leisure comes from the Latin word *licere* which means giving 'permission'. Having leisure time is a way of giving ourselves permission to enjoy life. It's very easy to get caught up in our day-to-day tasks of working and doing for other people and forget about our own basic needs. It's important to pay attention to when our bodies and minds need a break. If you're allowed to take breaks during the day, take them. You don't even have to leave your work area. A few minutes of silent reflection and meditation, listening to peaceful music, or pleasure reading can re-energize you and help you make it through the day.

Make times in your week for activities that are

enjoyable to you. Leisure activities can be some form of recreations, socializing, entertainment or hobbies. Relaxation activities like yoga, meditation, aromatherapy and beach walking {or good path rolling in a scenic place} allow you to unwind and let go of the stresses and strains in your life. Creative outlets like music, painting and pottery can give you the chance to express yourself in ways that are very personal and private for you. All of these activities are good for the mind, heart and soul. Check your local recreation centers and community college for classes or workshops in your areas of interests.

EXERCISE

Some of the stress-reducing benefits of exercise include:

- reducing muscle tension
- increasing endorphins or 'pleasure' hormones
- improving circulation and lowering blood pressure
- clearing the mind or worrying thoughts
- providing a balance to our other activities and responsibilities.

Gentle exercise that includes trying to maintain a good range of movement and prevent your joints stiffening and adhesions forming is good for your general health, mind and wellbeing. No two polio survivors are the same and therefore there can be no printed pattern of what you should do. You will need to work with your doctor and a polio and PPS knowledgeable physiotherapist to build a plan that works for you. Repeating and/or sustaining any exercise action should be to your level and should stop before pain or fatigue are reached. Listen to your body and working with your therapist be guided by what it tells you.

DIET

A major anxiety-producer in our diets is caffeine. Most people associate excess caffeine intake with coffee, but other common culprits are also chocolate, cola and tea. These may feel like relaxers but they act more like stimulants in our bodies which makes us want more once they've gotten out of our system. Gradual reduction and/or elimination of caffeinated products can do a world of good for the nervous system by reducing jitteriness and allowing you to sleep better. Try to develop eating habits that are enjoyable to you. General advice for a healthy diet includes eating lots of fresh fruits and vegetables, whole grains, and other high fibre foods. Our bodies can get

bogged down with digesting highly processed foods, junk food and high fat food. If you're a meat lover, you don't have to eliminate it totally but try and stick to the leaner cuts. Make meal times a quiet or social time for you, and allow yourself plenty of time for digestion before moving on to your next activity.

Self-Nurturing Activities.

The following list has been very helpful to many of my clients who suffer from anxiety disorders or depression. By performing at least one or two items from the list every day, or anything else you find pleasurable, you will grow in the important skill of becoming a good parent to yourself. You have nothing to lose but your sense of insecurity and inadequacy - nothing to gain except increased self esteem,

[Source: The Anxiety and Phobia Workshop]

- 1 Take a warm bath.
- 2 Have breakfast in bed
- 3 Take a sauna
- 4 Get a massage
- 5 Buy yourself a rose
- 6 Take a bubble bath
- 7 Go to a pet store and play with the animals
- 8 Walk or wheel on a scenic path in a park
- 9 Visit a zoo
- 10 Have a manicure or pedicure
- 11 Stop and smell some flowers
- 12 Wake up early and watch the sunrise
- 13 Watch the sunset
- 14 Relax with a good book and/or soothing music
- 15 Go rent a funny video
- 16 Play your favorite music and dance to it by yourself (shut your eyes and pretend if you are physically unable to do it)
- 17 Go to bed early
- 18 Sleep outside under the stars
- 19 Take a 'mental health day off' from work
- 20 Fix a special dinner just for yourself and eat by candlelight
- 21 Go for a walk or wheel
- 22 Call a good friend - or several good friends
- 23 Go out to a fine restaurant just with yourself
- 24 Go to the beach
- 25 Take a scenic drive
- 26 Meditate
- 27 Buy new clothes
- 28 Browse in a book or record store for as long as you want
- 29 Buy yourself a cuddly stuffed animal and play with it

