

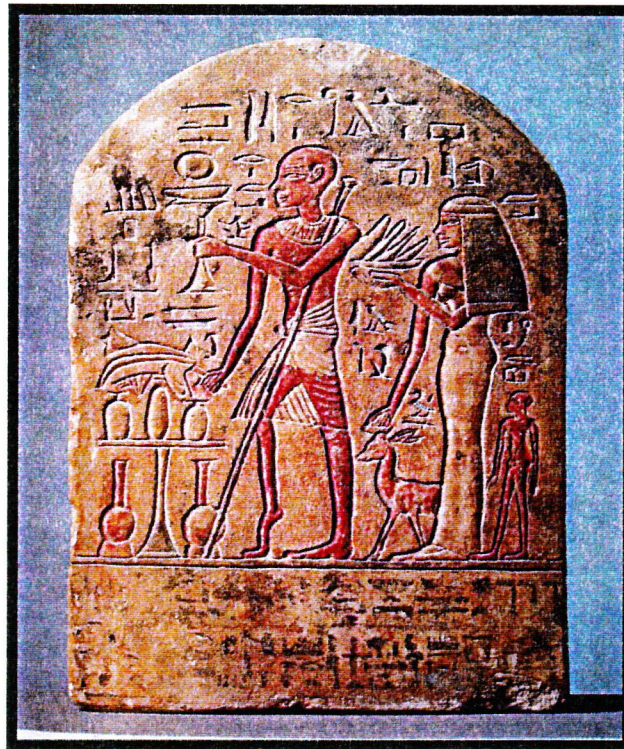


The LincPIN

The **L**incolnshire **P**ost-Polio **I**nformation **N**ewsletter

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

Stella of Roma
from the first half of the 14TH Century B.C. (18th Dynasty)
Reign of King Amenhotep III



M. Jørgensen, Catalogue: Egypt II, Copenhagen 1998, p. 119, no. 39
(stela AEIN 134 in the Ny Carlsberg Glyptotek in Copenhagen)

*Seasons Greetings
to all our Members and their Families
all over the World*

Remember the opinions expressed are those of the individual writer(s) and do not necessarily constitute an endorsement or approval by the Lincolnshire Post-Polio Network. Although it does not provide an endorsement, it is provided as a service to those seeking such information. ALWAYS consult your doctor before trying anything recommended in this or any other publication. **Lincolnshire Post-Polio Network - UK Registered Charity No. 1064177**

Editorial

The Committee wish you
All the very best for the coming Season
and a Healthy New Year.

I am writing this in the beautiful sunshine state of Florida. It is very strange going away in the winter to better weather than we had in the UK this summer. Richard has improved well from his shoulder surgery last February and has been able to use his right arm for all activities since the end of August but it is taking longer than we expected to gradually increase the time doing. In the ten days we have been here he has started driving short distances again and has been doing some small jobs in his workshop. As with everything with PPS it is constant monitoring of how much to do, how much to rest and how often. It looks as if it will take nearly a full year to recover from the surgery. It has been a very slow frustrating time for us both, but the results are worth it.

My thanks to Mary McCreadie who stepped in at the last minute when I was unable to get to the Bristol meeting of local members. It was difficult getting in touch with everyone at such a late stage and apologies to anyone we missed. Mary reports it was great meeting those who could make it and if you would like to join their informal group please ring her on 01594 530314 evenings. I was just walking into the Lincolnshire Neurological Alliance meeting when my mobile rang. 48 hours earlier I had booked an automatic people carrier through Enterprise and here less than 24 hours before collection I heard the words, 'We have made a mistake, we don't have automatic People Carriers, will you take a manual?' Having spent some time the week before discussing the fact that I had tried seven firms without success trying to find an automatic till I found them and their choice of three, I was almost speechless! Later that morning I tried another ten firms to find that automatic people carriers are like Hens Teeth. Luckily my daughter had booked a weeks holiday for the following week and was available from Sunday to drive the manual Galaxy that we hired from Thrifty to take us to see my parents and then onto Gatwick. Gerald Perkin and his wife came to the Gatwick Travelodge and we had a lovely chat. It's so nice meeting up with members. I look forward to meeting up with the Bristol folks next Spring en route to visit my parents in Devon.

I have included a report on the Seminar I went to on the Management of CFS/ME. I am sure you will find it interesting as I did. Once again it shows us that there is a huge similarity in problems being experienced by those with other neurological conditions. I would be interested as always in your comments on the content of the newsletter. I do try to

make it varied. Newer members don't forget that this is issue 32 and there are many articles on pps issues in back copies.

We have taken the first step to improve the newsletter as requested in the survey results by having this printed instead of photocopied. More changes will take place over the next few newsletters. We are in the process of reformatting our information and one new addition will be a list of contents of previous newsletters. More information on this in the next newsletter. Please can we have items for the next newsletter as soon as possible and definitely by January 15th. We look forward to hearing from you.

Report from Lincolnshire Neurological Alliance Meeting on November 8th in next newsletter.

PPS is mentioned at European Health Summit. See page 23. If anyone would like a copy of the briefing document on PPS please contact Wendy. Whilst I am away all mail is being redirected to Wendy and Frank. If you wish to phone then ring Janice on 01663 743870 daytime and Wendy and Frank on 01400 282546 evenings. If you are not on the Internet and wish to speak to me then they will gladly pass a message to me with your phone number and I will call you back.

If you do not have Internet Access and would like to write to contributors to this newsletter then please contact us for their postal addresses. They would love to hear from you.

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Amusings

The turkey shot out of the oven
and rocketed into the air,
it knocked every plate off the table
and partly demolished a chair.

It ricocheted into a corner
and burst with a deafening boom,
then splattered all over the kitchen,
completely obscuring the room.

It stuck to the walls and the windows,
it totally coated the floor,
there was turkey attached to the ceiling,
where there'd never been turkey before.

It blanketed every appliance,
it smeared every saucer and bowl,
there wasn't a way I could stop it,
that turkey was out of control.

I scraped and I scrubbed with displeasure,
and thought with chagrin as I mopped,
that I'd never again stuff a turkey
with popcorn that hadn't been popped.

Fred Astaire and Ginger Rogers were having dinner at an expensive New York restaurant. It was the place to be seen and both had dressed for the occasion. Ginger was resplendent in a ball gown and diamond tiara while Fred wore his smartest morning suit. But the evening was marred when the waiter bringing their deserts tripped and covered Fred from head to toe in treacle sponge. "I'm terribly sorry," said the waiter.

"You should be," replied Fred. "Thanks to you I've got pudding on my top hat, pudding on my white tie, pudding on my tails."

While driving in Pennsylvania, a family caught up to an Amish carriage. The owner of the carriage obviously had a sense of humor, because attached to the back of the carriage was a hand printed sign...

"Energy efficient vehicle. Runs on oats and grass - Caution: Do not step in exhaust."

We could learn a lot from crayons:
some are sharp, some are pretty, some are dull,
some have weird names,
and all are different colours

But they all have to learn to live in the same box.
From Sylvia in Hampshire

Some years ago on a visit to a Polio Unit the Ward doctor mentioned my weight, I said 'My care assistants do my cooking for me and not all know how to cook, I am thinking of training a chimp'. He carried on writing then looked up at me and said in a serious tone 'Would you like to see our psychiatrist while you are here?' I asked, 'Why? Is it because I mentioned the chimp as a helper?' Still straight faced he told me that he offers for everyone to see the psychiatrist, so I went. The psychiatrist had a good laugh, he knew I was not serious. Maybe the doctor should have seen him?

A man was driving past a farm and saw a four legged chicken racing along. He asked the farmer about it, who replied 'Aye, I breeds em because me, my wife, son and daughter all like a leg each.' I asked 'What are they like'. The farmer replied 'I don't know I have never been able to catch one of them yet.'

Quotable PPS Quotes.

'I need help taking my body orthoses off because most of my muscles live in the cupboard.' - Sylvia

With only one good arm and using an electric chair its difficult carrying a hot drink anywhere 'I wondered if deportment lessons would help so I can balance a meal or drink on my head'. - Sylvia

Can you turn on the air conditioning, I just dont have the energy to sweat! - Richard.