- 30 Write yourself a love letter and mail it
- 31 Ask a special person to nurture you (feed, cuddle, and/or read to you)
- 32 Buy yourself something special that you can afford
- 33 Go see a good film or show
- 34 Go to the park and feed the ducks, swing on the swings, and so on
- 35 Visit a museum or another interesting place
- 36 Give yourself more time than you need to accomplish whatever you're doing (let yourself dawdle)
- 37 Work on your favorite puzzle or puzzlebook
- 38 Go into a hot tub or jacuzzi
- 39 Record an affirmation tape
- 40 Write out an ideal scenario concerning a goal, then visualise it
- 41 Read an inspirational book
- 42 Write a letter to an old friend
- 43 Bake or cook something special
- 44 Go window shopping
- 45 Buy a meditation tape
- 46 Listen to a positive, motivational tape
- 47 Write in a special diary about your accomplishments
- 48 Apply fragrant lotion all over your body

How do you handle adversity?

A daughter complained to her father about her life and how things were so hard for her. She did not know how she was going to make it and wanted to give up. She was tired of fighting and struggling. It seemed as one problem was solved a new one arose. Her father, a chef, took her to the kitchen. He filled three pots with water and placed each on a high fire. Soon the pots came to a boil. In one he placed carrots, in the second he placed eggs, and the last he placed ground coffee beans.

He let them sit and boil, without saying a word. The daughter sucked her teeth and impatiently waited, wondering what he was doing. In about twenty minutes he turned off the burners.

He fished the carrots out and placed them in a bowl. He pulled the eggs out and placed them in a bowl. Then he ladled the coffee out and placed it in a bowl. Turning to her he asked, "Darling, what do you see." "Carrots, eggs, and coffee," she replied.

He brought her closer and asked her to feel the carrots. She did and noted that they were soft. He then asked her to take an egg and break it. After pulling off the shell, she observed the hard-boiled egg. Finally, he asked her to sip the coffee. She smiled as she tasted its rich aroma. She humbly asked, "What does it mean Father?"

He explained that each of them had faced the same adversity, boiling water, but each reacted differently.

The carrot went in strong, hard, and unrelenting. But after being subjected to the boiling water, it softened and became weak. The egg had been fragile. Its thin outer shell had protected its liquid interior. But after sitting through the boiling water, its inside became hardened. The ground coffee beans were unique, however. After they were in the boiling water, they had changed the water.

"Which are you," he asked his daughter. "When adversity knocks on your door, how do you respond? Are you a carrot, an egg, or a coffee bean?"

How about you? Are you the carrot that seems hard, but with pain and adversity do you wilt and become soft and lose your strength? Are you the egg, which starts off with a malleable heart? Were you a fluid spirit, but after a death, a break-up, a divorce, or a layoff have you become hardened and stiff. Your shell looks the same, but are you bitter and tough with a stiff spirit and heart? Or are you like the coffee bean? The bean changes the

hot water, the thing that is bringing the pain, to its peak flavor reaches 212 degrees Fahrenheit. When the water gets the hottest, it just tastes better. If you are like the bean, when things are at their worst, you get better and make things better around you.

Are you a carrot, an egg, or a coffee bean?

Tips For Living With Dysphagia by Polio Survivor Ellen Riddle <Lonellen@harborside.com> Lincoln City, Oregon, USA

I am not a doctor or nurse. If you think you may have Dysphagia and haven't had it checked out ask to visit a specialist who can administer the barium swallow test; referred to as a Video Fluoroscopy.