Things I have learned...

That my dog doesn't like the broccoli either...

An older couple was lying in bed one night. The husband was falling asleep but the-wife felt romantic and wanted to talk.

She said: "You usec to hold my hand when we were courting." Wearily he reached across, held her hand for a second and tried to get back to sleep.

A few moments later she said: "Then you used to kiss me." Mildly irritated, he reached across, gave her a peck on the cheek and settled down to sleep.

Thirty seconds later she said: "Then you use to bite my neck." Angrily, he threw back the bed clothes and got out of bed.

"Where are you going?" she asked.

"To get my teeth!"

To Exercise or Not to Exercise by Dr. Henry Holland.

Many of us with PPS have had to address the advantage and disadvantages of exercise. Some of us are prescribed various types of exercise by our physicians. Most of us follow the advice of our physicians because we trust their training, experience, and expertise. Most physicians want to help and to do what is best for their patients. After surviving acute polio and much painful physical therapy, most of us were advised to exercise in order to strengthen our polio-damaged muscles. In most cases this advice proved beneficial as many of us regained considerable muscles use in the first two years after acute polio. Some of us were probably overachievers in various exercise endeavours. Others of us probably did a lot of involuntary exercising trying to do many physical tasks that were more challenging and difficult than before acute polio.

What is exercise? Exercise is a form of exertion made for the sake of training or physical fitness. We live in a time when exercise is almost epidemic in our society. Health clubs, aerobic programs, working out with weights and machines, jogging, power walking, and even stretching exercises for the elderly abound. It is not uncommon for individuals to have a personal trainer. This person may be as important as a doctor, lawyer, accountant, broker, or hairdresser/barber in a person's life. I live near the University of Richmond - joggers and walkers of all ages pass by my house all year round, but this time of year, they are almost constantly in sight. Exercise and working out is therapeutic for most people. Almost every system of the human body seems to benefit. The cardiovascular, pulmonary, musculoskeletal, and central nervous systems probably benefit the most.

Thus, it would seem logical to conclude that polio survivors would benefit from exercise and working out just as we did years ago. If exercise helps the able bodied, it should also help us. It also seems logical that we should condition our bodies in order to aid our own cardiovascular, pulmonary, musculoskeletal and central nervous systems.

In view of all that I have written above, my main concern is that too many post polio people are being advised to exercise when exercise may increase the pain, fatigue, and weakness of PPS. I would like to offer some guidelines about exercise for people with PPS. The following is

only my opinion and is based on reading the literature, talking and sharing with PPSers, and from my own experience.

There is more medical literature that advises some form of exercise for PPSers than literature that cautions against it. However, most of this literature contains a lot of qualifying statements. It is my opinion that many of us should be very mindful of these qualifying statements.

If your muscles hurt in a more sustained fashion after engaging in exercise, you should probably not be doing that exercise. If your muscles recover and the pain subsides in a twenty-four hour period, then the exercise is probably not harmful, but still might become harmful over time.

If the effort of exercise results in fatigue that lasts beyond twenty four hours, then the advantages of the exercise must be evaluated against the increased fatigue and the exercise should at least be temporarily halted.

Muscle strengthening exercises for polio-damaged muscles have little chance of increasing strength. Muscle strengthening exercises for muscles unaffected by polio may improve strength, but also may contribute to a pattern of well established overuse and can possibly be an adverse endeavour.

If the activities of daily living such as dressing and undressing, maintaining personal hygiene, transferring from one position to another, and getting about are maximum achievements of your daily effort, then exercising will likely be an added drain on a precarious personal energy balance. You would be wise to make an intelligent choice on what is more important to you.

Trying to maintain some form of physical conditioning is important. In addition to the activities of daily living, it is advisable to avoid weight gain, maintain a relatively high protein diet, sustain good hydration, control blood pressure, get restful sleep, try to get intermittent down time during the day and use your mind.

Passive movement of a stretching type and gentle massage can be helpful to body and mind. Many PPSers find that extremity movements in a heated pool are therapeutic. However, if the effort to get out of the pool and get dressed leaves you exhausted, again you have to make an intelligent choice as to what is more important to you.

Polio Survivors may tend to be a little masochistic. Because many of us have lived with some pain most of our lives, some of us identify more pain as being a sign of some gain or progress. This type of thinking is no longer valid. When we have more pain, our bodies and minds are telling us that we are doing something wrong or that something is wrong. Show proper respect for pain. Don't indulge it.

Mental stimulation such as reading a good book, enjoying family and friends, observing nature, using a computer, and spiritual searching can be a form of conditioning that cannot be easily measured in its overall benefit. Nevertheless, I believe the benefit is there.

If life with PPS is a daily struggle, why add to that struggle with voluntary exercise? Because of this daily struggle we may already be at risk for a cardiovascular event such as a heart attack or stroke. Before attempting any form of exercise, get the opinion of a physician who is very knowledgeable about PPS. Usually a physical medicine and rehabilitation specialist is most likely to be the best informed about PPS. Dr. Jane Wootton of the Sheltering Arms Post-Polio Clinic here in Richmond is one such physician.

Keep in mind that many polio survivors have spent much of their lives in trying to overcome physical limitations, physical barriers, and cognitive challenges. To exercise or not to exercise is really your choice and not something that you have to do in order to overcome PPS.

Polio Deja View Editors Note - Way back in 1966 when I first moved to Long Island, I looked for a doctor who knew something about polio (even then they were getting hard to find) as I felt that if and when I had a problem, I wanted someone who was familiar with polio. When I started having post-polio problems in the early 80's, it was oddly enough, not with my very obviously polio paralyzed right leg, but with my left arm which had never been diagnosed as being affected. It was several years before my leg started giving me problems - weakening and becoming more and more valgaged (tending to go toward the left leg [knock kneed]) My doctor, Dr. Joseph Farrell, was most instrumental in persuading one of the local hospitals - one that had actually been 'the polio hospital' during the epidemics - to open a Post Polio Clinic (it only took us four years). When I went to him with my right leg, he confirmed that it was weakening and when I asked about doing some exercising to strengthen the leg he told me that 'it would be

a futility as there were no muscles there to strengthen'. This is something many of us refuse to realize - if our limb is really and truly deemed 'paralyzed' there is NOTHING we can do to bring back those muscles.

Remember that 'No pain, No gain' rule NO LONGER applies to us. We now have to 'CONSERVE IT and PRESERVE IT.'

[Note from Rancho Los Amigos Support Group Editor This article contains excellent advice. I would probably be even more conservative than Dr. Holland in his second and third points. I believe that the threshold of twenty-four hours for pain or fatigue is too high. It appears to me that if, after exercising, your pain and/or fatigue lasts for more than one hour, you've probably done too much.]

First printed in 'Deja Vu' Central Virginia PPS Support Group Newsletter reprinted in Ranchos Los Amigos PPS Support Group Newsletter.

[Note from LincPIN Editor. If I go to a Meeting, Conference, Fly the Atlantic, then this uses up much more energy than I have available for a day and I know that the next few days I will be totally fatigued and unable to do very much at all. We are all different and the best thing we can do is to listen to the advice being given by others and then assess ourselves and continually monitor what we do and how much pain and fatigue that gives us. Then we can make informative decisions. Dr. Dowsett has said at many meetings that we must enjoy our life and planning in a days events that we know is too much but that we will enjoy can be more beneficial than not doing it.

We travelled for 14 hours from the Travelodge at Gatwick to Richards home and spent the next four days time warped, brain fogged, and jet lagged. Six days later we are beginning to get back to some semblance of 'normal energy status'. Thank goodness for ready prepared food, good neighbours and friends, freezers and microwaves.]

The following two articles followed Dr. Hollands in the Ranchos Los Amigos PPS Support Group Newsletter. We are printing them with the permission of the author.

Part I

Dear Linda,

I can't seem to do as much as I used to be able to do. I used to walk about a mile every day and

Ask Linda *by Linda Wobesky, M.S. P.T.*

now I get very tired after only about half a mile. I usually push myself to finish my walk anyway because I know exercise is important. What exercises can I do to get stronger?

Getting Tired in Tewksbury.