Do you find food going down the wrong pipe more than the rare occasion? After eating do you have a slightly husky voice? Are there times that you have to swallow a number of times just to get one mouthful all the way down? Is swallowing getting to be a worrisome concern for you? Do you find yourself clearing your throat a lot, even when you don't have a cold or cough? Is gargling a problem for you? Is it difficult to create a good wad of spit?

If so then you may have a problem the medical community refers to as Dysphagia. It has various causes. One is neuromuscular conditions, such as Polio and PPS.

The simple explanation of this condition is as follows: when one swallows there is frequently a tiny "pre-swallow". A small bit of food or liquid simply slides on past the back of the tongue just as the person begins to swallow.

In most cases only one in about a hundred of these pre-swallows will end up with the pre-swallow going down the windpipe. This is the case even when the pre-swallow occurs consistently with every swallow.

I found out I had this condition in 1992 when I went to a PPS Clinic in Texas. Among my complaints then was an increase in my problem with swallowing.

I was sent to the speech therapist for a "Fluoroscopy". Once I was seated in a comfortable chair, much like a dentists chair, an x-ray type machine connected to a TV was focused on my head. The therapist came in and feed me spoonfuls of barium-laced foods. This included everything from water to a bit of meat with at least

one sample of every possible texture of food. The result was that I have Dysphagia on both sides of my throat. For me this pre-swallow occurs with every single swallow regardless of the consistency of the food I'm eating.

She explained that this is one of the possible side effects of Bulbar Polio. She went on to explain that I could have had this problem since my first bout with polio, that it could be getting worse with PPS, or it could be relatively new due mainly to PPS.

The important thing was to learn how to live comfortably with this problem, eliminating as much as possible the real dangers of choking and aspiration of liquid and food into the lungs which can present another whole host of problems including pneumonia.

I knew my weak tongue was a culprit here as it's been weak since my original polio. There are just certain ways my tongue can't move. What I never realized is that different jaw and mouth muscles either were or are now also affected. I found out that I don't chew like other folks. I discovered that instead of an up and down chewing (normal) I chew more like a cow does (the therapist's description) with more of a side-to-side motion. I simply don't have the muscles for the normal chew. This adds to the pre-swallow problem.

I have learned some things, which do help to prevent the pre-swallow from ending up in a choke.

1. Take very small bites and drinks. It's still important to chew well, but the longer the food/liquid is in the mouth the more of it can slip past in the pre-swallow.
2. Be sure to avoid tipping your head back when drinking as this actually opens the windpipe more and increases the chance of choking. Using a straw, glass or cup and avoiding drinking out of a can or bottle help this.
3. Tilt your head down slightly towards your neck. This helps close the windpipe.
4. If you are over-tired, emotionally upset or excited try not to eat till you are rested and/or calmed down.

So far I've not had a serious choking incident. Instead I've had some that were embarrassing. I hope to keep it this way, but know that like with other PPS related problems no one really knows what the future may hold for this problem. So, on my own I've added a few more things that I try to do to keep the muscle tone that I do still have in

my neck and jaws and also to apply the "rest and preserve" philosophy to this problem.

5. Do the stretching exercises designed to help prevent wrinkles and sagging of the face and neck.
- 6.. Try to give your neck adequate support and rest. For example:
 - (a). When resting in a recliner or comfy chair make sure to place something behind your neck to give it extra support. I've found the bone shaped pillows work for me.
 - (b). When taking rest breaks lay down whenever possible instead of sitting, making sure your neck and head are as relaxed as can be.
 - (c) If you can get to a massage therapist make sure he/she works gently on your neck and upper back to help these muscles fully relax.
 - (d) If you can't do (c). then get yourself a small massager and use it on your neck muscles.
7. If you are just looking into getting a power chair or scooter talk over your need for neck and head support and include this when ordering.
8. Whenever your head starts feeling "too big" for your neck to hold up or you find yourself leaning your head to one side or the other, or resting it on your hand these are clues that's its time to take a rest.

I have benefited greatly from using your WebSite and hope that the above tips are helpful to you in your quest for answers to your problems. Gentle exercise and massage, pacing and resting and the above have helped me. Please remember that no two polio survivors are identical and that it is important that you are properly assessed and advised by polio and post polio specialists.

Roger Brown from Melbourne Australia tell us his story and following that permission to print his answer to a question about trouble with voice control when singing.

I should first explain that my polio affected my upper left arm - mostly (but not entirely) from the elbow up. Th upper part of the arm has virtually no useful muscle left, The lower forearm is about 75% of normal and my wrist and hand strength and movement are normal.

There was quite a bit or initial concern that there would be some effect on my breathing capability and I imagine that I am in fact quite lucky that that

turned out not to be the case. Part of the concern was that as a young child I was VERY suspect to bronchitis and in that context I was taught intercostal breathing,

I didn't really understand its significance at that time but in my later years as an organist/choir trainer that knowledge became much more useful.

My parents were like many of their generation - anxious for all our family to learn music and I think would always have been evident that I was musical. I can't remember not being able to read music or sight sing. My early piano exam results were however a bit mixed - comments like "candidate is musical but must overcome an undisciplined left hand" were pretty standard. Quite rightly, you don't tell examiners about things like polio and if you did, they couldn't "make allowances". You can either play a musical instrument or you can't - end of story.

But later things went better as I got older and stronger and I studied piano right through my school days. Inevitably there was the Sunday School piano and church organ - the latter an old pedal harmonium - we lived in the country and I never even SAW a real pipe organ until my early 20's when I moved to the city.

When I did get the chance though, I soon found that the organ was a much better instrument for me than the piano simply because the instrument has a pedal keyboard that takes quite a bit of the physical pressure off the left hand. So I found that I was able to get right up to professional standard on the organ. I had lessons with a top teacher and did some good professional diploma exams - I'm very proud of that FTCL (Fellowship of Trinity College London) because of the extra effort involved. And I'm even more pleased because a friend of mine happened to visit the examiner on a trip to the UK (they send an examiner out from England to do these diploma exams) and mentioned my polio. The examiner was apparently quite unaware of anything of the sort and was extremely surprised.

Of course the effort in all this did tell and significant PPS related weakening started to emerge. As I detail in my little WebSite piece, I had to find a way, if I wished to continue playing, to reduce the strain on my arm. This I was able to do with the use of a flail arm splint - a method which had been very successful in allowing me to continue and even to improve some aspects of my playing due to the reduction in physical strain. I put the little webpage piece on my site (after a long period of thinking it better to keep this aspect of

my life fairly much to myself - that has been the way I was brought up) in the hope that maybe it might give someone else some encouragement. You can see more about that on <http://rogerbrown.tripod.com>

Now if you are going to be a church organist you will work with choirs and for many years I have attended summer schools of the Royal School of Church Music here in Australia. I even attended a 6 weeks summer school for overseas students in England years ago - and one of my best memories is playing a service postlude (one of my big showpieces) at Westminster Abbey.

Now you will understand from the above that I have now been a church organist and choirtrainer for many years. Part of what EVERY choirtrainer needs to know and a subject often covered at summer schools is all about vocal technique - how to teach choristers to sing correctly. And it all comes back to the same technique of intercostal breathing that I learned as a youngster in polio clinics all those years ago.

And in fact these are the same techniques that are used by speech therapists to help people in any occupation where vocal stress is a problem. Many of my relatives are teachers (a profession notorious for vocal stress) and what they are taught to cope with those demands are the same principles as singers use viz.

- proper breathing technique
- use of the muscles at the base of the stomach and lower back (diaphragm) to control the airflow
- production of volume purely through air volume and with NO stress of throat or neck muscles
- use of the chest and nasal mask to resonate and amplify the sound

The email I responded to concerned a lady who stated that when she sang a couple of hymn verses or otherwise put her voice under stress, she suffered later loss of voice. This seemed to suggest that her vocal technique may have been incorrect - possibly involving unnecessary stress - but it may flow from posture problems arising from PPS weakness. I certainly don't maintain that any of the above suggestions (or the reply to the email following this) will prevent problems from PPS people who have muscular weakness or paralysis - especially if it involves the vocal cords.