Dear Getting Tired,

This question falls into the category of frequently asked questions! Many polio survivors report their daily battles with tired muscles and decreasing ability to do the things they want. The most successful approach to solving a problem is to first understand its cause. Today's column will explain the causes of muscle fatigue. The next newsletter column will present a variety of strategies for coping with muscle fatigue.

The cause of muscle fatigue is related to your recovery from polio. The poliovirus damaged or destroyed the nerve cells (motor neurons) in your spinal cord, which transmit the messages from your brain to your muscles. If you want to wiggle your big toe, your brain sends the message down your spinal cord to motor neurons, which then conduct the message down your leg to stimulate the muscles that wiggle your big toe. Each motor neuron is connected to specific muscle cells in a particular muscle. The poliovirus damaged or destroyed these motor neurons in our spinal cord, which cut off communication between your brain and your muscles. The specific muscle cells that depended on that particular motor neuron were orphaned or lost their communication line to the brain. The motor neurons that were spared during the polio attack sprouted extra branches and reconnected as many of these orphaned muscle cells as possible. This is one of the ways you recovered your strength. However, the result was one motor neuron now controlled as many as five times more muscle cells than it was originally designed for. For example, if that particular motor neuron originally controlled 200 muscle cells, it might now control over 1000 muscle cells. This means it sprouted over 800 extra branches.

As the years go by, the motor neurons become less and less able to support all these extra branches. As a result, these branches begin to slowly die off. Here is an analogy. Imagine that you added 3 - 4 new rooms to your home during the years when heating oil was plentiful and

inexpensive. Then there was a crisis in the Middle East and fuel prices skyrocketed. What would you do? You would close the doors of these new rooms. When the motor neurons 'close the doors' to these extra branches, the branches die off. The muscle cells again lose their communication line with the brain. When the brain sends a message down to that muscle, fewer muscle cells actually received the message. What you experience is new muscle weakness.

There is another important point to consider. Your muscles can not differentiate between activities you consider 'exercise' and regular daily activities. The quadriceps muscle in our thigh works when you use the stairs in your home and when you exercise it at the health club. Your motor neurons and muscle cells don't know the difference. So everything you do during the day is experienced as exercise by your muscles.

Let's take a moment now to reconsider your situation. You used to walk for a mile and now you feel quite tired after half a mile. Your mind says, 'A half mile should not make me feel tired. It's not that far.' The truth is, it doesn't matter whether you think a half-mile, or even a half block is very far. Your muscles are telling you that it is more than they can do. When you push yourself to walk the mile, you are ignoring this message. If you ignore the message, you risk serious and perhaps permanent damage. When you continue to exercise when your muscles feel tired, you're taxing your already overworked motor neurons. You may be helping those extra branches to die off. Is this something you really want to do?

When you first had polio, exercise was the means to increased strength and function. So it makes sense to think that exercise will help now. However, your original weakness was caused by the polio infection. The cause of your current problem is described above. Different causes require different treatments. So you might guess my answer to your question regarding which exercises you need to add to your day. More exercise will not help you to get stronger. In fact, more exercise could cause you to lose strength permanently. 'But,' you say, 'I have to do something!' I most heartily agree. There are many things you can do to feel stronger and to feel better overall. I will discuss these in the next column. Stay tuned!

Part II
Dear Getting Tired,

Thank you for your patience with this 2-part answer. The first part explained the causes of muscle fatigue. You may recall we discovered one way in which you recovered your strength after polio. The undamaged nerve cells in your spinal cord (motor neurons) grew extra branches in an effort to keep the communication lines open between your brain and your muscle cells. The result was one motor neuron controlling as many as five times more muscle cells than it was originally designed for. Now, many years later, these motor neurons have become less and less able to support all those extra branches. The extra branches begin to die off and your muscle cells again lose their communication line with the brain. When the brain sends a message down to your muscles, fewer muscle cells are able to respond, because fewer muscle cells actually receive the message. What you experience is new muscle weakness. More importantly, what you experience is a decreasing ability to perform the activities you enjoy.

As promised this column will present some strategies for coping with muscle fatigue. First, in my experience the key to the success of any coping strategy is commitment to change. Doing more, doing less both require a change in one's lifestyle and neither happens consistently without a commitment to this change. Commitment requires a belief in the potential outcome resulting from change. What are your beliefs about healing yourself and helping yourself to feel stronger?

Let's look at the question in our letter: 'What exercises can I do to get stronger?' This tells me that, in your mind, perhaps the cure for weakness is more activity, more exercise. This belief makes a lot of sense based on your initial experience with polio. When you first had polio, exercise was the cure. You experienced increased strength and function after lots of exercise and hard work. Unfortunately, exercise is not the cure for your current problem because the cause is different. As discussed in the last issue, your original weakness was caused by the polio infection. Now, the cause of your weakness is too much activity: more activity than your overworked motor neurons can handle. More exercise is unlikely to help you and is very likely to make you worse. This fact may be in direct opposition to your beliefs. It is extremely important to recognize that if you believe exercise is the best cure, it will be very difficult for you to try anything else.

So the first strategy for coping with muscle

fatigue is to become aware of your beliefs about healing yourself. Are your beliefs consistent with the facts? The clients I have known who were most successful in achieving healthier and happier lives slowly came to accept the facts about post polio syndrome and changed their lives accordingly. It took a lot of hard work and it was a great achievement. And they were unable to start making successful changes until they changed their beliefs about what they needed to do to become healthier. This does not mean their old belief system was bad. It simply no longer served their needs.

The second strategy for coping with muscle fatigue is to notice when you are falling prey to what I call the 'All or None' thinking process. When you hear the words 'pacing' and 'energy conservation', do you immediately think, 'No way. I'll have to stop doing everything I like?' Does not doing everything mean not doing anything to you? This belief will also keep you from making helpful changes in your life. Pacing and conserving energy means accepting the fact that you have a finite amount of energy and making healthy choices about how you want to use that energy. The truth is, making several small changes can often add up to feeling a lot better. For example, you know you get very tired after walking for a half mile. Don't ignore your symptoms and walk the full mile. That's doing it all. Don't skip you walk entirely. That's doing nothing. Try walking a distance that does not tire you such as a quarter of a mile. Think of it as choosing to compromise. You could push yourself through the pain and fatigue, walk the full mile and risk the future health of your muscles. You are choosing not to. It's also important to acknowledge that it's a difficult choice. That's where the hard work comes in. Accepting undesired changes in your body is hard! But, as a polio survivor, you're no stranger to hard work. This is just different kind of work.

The third strategy is to consider all options available to help you save energy. It's like clipping coupons for the grocery store. Thirty cents here and forty-five cents there can add up to significant savings. Where can you save energy? Try reversing your thinking. Do you choose to use the stairs as often as possible? Do you park in the furthest parking space, just to get that extra exercise? Each time you think of some way to get some extra exercise, do the opposite. Each time you use an elevator instead of stairs, you have saved that energy to use elsewhere.

Another energy saving strategy is the use of a

cane or a brace. Most people I have worked with smile and shake their heads 'no' as soon as I say the word 'cane'. And yet I persist. A cane is one of the best energy saving devices I know. There has been a lot of research that shows that when one's walking pattern involves extra motion in either the trunk or legs, it takes more energy to walk. A device like a cane or brace, which decreases this extra motion, saves energy. Does your body sway from side to side when you walk? Do you have to lift one leg extra high to keep from catching your toes and tripping? Once again, thinking about an energy-saving device involves a choice and a compromise. No one wants to use a cane. Yet using a cane may mean being able to walk farther with less fatigue. A doctor or a physical therapist can tell you if one of these devices could help you to conserve your energy. Then the choice is up to you.

I hope you have found this column helpful. Change of any kind can be very challenging and usually happens slowly, with many stops and starts along the way. I encourage you to acknowledge your courage in taking any small step toward changing your life for the better.

Source. TRIUMPH, the newsletter of the Greater Boston Post-Polio Association, Winter 2001. *Question - Do polio survivors usually have progressive memory loss? When I am very fatigued or stressed will I totally forget the word I was going to use. I'm frightened. Am I getting Alzheimer's disease?*

Answer - You are experiencing word-finding difficulty, a problem for polio survivors that has nothing to do with Alzheimer's disease. In our 1990 National Survey, 79% of polio survivors reported difficulty 'thinking of words I want to

PPS Forum
by Richard L. Bruno PhD
from New Mobility Magazine, January 2001

say'. 37% reported frequent moderate-to-severe word-finding difficulty.

In the July 2000 issue of the American Journal of Physical Medicine and Rehabilitation, we describe testing polio survivors and finding that they do indeed have 'tip-of-the-tongue' experience - knowing the word you want to say but not being able to say it. Polio survivors have difficulty with naming objects and sometimes even people they know well. Our results indicated that word-finding difficulty was not associated with memory or thinking difficulty - symptoms of Alzheimer's disease - but was

related to trouble focusing attention, a characteristic symptom of post-polio fatigue.

We also found that difficulty in word-finding and focusing attention were related to polio survivors' brains making less dopamine. Low dopamine is the cause of Parkinson's disease, and we found that word-finding difficulty was identical in both polio survivors and Parkinson's patients, even though polio survivors do not experience the tremor and rigidity of Parkinson's. In 1996 we published a study showing that bromocriptine, a dopamine replacing drug, reduced word-finding difficulty, attention problems and fatigue in polio survivors. However, medication is not necessary to treat word-finding difficulty or any PPS symptom. Reducing physical and emotional stress decreases all PPS symptoms. So don't worry that you have Alzheimer's disease. If you're having trouble thinking of a word that you want to say, try to 'talk around' the word by describing what you're trying to name. If you are forgetting your friends names, try calling everyone 'Buddy' or 'Honey'.

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. Please email questions directly to him at PPSENG@aol.com

[Editor - Many polio survivors who ring report this and are relieved to know they are not alone. I use the following visual explanation. In our brain there are many folds, little hills and valleys. Sitting in the valleys are tiny little men who have a board with one word on it - just like the country boards at the Olympics. To speak each word that we do, the little men have to lift their boards up to the level of the top of the hills so that we can say each word. Now as with all men - sorry fellas - some are a bit 'ornery' and they just continue sitting down. Now we can't do actual handstands to knock some movement into them so we have to shut our eyes and pretend to do one. Most times it works. But how many of your men have let go at 3.00 a.m. in the morning? You wake and say 'Consolidated' that's the word.]

Tips from PPSers

I believe that this idea of "conserve to preserve" is widely misunderstood.

Post polio victims experience much less resistance to physical exertion than just polio victims. What this means is that before post polio one could go out, jog for half an hour and feeling invigorated and strong, shower and then go to work.

A PPSer on the other hand will be totally exhausted to even get undressed (that is why so many of us shower with our clothes on).

If one has obligations, responsibilities, priorities, one needs to avoid, whenever possible, doing excess physical work so as to not be demolished and be unable to do anything else. It isn't that if one engages in physical activity, the energy will disappear and never return. No. Even PPSers are able to eventually recharge the energy cells; it just takes much longer to do so and the usage span lasts much shorter, but you do get back the energy. PPSers are told to conserve energy so that they may preserve some of it to meet their choices to do much more with their lives later on.

There may be times when it is worth it to push oneself to the limit (as when one visits grandchildren or prepares for a Thanksgiving family reunion) realizing that following the "big event" there will be several days of pain and fatigue... and forced inactivity.

No doctor, philosopher, prime minister, senator or basketball player can tell a PPSer how much or how little to do. For some it may be walking two blocks, to others it may be walking sixty steps. Notice how many of the ladies in this group "conveniently" claim that feather dusting causes soooo much fatigue that it should have been included as a major deterrent in the March of Dimes publication

El Panadero - USA EMPANADAS@AOL.COM

I find an inflatable air pillow or cushion is essential for scoliotic back comfort, and I buy mine from an outdoor/camping shop for a few pounds. I blow it up to about half-full and put it in a simple cotton bag (I have several freebies given me by a friend from aeroplane trips). I can then put it over my shoulder when I go anywhere and put it straight behind my back when I sit down.

I have one pinned to the back of my wheelchair and it is extremely comfortable - no other pillow gives me

the right support all over my back, whatever my shape. I also have one at my back in the car.

The secret is to inflate the pillow just enough to give support right across the back. Mine are a little floppy, but when I lean back I am perfectly comfortable - in fact, the harder I press, the more the pillow supports me, even when moving about in the chair.

By the way, don't get a pillow with separate inflatable panels or with areas stitched down - the air must be free to move throughout the entire pillow..

Sitting on one might help with jolting when out in your wheelchair, but I think you would need a stronger one to sit on - you don't want it suddenly discharging all its air, attracting a lot of accusing looks at the sound coming from your direction....

Anne Wood - UK <bumble@beeb.net>

Hullo everyone - Apart from promising to let everyone know how I was doing after my bladder being removed I would also like to share with you what three operations in a year does to those of us suffering from Post-Polio Syndrome (PPS).

In March this year as most of you know I had minor surgery to my bladder which was unsuccessful due to surgery being done without tests beforehand.

In May this year I was in theatre for four hours as I had an Iliac Conduit which is the re-routing of the bladder to a bag. It was successful but I was in continual pain in the bladder and felt as if I wanted to go to the toilet to urinate when in fact I have a bag. My husband Len would often catch me sitting on the toilet and ask me what on earth I was doing there. <smile> (Because of the intricacy of removing the bladder it is not done when one has an Iliac Conduit unless you have cancer.)

I have just had my bladder removed and have no pain in it or the urge to urinate through the vagina anymore. What a pleasure! <broad grin>

Dr. Bruno asked me if this surgery was necessary. He felt I was having too much surgery in such a short time for a PPSer. He was right.

I used to be able to shuffle if I felt I couldn't manipulate my wheelchair to my destination. Now my legs are like Jell-O and I daren't shuffle to the bathroom or anywhere else if Len isn't home. I can't even get into the bath anymore. Len used to help me in and I'd get out on all fours.

My typing speed was 147 w.p.m. and I was proud of

it. I wobble and shake when trying to type. It is important to me to type so I confine myself to short periods of typing.

My speech is affected when I talk I make errors and sound confused.

I am pacing a great deal and due to a bit of infection have not been able to type because it is painful to sit.

I'd like to share with you that it is worth thinking about how much surgery one should have in a year. One day surgery is a no-no and going home too early because you feel well is not a good idea.

It's going to take me a long time to recover I say this because I am hopeful that I don't stay like this. My typing is necessary. My friends on email and the Post-Polio Network Z A are my life as I have always been confined to the apartment but now I am totally housebound. I have steps to go down and come up and at present am at loggerheads with our body corporate regarding accessibility. (When we bought we knew nothing of PPS.)

To those of you who have an option think carefully about surgery. I didn't have much of an option and am paying the price.

Have I crashed? I'm not sure of what it is like to crash I just know I am following the advice of many wonderful friends overseas and pacing. Those of you overseas make use of your wonderful medical staff before surgery, and also, it is very important to think of the impact it is going to have on yourself and your immediate family if you come home wobbling like Sunday's Jell-O and custard.

If this helps just one person I feel my experience has not gone wasted.

Cilla - South Africa
Post-Polio Network Z A
<postpolio@scottburgh.co.za>
<http://www.sco.eastcoast.co.za/support/>

Here are a few swallowing tips I was given some time back when I first discovered I have dysphasia on BOTH sides. I seldom have any real problems and I credit it to really observing these tips.

Since I have it on both sides the speech therapist taught me to tip my chin slightly down as I swallow. This helps to close the air pipe.

But, as most of my problems are from the pre-swallow the most helpful things I was told I can do are the following:

*Take small bites, sips of drinks.

*Avoid foods that seem to slip down easier than others. (one of these for me is peanuts of all things, and I love peanuts). *Try to be relaxed while eating. And, not over-tired. I find if I am upset or too tired when eating I will have more problems than when I'm not. Actually, this one has helped curb the late night snacks <Grin>.

*Use straws rather than drink out of bottles or cans. Think about it.. the action when drinking out of a bottle or a can is to put one's head back, this creates a direct path for the liquid to slip past during pre-swallow even easier.