But I would suggest that any one who has a problem in this area might consider whether use of correct vocal technique would help them make the best use of what they have.

The question was *'I find if I sing a couple of hymns*

I lose my voice for the rest of the day, I've given up hollering at basketball matches too.'

Whatever the primary cause of your vocal problems may be I would certainly be looking hard at matters of vocal technique. If you really understand some basic things about HOW you should be using your voice you can minimize strain and reduce any adverse affects of sustained use.

The sort of things I would look at are:

Breathing. Most people breathe inefficiently using only the upper part of the chest. They then create volume by straining from the throat which creates unwanted tension and can cause nodules on the vocal cords. People in occupations which involve sustained vocal use AND stress, are very suspect to this. Teachers often suffer.

If you had polio with any effect on the upper body you might easily have been shown the correct method of intercostal breathing. Very simply it is to raise the chest and tuck in the stomach BEFORE breathing in, then breathe in. This will fill the lower portion of the chest - creating what I always call the pregnant lady/ beer gut effects (according to gender).

One famous English cathedral musician had it pretty right. He would tell his boys to "make like Tarzan" - then breathe in. That automatically got them breathing in the correct manner,

Then you control the release of breath (when you sing, holler (as you call it, or speak) by using the stomach muscles. You should also have the sense of drawing in the muscles of the small of your back as you release air.

When you sing or speak loudly, you should have the sense that the ONLY thing creating the increase in volume is that more air is being pushed through the vocal cords - nothing else - no straining in the throat or neck, In fact if you place your hand on your throat (at just below the Adams apple) there should NEVER be the slightest tension whether you sing or speak loudly or softly

This gives you a way of providing volume without strain and simply paying attention to this aspect will greatly reduce vocal stress.

'As my job involves telephone conversations where I do 70% of the talking, I think it's time to change it.'

So it may simply be a matter of a few bad (though common) habits causing vocal stress. Or indeed PPS may be a factor. But being sure you are doing everything you can to avoid vocal stress is certainly something you should look into.

Perhaps the music director or choir leader at your church may have the skills to help you address this. Since your voice is your job it is important and I think its a great pity your medical people have not been a bit more helpful. A good vocal specialist should have been able to establish at least some remedial measures.

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THE SUNSHINE VITAMIN & OSTEOPOROSIS by member Vivien Holland.

In my last article I told you about some full spectrum light bulbs I'd come across that gave us the benefit of "daylight" indoors. At the time I'd just sent away for mine, so hadn't actually used them personally. Now that I have had a chance to use them I wanted to let you know how helpful I've found them.

They give quite a bright, white light and really make the room light and airy. Incidentally, the room I use mine in is at the front of the house on the ground floor. The room is so bright that I am sure the whole room would be visible to passers-by, despite the fact that I have net curtains. Strangely enough, this is not the case, however I would advise that you check that you're not on view!

These bulbs certainly brighten up a dull day and even on a sunny day extend the benefits of sunlight indoors. Remember, if you're indoors you're not getting all the benefits of sunlight, even if the sun is streaming through the windows. So although I initially thought of them as particularly helpful during the short winter days, I now feel these bulbs are going to be beneficial all year round, especially for those who are housebound, or living in flats and maybe not able to get outside much. (There is actually another company that specialises in this type of lighting, giving a wider range of products including strip lighting for the kitchen. They are called Full Spectrum Lighting Ltd. Tel: 01494 52605 - again, I have no connection with them.)

As mentioned in my previous article, using these

light bulbs will help to produce Vitamin D in the skin in the same way as sunlight itself, but for this to happen it will obviously be necessary to expose a bit of flesh for a while each day.