Even with this it seems I have at least one minor choking episode every few days or so.. more if I'm tensed up or over-doing.

I was told at the time I had my video test done (about 8 years ago now) that this pre-swallow problem is one of the side effects of having had bulbar polio. Also, that normally it only affects one side not both. In fact, the speech therapist had me do some of the test a second time to double check it. Me, I was totally enjoying watching my skeleton as it swallowed on the video.. didn't even mind that the food samples were cold and laced with that barium stuff.

This is one test that is actually fun, not painful.

The only thing was afterwards the speech therapist gave me a group of tongue and mouth exercises to do (most of which got me to giggling uncontrollably at first). When I went back for follow up we found none

of these had made any difference. I asked why I was doing them. She said, "well, we have to do something." Will they help? I asked, 'not really.' Needless to say those went out the window.

Hope this helps folks with similar problems.

Ellen Riddle <lonellen@harborside.com> USA

Should we put on a happy face for the benefit of others?

I think we should paste on a happy face for our own benefit. I truly believe that each of us has the choice upon awakening in the morning as to whether or not it will be a good day. Even a pain wracked day can have its benefits if we so choose.

Millie Malone <milmal@FRONTIERNET.NET>

More from Millie on page 21.

Advantages of Power Wheelchairs/Scooters
 from Mary Ellen and Ernie Buell

- * Good parking places (most of the time)
- * Always have a lap available for babies & pets
- * Don't have to worry about seeing myself aging - mirrors are too high
- * Get great seats at concerts, games and shows without waiting in line
- * Don't have to worry about slipping on wet tile floors or icy walks
- * Besides having a comfortable seat in long checkout lines, I can rush back for forgotten items when others are too exhausted
- * Can buy different shoe styles (clogs, boots, moccasins) that I've always wanted and they don't wear out
- * Don't have to iron the backs of slacks or skirts
- * In a room where others are searching for seats, I already have one
- * I can go faster and farther than everyone else for the first time in my life!!!!
- * I can push heavy items all over the garage
- * The able bodied have really gotta watch where they put their feet
- * My dogs are always beat and ready to rest after our 'Rolliess'
- * My 4 grandsons always have an amusement ride at the ready - round and round, figure 8's, fast forward, turn - fast reverse etc or just a lap to rest on
- * Of all these the wind on my face is the most powerful sensation I remember when I got my first scooter, it got only better with the electric chairs I have had as they are faster and much more controllable with only the slightest of effort on my part.

What I am doing now I have learned about PPS.

- * I'm reading more and dusting less.

- * I'm sitting in the yard and admiring the view without fussing about the weeds in the garden.
- * I'm spending more time with my family and friends and less time working.
- * Whenever possible, life should be a pattern of experiences to savor, not to endure. I'm trying to recognize these moments now and cherish them.
- * I'm not "saving" anything.
- * We use our good china and crystal for every special event such as losing a pound, getting the sink unstopped, or the first Amaryllis blossom.
- * I'm not saving my good perfume for special parties, but wearing it for clerks in the hardware store and tellers at the bank.
- * "Someday" and "one of these days" are losing their grip on my vocabulary.
- * If it's worth seeing or hearing or doing, I want to see and hear and do it now.
- * I'm trying very hard not to put off, hold back, or save anything that would add laughter and lustre to our lives.
- * And every morning when I open my eyes, I tell myself that it is special.
- * Every day, every minute, every breath truly is a gift.
- * "People say true friends must always hold hands, but true friends don't need to hold hands because they know the other hand will always be there."

Tips via Cilla in South Africa.

- * In order to prevent small children from leaving their bedrooms without your knowledge, just attach a small set of Christmas type, jungle bells on top of the door. The moment they move the door, the bells will alert you.
- * Try placing clean water into an empty roll-on deodorant applicator (rinse it out first). Then use it for wetting the back flap of envelopes in place of licking them, also a great idea for stamps.
- * Try using your ironing board as a temporary bed

Letters to the Editor

A LIGHT HEARTED BUT PRACTICAL LOOK AT P.P.S AND DIY

My Husband, Robin had Polio as a child. It affected his upper arms and legs. The result of this is that although he is very mobile, anything above elbow height is beyond him. We have divided the DIY jobs and gardening into two parts as follows.

In the allotment he now finds using a spade very tiring. I am frightened of worms (Yes I know that they are perfectly harmless and don't bite. That information cuts no ice I'm still terrified of them.) So I do the digging. (At least I can keep the little monsters at spade distance.) Robin does the weeding and the planting. It's low level and he can manage either by kneeling or by sitting down. When it comes to pruning he does the small stuff. (Under supervision or everything gets pruned down to six inches.) and I do anything that requires the loppers or a saw.

Recently our small pond needed its' three yearly clean out. Well, we knew that it was going to be a dirty job. We pumped out most of the water and I removed as many frogs as I could find to a bucket in the shade telling them that they were having their home redecorated. We have no fish. It is a nature pond. That done and the plants and water weed removed and sorted we were faced with about eighteen inches of slimy black sludge. Robin sat on the edge with his feet in the pond and, helped and 'assisted' by our two dogs he scooped the mud into buckets which it was my job to carry down some very slippery steps and empty into the compost bin. (We are going to have some very good compost this year) By the time we had finished and the frogs were back in their nice clean pond (I don't think they appreciated it at all) all of us, dogs as well were black from head to toe. We didn't smell too good either. BUT IT WAS FUN!!!

The same rules apply when it comes to decorating. This year it was the turn of our dining room. I stripped off the paper and hung the new then gave Robin a paintbrush to do the bottom four feet. All went well until we decided that we really would have to change the central light fitting. Now I know nothing about electricity and Robin couldn't reach it. So after being constantly reassured that, Yes the power really was turned off, and, No I wouldn't get a shock, up the ladder I went. Under constant instruction

from the 'foreman' at the bottom of the ladder I installed a new light fitting and fitted a plaster ceiling rose.

Our next problem was drilling a hole in a concrete window lintel. Now however hard I try drilling holes is just not my thing. The drill always wobbles and I break the bit or nothing goes straight. Somehow we had to get Robin and the drill up level with the top of the window. I climbed up one step ladder and bent over double making a 'bench' with my back. He climbed up the other step ladder and by leaning his elbow on my back could support the drill. Maybe not the most conventional way to drill a hole but it got the job done and the wind bell that we were trying to hang is now in place. I just hope that none of our neighbours were looking in our window at the time. I'm sure they would have asked 'What position is that?'

We have found that there is nearly always a way to do something if you give it a bit of thought and don't mind making a fool of yourself at times. The only thing that we have decided we would not attempt again is anything to do with plumbing. Our last attempt involved draining and taking a radiator down off the wall. All went well until the wrong nut came loose. I ended up going over backwards with a face full of dirty water and we had a small flood till we got it under control. So from now on the plumber will come to call.

Pauline Butler<ROBINBUTLER@care4free.net>

East Anglian Mobility Ltd has been up and running for just on five years now, started by husband and wife team, Peter and Tina Chapman and with occasional input from Tina's brother Nigel, a truly family concern.

The aim was and still is to offer quality products at sensible prices, the best advice and a service second to none. However Peter is keen to point out that the staff are only human and sometimes, not often, can get things a little wrong, if and when this happens they are only to happy to help sort things out.

He goes on to say, 'We are here to help people regain some of their lost independence and dignity by helping them to choose the best scooter or wheelchair (manual or electric) for their personal needs, not the one that gives the biggest profit, as happens so many times these days.'

Like some other mobility shops, they abide by the strict rules of conduct as laid down by the

British Health Trades Association and are also Motability accredited for the sale of Scooters and Wheelchairs.

Based in the picturesque estuary town of Maldon, where the famous sea salt comes from, they have just moved into the ex-Rover cars showroom, next to the Shell garage in Heybridge, Maldon. Now with a much larger show room and ample safe off road parking, they will be able to provide an even better service and a larger range of products.