I'm sure we're all looking forward to a bit of warm weather after quite a difficult winter, hopefully it won't be too long before we have the opportunity of sitting out in the sun at least occasionally. There's nothing like the real thing, is there! My husband and I have never been ones to sunbathe much, but last summer we put a couple of chairs and a little table by the back door, a spot that gets the early morning sun, and whenever possible we had our breakfast out there. Neither of us likes strong sunlight, but early in the day it was really pleasant. With the worry of skin cancer these days, I wonder if we've become a bit overanxious and could be losing out on the benefits of moderate sunbathing. I was reading recently that a little daily UV even protects against skin cancer, which is apparently more prevalent in office workers than those used to working outside. This seems to highlight the need for moderation in all things, including sunshine exposure, taking care of course to avoid the very hot part of the day.

The reason I'm emphasising our need for Vitamin D so much is the role it plays in helping our bodies absorb calcium and strengthen the bones. With one in three women and one in twelve men at risk of osteoporosis, and for some of us our inactivity making us more at risk than most, anything we can do to strengthen the bones needs to be a priority.

I read recently that a trial is underway to give elderly people Vitamin D jabs, as they are often low in this vitamin due to poor diet and lack of sunlight. The doctors are hoping to reduce the incidence of fractures, and if the trial is successful foresee that annual Vitamin D jabs could be given to older people each winter along with the flu jab. In the meantime, we can help ourselves with good diet, supplements like cod liver oil, and also sunlight. The jabs may be useful for many, but I think I'd rather do it the natural way anyway.

Most people know about calcium for the bones but this is not the whole picture. Many other minerals are involved, particularly magnesium. Dairy produce is often recommended as a source of calcium but it is very low in magnesium. A wide variety of fruit and vegetables, whole grain cereals, nuts and seeds will give you a better balance of nutrients in general and if you are taking a calcium supplement, try to find one that includes magnesium too.

Next time I'll be writing in more detail about osteoporosis and what we can do to help ourselves nutritionally. If anyone would like to write to me to comment on anything or to suggest a future topic, I'd be very pleased to hear from you.

"Vivien Holland"
<vivienholland@hotmail.com>

Sylvia Dymond member from Hampshire UK

I contracted polio aged 15 years 8 months, although all my limbs were affected by far the worst hit was my middle. I wore a Milwaukee brace and a calliper for two years with extensive physiotherapy plus willpower I eventually left the calliper and brace off. It was not until my late thirties I began to have made to measure corsets, then in 1988 the company closed down. I sought help from the local hospital and on my first visit I was told by the doctor "we are not here for cosmetic reasons", as if a body support for a polio victim was that!

Six more years went by, I was too weak to go out during those years I was told at St Thomas' and Papworth they could not help. I found a private orthotist and on the day she arrived in 1997 she was so upset to see my collapsed "middle" she wept. She said she would have supports made but not to be up for more than an hour at a time, then rest. I have found this way of life so difficult. I had to go into a powered wheelchair in 1992, first for going out and then I had to start using it indoors. I progressed to doing cooking from it but am so weak now I have a carer three times a day but without my powered bed and powered chair I could not cope alone, so those of you with powered chairs start using them early enough and save your strength for longer. P.S. I am writing from a nursing Home to which I came twelve days ago to give my carers a break for 2 weeks. Unfortunately I have suffered since the first night because I did not have it in writing that 24-hour heating would be supplied to the same temperature as I have at home. I have not had the heating I need so have spent 12 days very cold and at times felt frozen, I am also not cared for the way my carers care for me as they do not understand our ways of doing actions and pacing and resting. Do any of you become frozen and in pain the way I do if the temperature is not how you normally have it? I would be interested to know. If you do feel the cold badly before you go away anywhere, check about heating and ask for a reply in writing. I have had this problem before but as I

was only told a couple of days before going that there was a vacancy I plain forgot. I would love some polio survivor penpals, UK, USA anywhere. Please write c/o the LincsPPN.