Pop in for a visit, you will be assured of a warm and friendly welcome, like so many others do, you will not be disappointed. Even if you live some distance away why not ring or email them for a price. They will also mail or overnight items to customers. [Advert page 22]

R.E. PORTER, 2001

[Editors note - Despite distance from Lincoln, this firm was recommended to me in 1998 and they fitted a Bruno hoist to my Motability car. I had problems with my Bruno Scooter a couple of months back - this was diagnosed over the phone, replacement reconditioned parts and instructions were overnighted to me.]

PHIL THE COBBLER and THE CORDWAINER

I am a Polio Survivor. I trained as a shoemaker and repairer from the age of eleven at Lord Mayor Treloar College in Alton, Hampshire, under the wing of two of the country's finest shoemakers: Peter Shaw and John Haevan. At sixteen I passed my City and Guilds exam in surgical shoemaking. For the next five years I worked alongside Stan Knight, a City and Guilds examiner, and Bill Tuck at the Royal National Orthopedic Hospital at Stanmore, Middlesex. I thought then that I knew it all, but nineteen years of working in three of Lancashire's major companies has made me realise that there is never an end to learning. I opened for business as The Cordwainer in 1996 and have relished the challenge of being able to help so many people on an individual basis. Now in it's fifth year and having made around 950 pairs of shoes, I will admit there is still much to learn, but as long as my customers keep challenging me to improve my service to them, I will continue enjoy my chosen profession.

I am continually looking at ways to improve our footwear and your feedback is vital. During 2001 we attained ISO 9001 (New standard) and issue customer review

sheets regularly for this purpose. [Advert page 22]

Adaptive Equipment - Friend or Foe.

Most people who experienced polio in their earlier lives have overcome large physical barriers. Many regained the ability to walk and had no idea that in their forties or fifties they would have functional decline as if they had reached ninety plus. Very few considered themselves to have the label of 'disabled'. It's not surprising therefore that they react strongly when its suggested that it might be time to start using an aid or assistive device. To them its negative, a downward step, a loss not a gain.

Many of our elderly relatives say 'I am not that old' when its suggested that a scooter or electric rise leg raise chair might make life easier. It's the label that the equipment has on it that's the problem. Even the way its advertised can be offputting.

There is only one way to think of any aid or adaptive equipment that is offered to you. What difference could it make to your quality of life?

If you are being told that it could mean less pain, less fatigue and an ability to do more for yourself is it sensible to just dismiss it, or say 'maybe next year'.

Take your time and look at all the options that are on offer. Discuss this with other people, users and suppliers. Ask about servicing and repair costs, warranties and what they cover. Is it user friendly, will it fit in your house. If you need to transport it then how will you do that. What costs are involved and if you don't have the money then what funding options are there. How will your family and friends react to your using this new equipment. Very important is how long each day are you going to be using this. That is the minimum time - unless its made to measure - if at all possible that you should test it out to ensure its comfortable.

But most important of all is that its your decision, it's you who is going to use it and there is nothing wrong in asking for time to research and think about it.

Adapted from other articles by Hilary Hallam.

BEFORE PACING COMES FACING

**Report of the Management of CFS/ME Day
organised by
Lincolnshire County Council Social Services and
presented by Westcare Limited.**

[The title I have given this report comes from one phrase during the day that I believe is very relevant to Polio Survivors experiencing PPS. This report is taken from extensive typed notes. Due to the great overlap in experiences of the CFS/ME patients mentioned and ourselves there are occasions when I mention polio which was not necessarily mentioned at the time by the speaker. Post Polio was mentioned during the day not only by ourselves but also by health care workers with polio survivor patients.]

Westcare, are a charity in Bristol who have been working for 12 to 13 years exclusively with CFS and M.E. They are not a self help group, but provide advice and information on the illness to sufferers and for health professionals. They are involved in research, training, discussion, are part of the Task Force on CFS and provide rehabilitation courses for patients including individual appointments with trained counsellors.

Westcare UK, 155 Whiteladies Road, Clifton,
Bristol. BS8 2RF 0117 923 9341
www.westcareuk.org.uk

The Lincolnshire Neurological Alliance were offered a place at this event and I took advantage of this. The whole days event was attended by a wide variety of Social Services Staff and there were plenty of occasions where the similarity with Post Polio and Fibromyalgia - in fact that the problems being discussed went right across neurological conditions - were brought up. Some good contacts were made and requests were made for more round the table discussions patients and staff for the benefit of all.

The first speaker was Professor Peter Champion, PhD FRCGP MRCP(UK) DCCH Professor of Primary Care, University of Hull. He was a GP in Liverpool and still works one day a month. He is well published and runs a fortnightly clinic for people with CFS.

He started by making assumptions that those attending had a little knowledge of M.E./CFS. Is it new? We do not know but how many remember the diagnosis of 'Neurasthenia' that used to be written on sick notes when he was a GP. This was first described in the USA by George Beard and then Van Dreusen in 1869. Then Cobb in 1920 as undue excessive fatigue. It did not contain exclusions. There was

controversy over the cause. Peripheral, central, social and psychological. In fact A.J. Cronin who wrote Dr. Finlay treated it with magnesium injections. It now includes depression, coded as ICD9 and ICD10. In the list of diseases. 0.3% were recorded as having Neurasthenia in 1987 in Germany.

From Neurasthenia to Chronic Fatigue Syndrome and then in the Lancet to M.E. 1956 561 789-90 following the incidence at the Royal Free Hospital where many staff became ill.

There are clusters of M.E. in children. There are Post Viral theories that Polio and Epstein Barr causes Glandular Fever. Looking for explanation in the 80's was looking for persistent viruses. After false starts this was not the case. It's now accepted that its not persistence of virus. There is a link with glandular fever but that is a specific fatigue syndrome following glandular fever where most recover effectively.

One important point he made was that not all research is true. There is a danger in thinking that because its been published it must be true. Up until about twenty years ago it was common for some to pick research that matches their theory to write their narrative

Dr. Clare Fleming MRCGP was the next speaker and she had suffered with ME for six years. She explained that it is not like golf where you hit a ball and see where it goes, it's more like snooker where you hit one ball that hits others and they can go in many different ways. One problem in dealing with CFS is that there are variations of the illness that overlap. There is a great need for early recognition of symptoms so that the patient can see that something is happening. The longer it takes for your reported symptoms to be taken seriously the more problems you are likely to have. Regardless of neurological condition the problems are the same. Problems with trying to keep on working, applying for benefits, your family understanding that you do have a condition and are not shaming, being given appropriate aids and equipment to help you manage your life, etc etc. The longer this takes the more stress you go through, and stress makes us worse.

She spoke of serious consideration and discussions with your health professional being given to 'should I have the flu jab', 'should I go on holiday to a country where I need to have many inoculations', 'should I have surgery', 'should I stay in the house when its being spring cleaned with many chemicals'? These are all things that have been known to cause relapses. Another cause of relapses is doing far too much, pushing yourself beyond the limits. The best thing to do is to weigh up the pros and cons and make informed decisions.

What you have to do is to be realistic. What is wrong with me? What can I do about it? This is reality, it's not going to go away overnight. Think about the bad days and ask yourself 'Did I do anything to make it bad?' If you did then plan the next time you want to do a similar thing differently. Take a positive attitude. How often have you heard about Graded Exercise, when actually Graded Activity is where you should start. Pace and Rest and spread your available energy through the day for when you need it. Think of it like a see-saw. You have energy and you have activity to do, if you balance it right you can see-saw gently up and down, if you don't then you are either stuck up in the air, or bogged into the ground.

There are two different groups of people. One group deal with it by denial. Look at the needs of others and are focused on doing, doing, doing. They don't look at what's going on inside and are too active. They are not listening to their own resource level and at a cost to themselves. They are unrealistic about their own needs. They tend to get caught in a trap of doing things, don't stop till exhaustion and then drop. They are then all behind and try and do twice as much to catch up, its a vicious circle and they are trapped.

The other group tend to withdraw in case they get hurt or harmed. Their primary goal is avoid getting harmed so they stay in a safe and secure boundary. They try something and it makes them worse so they are fearful about what they are being asked to do. They put up a brick wall and disengage. If what they are being asked to do is far too much then on one level its helpful to do this, but the problem lies when they do too little and lose what fitness they do have. Fitness is not only physical but also emotional. If you stay at home and do not go out and are then suddenly confronted by a huge crowd of people you can be totally phased by it and stay in even more.

She advised that health professionals must get to know who they are working with. Ask them how do they feel about what is happening to them and their lives? The important thing is that whatever you call your plan to help them it must be Graded Activity first based on their daily life. It could be as little as sitting up in bed for ten minutes instead of five. It could be getting whole self dressed instead of half dressed. You must treat them like an adult, become a friend and work together on realistic goals. If the goals are realistic and achieved then you can plan the next goal. Complimentary Therapy can be helpful but often this is not possibly financially.

To summarise. It has to be teamwork, there are other health professionals and other people in this persons life that also need to be included. You must consider the whole person and identify the symptoms and problems. Identify perpetuating factors. Choose

priorities and set realistic and achievable goals. Support and encourage. Think like a jigsaw. If you put the pieces together you get the whole picture.

The whole person is divided into three - Mind, body and spirit - if one does not work properly it changes the shape of others. Find out what problems are relevant to the client at this time in their life and work off that list. What is most important to them. Remember you can eat a whole elephant but not all at once! The following many of us will relate to...

I used to be able to run for miles
but now I can't even jog my memory

Don't disturb daddy he is having a rest so
that he has the energy to go to bed.

Pat O'Hara, MSc BA Dip COT SROT an Occupational Therapist with her MSc in Pain Management has worked with Westcare patients both residential and in the home environment for eight years.

Firstly you need to know that the people you will be visiting could be sensitive to chemical smells, so it is important that you work scrubbed clean and without perfume.

A lot of clients have more neurological problems than you would expect. Pins and needles; one side does not seem to work right; this part of my body feels like a dental anaesthetic wearing off. This can be more frustrating when tests that are done come back without an answer for the symptoms. Too often the person is 'not believed' 'it's all in your head'. You must listen to what the person is saying to you and work from that.

How difficult is it to explain to a boss that some days you can work ok, but others you are so tired you have to spend them in bed, explain to your kids that yes you did manage to take them to football last week but this week you don't have the energy? How difficult is this when there are still health professionals who do not believe that the condition exists?

Again she emphasised Graded Activity. Work to your patients level. Ask them what would they like to achieve? Help them to do that. Help them to change their daily life by managing it in chunks. Provide the right equipment to help them achieve their goals. Prioritise and plan ahead.

Rest means rest. It means turning the phone to ansaphone, disengaging the doorbell. Not reading a book, or watching TV, but in a darkened room, suitably comfortable so that your mind and body can switch off. [See positions of rest on page 19]

There are other times when you can relax with soft music playing, watching TV, but remember this is relaxing and not resting. It also needs planning into the day.

Kate Sweeney MCSP - see article page 18 and 19 - specifically mentioned relaxation. It is an art and has to be practised. It can help improve circulation. Helps prevent leaky energy batteries. Eases pain in joints and muscles and calms the mind. There are various methods, stretching groups of muscles that tend to get tight, tighten and relax muscles in turn, think about your body and it resting, visualise using music and sounds like softly lapping waves. Complimentary therapy like reflexology although its not suitable for everyone. Breathing techniques. The Alexander technique is particularly good where you teach them to think about the tension in an area and then 'let it go'.

Work on economical movement. Think how you do activities and if necessary change the way you do it, or break it down into smaller chunks with rest in between. How hard do you grip the toothbrush to clean your teeth and how vigorously do you do brush them? Can you reduce the tension in the way you do this? Would an electric toothbrush help?

Kate runs a class on exercise for people with M.E. She starts with relaxation and then goes through a set of exercises that can be done standing or sitting and everyone repeats these to their level. The exercises are a guide to help your fitness. People are encouraged to do whatever suits them, which can go from not doing it, through one repeat, to repeating it five times. This enables everyone to get out of the class what they need. She also teaches breathing to go with each exercise, e.g. breathe in as you stretch your arms out and breathe out as you bring them back in. [How often do you stop breathing to concentrate on the activity you are doing?] It is important not to have contractures in limbs and if that is happening and exercise is not possible then you need to have passive therapy prescribed for you. [where the therapist does the moving of your limbs, and uses light massage to help circulation]

Marie Simmonds PhD BSc BACP Registered Counsellor - then spoke about the need for counselling. She told of many patients reporting 'not being believed' 'its all in your mind', being passed from consultant to consultant with each looking at one bit of you and no-one looking at the whole person, totally opposing reports from consultants who have differing views on the condition. Distressed about what is happening to you? Have you felt frustrated, confused, doubted yourself and others, angry and fearful of the future. Do you think much of

this is associated with the problem you have had getting a diagnosis - all those unproductive medical appointments where you leave no better off than when you arrived?

Did anyone ask you about your previous life, what qualifications you have, what employments, what hobbies? Were you asked how you felt about the changes that are happening to you, how much of your daily life you can now manage compared with a few years ago? Have you been to the neurologist or other consultant who referred you to a psychiatrist who after spending an hour with you tells you 'you don't need a psychiatrist you have a medical problem and need to see a doctor'. Some ME patients report then being told by the doctor that they are suffering from hysteria and need to see a different psychiatrist!

Are you confused, doubting reality, wondering if maybe your doctor and family are right, how can you face what is happening to you when you don't know what you are facing. Are you finding you can't hold down your job, you are not the breadwinner any more, you are sitting there watching your wife mow the lawn.

Another is shame. You recovered from polio. Now you are having to claim benefits which is bad enough in itself but then you get turned down. Did you experience a DHSS Medical examination where you were asked to stand from a chair, walk a few paces across a room, pick up something from the floor and told you look alright to me?

Teenagers struggling with ME who find it hard to attend school manage to get there that day and due to lack of understanding of the condition can be met with 'Oh you have decided to put in an appearance today'. Shame drives people to do far more than they actually can. Many have spent all the family savings and even taken second mortgages trying to find a cure.

So how can you cope? There are two functions to coping, one is the management of the problem and the other is the regulation of the emotions. Did you notice a change in yourself when you learned PPS existed, and/or when a medical professional diagnosed you with PPS and gave you medical advice, information, and possibly aids to help you manage? CFS Clients tell their story to me. I help them make sense of what's happening to them. They are helped by having someone listen and believe them, to empathise and validate their experience.

At Westcare we make sure our clients are comfortable, chairs, cushions, curtains closed because bright light affects them, whatever they need. Often there is a sigh of relief when someone finds that a

particular symptom is also experienced by others 'So I am not a nutcase then?'

Often the largest problem is wondering where can I get a diagnosis? Without a diagnosis what do you tell people what's the matter with you. No diagnosis not regarded as legitimately ill and this leads to problems with claiming benefits. Some would rather have another condition that ME/CFS, one that is well recognised, even cancer, just to get away from the roulette of finding medical professionals who understand your condition.

There is a lot to cope with. You have to face up to losses that you experience. There is a long list, financial security, career, wife wanted kids but because of ME we don't have a family and that is painful. Loss of employment, home repossessed, move to a different part of town and lose social network. Change GP, inadequate needs in accommodation, poorer diet can all lead to a further deterioration in health. Having to give up a car, or just not having the energy to drive. Sudden withdrawal of DLA and you have to find the energy to appeal, and for some again and again. Many have won their appeal and then had a major collapse and become worse, even bedridden through all the stress. Polio Survivors go through this as well - and so do many others with neurological conditions.

To promote recovery with clients with ME I first have to help them face their problems before they can pace themselves. It can be hard sometimes on a good day and some think 'maybe I am not ill after all?' We have to balance activity and rest. Animals know this [large laugh from audience] so why not humans.

You are in a war of competing factions. It's a minefield. You need to find a still calm place inside you to move from being the victim to a sense of competency. To feel you have the symptoms rather than they have you. Pacing [and using aids and equipment] will allow you to regain control and give you a sense of satisfaction and achievement. Important is prioritising. Look at your life and decide what really matters. Ask yourself the question, 'What do I want out of my life?'

Some people live alone but they still have family and friends. Relationships can be a key part of this but also a double edged sword. They have the capacity to offer support but also to be a real source of stress. Give too much meeting others needs and not address their own. You have to set boundaries so relationships do not get toxic. Carers feel swamped by their own feelings, daunted by no matter what they do they can't work miracles and bring about a cure. It is very important to build supportive networks and be aware of toxic relationships.