To Wheel or not to Wheel, that is the Question?

I still walk. I don't use my scooter all the time, not yet anyway. But, I've found it to be a great energy saver and allows me to get out and do things I was starting to just not do as it took too much energy and caused too much pain. I'm now doing the same again as the scooter is not the right set of wheels for me with my upper body weaknesses that are getting more so then I expected they would. Now I am considering a powerchair.

To walk, stand, and/or use wheels are very personal decisions. I just know that for myself following up on my own decision to conserve more by using wheels has been more difficult to carry out than I expected. Now, for me, the prevalent attitude that being upright and walking was a major part of my own difficulty. Yes, do walk and stand as long as you can and want to (as long as you aren't feeling weaker for it, or more fatigued, etc).

It's not giving in to start using wheels. I was thrilled for the young man in the documentary mentioned when he could walk as it was so important to him. However I was dismayed to think that he was seriously contemplating ending his life when he couldn't. I know that fear and loss of self worth and confidence too well and have found that I'm still me no matter how much I have already lost to PPS or how much I may in the future.

Most insurance companies and Medicare as well, see wheelchairs as "luxury" items until you can't get out of bed without using one. As if anyone wakes up one day and thinks, "ahh, it would be so cool to use a powerchair...its so "in"...<Grin> This too, is a reflection on the lopsided view of the be all and end all of walking and standing. If we can't get out and about but can manage in the home then we've no business being out and about. In fact, my MNL made the mistake of saying just this one day when we were talking about my vain attempts to get approved for a powerchair. I CAN still walk but only with a cane. I do not have braces. I have a distinctive limp. I can do just fine with those doctor office visit walks of four or five paces. But, I can feel and see the damage and deterioration I am doing when I try walking or especially standing for more than ten minutes. I become totally exhausted

More about Breathing, Swallowing, Night Time Ventilation, Tracheotomy, in the next issue. If you have questions you want answered then pleaseas soon

and can do little more that day.

My good leg is now testing out weaker than my bad one. Scary stuff to me. I'm simply taking to heart the advice I've heard here and in many articles I've read. To conserve it to keep it. I don't want to join the others who waited till they fall and need surgery for the results of that. I also, fear losing my legs to where I would need to use my upper body to transfer. I choose to use wheels now so that I won't (I hope anyway) be permanently in a wheelchair or in need of help to do almost everything. Another scary thought for me.

Walk by all means, but please listen to your body and take plenty of little rests along the way. I've been on SSD (Benefits) for nine years now. It took me better than six of these to even consider using a scooter. Now, I hop on the store scooters so I can enjoy my shopping. I either take my scooter or rent a wheelchair at fairs, craft shows etc.. again, I do it because I simply have more fun and don't hit the Sudden Fatigue wall. To be honest it wasn't till that started happening more and more frequently that I was ready to consider wheels.

Before that I honestly thought that those already using them were just jealous of those of us still walking (happily I found out how wrong I was). I honestly hope and pray its a long long time before PPS lets you know its time to start considering using the store scooters at least.

Answer - You can go further on electric wheels.
Ellen by the seatree
<lonellen@HARBORSIDE.COM>

This is an interesting topic, and a very personal one. Everyone's situation is different. Personally, I wouldn't trade my years of standing and walking and generally overdoing it for any amount of increased mobility now.

wkd3@MINDSPRING.COM (William K. Davenport, III)

[Editors note - You can be prescribed a wheelchair or scooter in America but only if you need to use it to get round your home. There is no DLA mobility allowance, no financial assistance/benefits to help you and your wheels get out of the house to shop, visit the doctor, socialise etc. Its not easy taking that first wheel - and it might help you to try out a store scooter away from your home where no-one knows you - but the benefits both physically and mentally are tremendous. You do so much more]

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