Coping strategies you used to have may be gone - have you ever gone out and dug the garden or scrubbed the kitchen floor in anger? You will now have to find some different ones. Be creative, write it on a 'Pooh' stick and watch it float away - and for those that can't get out of the house there is alternative paper and a flushing system!

You may have to make your own decisions about how you manage your life if you get conflicting views from different health professionals. The problem is that we get stressed because we have difficulty being believed - and this goes right across the neurological conditions board. In fairness to most health professionals there is a massive amount of knowledge and information on each condition and they cannot be expected to know everything about every condition. What would be nice is that if they do not have much knowledge on your condition that they acknowledge this and refer you to someone who does or tell you and work with you to help you manage your condition.

Polio Survivors remember answering 'yes' to Can you climb the stairs does not tell the person asking you that you are sitting on your bottom and going up backwards! Remember to qualify your answers, Yes but I..... And as soon as you find something that helps you relieve pain, reduce fatigue, reduce stress then use it. Plan it into your life.

Hilary Hallam

80 Years ago a Kentucky grandmother gave a bride the following recipe for washing clothes.

- 1 Bilt fire in backyard to heat kettle of rain water.
- 2 Set tubs so smoke wont blow in eyes if wind is pert.
- 3 Shave one hole cake of lie soap in bilin water.
- 4 Sort things, make 3 piles. 1 pile white, 1 pile colored, 1 pile work britches and rags.
- 5 To make starch, stir flour in cool water to smooth, then thin down with bilin water.
- 6 Take white things, rub dirty spots on board, scrub hard, and then bile. Rub colored, don't bile, just rinch and starch.
- 7 Take things out of kettle with broomstick handle, then rinch, and starch.
- 8 Hang old rags on fence.
- 9 Spread tea towels on grass.
- 10 Pore rinch water in flower bed.
- 11 Scrub porch with hot soapy water.
- 12 Turn tubs upside down.
- 13 Go put on clean dress, smooth hair with hair combs. Brew cup of tea, sit and rock a

**Management of CFS/ME
from a Physio's perspective.
Kate Sweeney, M.C.S.P., S.R.P.
Westcare UK - Bristol.**

PRIORITY

Energy Management. We use energy with physical, mental, and emotional activities. **The BRAIN uses 20% of energy.**

Sensible management is achieved by:-

- 1 PACING.
- 2 CONSERVING: dont let it drain away.
- 3 GENERATING: recharging your batteries.

TACTICS to prevent using too much:

- a THINK before you ACT. You can't afford to be SPONTANEOUS until you are well on the road to recovery.
- b THINK. Do you have to do it NOW? Do you have to do it AT ALL?
- c BREAK DOWN TASKS into manageable proportions.
- d Don't do TWO THINGS at once, e.g. read and eat, talk and drive.

PACING.

Interspace ACTIVITY with REST. The rest is like a full stop after a sentence (which is the activity). How long the activity and rest periods are depends on your condition.

The AIM is to gradually increase activity and decrease rest. Have REALISTIC GOALS. Don't aim for the top of Everest straight away. Visit every base camp, there may be many, but there's a different view.

Depending on your condition DAILY LIVING ACTIVITIES can be enough exercise. As you improve increase your walking, go to the swimming pool, and move around in it (exercise) rather than swim lengths. Practice YOGA or CHI KUNG. If you go to a class YOU must be in CONTROL and REST when your body tells you to.

CONSERVING.

Use minimal muscle work to maintain positions and to move, think about how you are doing activity e.g.

- Sit with back and arms supported to eat a meal if in a severe condition.
- Don't grip the toothbrush, pen, phone, steering wheel too hard.

- Have good posture at all times (ALEXANDER TECHNIQUE is helpful)
- Develop a calm mind.

GENERATING.

RELAXATION - MIND AND BODY will:

- Increase blood supply
- Improve function of immune system
- Produce calmer brain waves
- Reduce anxiety
- Lower blood pressure, pulse and respiratory rate.

METHODS of relaxation:

Contrast - tighten a muscle group, then let it go and release the tension. Start at the feet and work up the body.

Physiological: (Mitchell)

Autogenic approach.

Alexander Technique

AIDS FOR RELAXATION.

Suitable resting position.

Correct breathing. This also prevents hyperventilation.

Massage.

Visualisation

Meditation

Reflexology

Tapes with instruction on relaxation / meditation, natural sounds, calm music. Find out what suits you.

JOINT AND MUSCLE PAIN.

Aids: Positioning.

Relaxation.

Heat. Hot/Cold - jelly packs available from some chemists.

Gentle stretching

Acupuncture

Reflexology

Massage

T.E.N.S. machine available from Boots the Chemist.

C.B.T. (Cognitive Behavioural Therapy)

Find out what suits you.

SET BACKS.

You will have them.

Temporarily reduce activity.

Don't blame yourself. Learn from them. Even if there is no obvious reason for it, BELIEVE that you will OVERCOME it.

Always top a negative thought with a positive one.

FULLY SUPPORTED RESTING POSITIONS.

INTRODUCTION.

The joints of the body are very sensitive, that is they have many, many nerves around them. When a joint is rested and fully supported in a position which does not stretch any ligaments or muscles it sends few messages to the brain.

This rests the BRAIN and the body.

The four positions described here can be modified to suit your needs.

CROOK LYING: lie on your back with your knees bent, use as many pillows to support your knees as you feel you need. This puts the lower back in a comfortable and well supported position. Support your head with one or two pillows. Place each arm on a pillow giving support from behind the shoulder along the length of the arm, wrist and hand.

SIDE LYING: is using as many pillows under the head as required. To support the arm which is uppermost support the arm with a double pillow. A pillow is then placed along the length of the back and 'tucked in' a little underneath you. This prevents you from rolling backwards. One or two pillows are placed between the knees and this puts the hips and knees into a position of comfort and prevents the pelvis from rolling outwards.

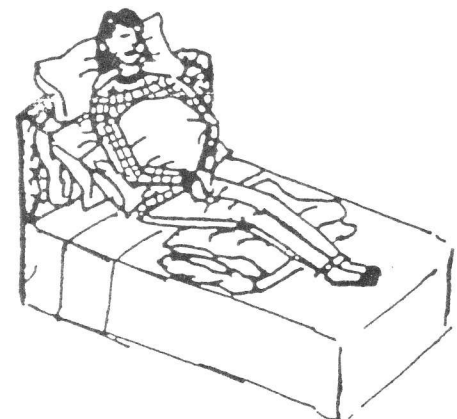
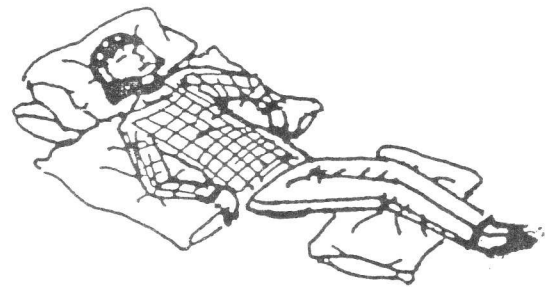
LONG SITTING; this is the position that people sit in when sitting up in bed. Put as many pillows behind the head as you need to support the head so that the muscles of the neck and shoulder girdle can let go. To further support the shoulder girdle, place one or two pillows across the front of the chest with the arms rested over the top of these pillows. One or two pillows will be needed to support the length of the back. Beneath the knees, it is important to have the support of one or two pillows, if the knees are left in a straightened position in long sitting, it can stress the muscles at the back of the leg.

CHAIR SITTING: sit in a high back chair with arms. Ensure that the head is fully supported using pillows or cushions if necessary. Some people find a small roll in the lower back supportive. This roll can be made by folding an 8" cushion in half, forming a roll which is approximately 4" in diameter. It is placed across the lower back at a level at which your forearm would reach across your back and is a little above your belt line. To support the shoulder girdle, place one or two pillows across the front of your chest with the arms resting over the top of them. The forearms may be rested on the arms of the chair or lightly placed on the lap. Ensure that your feet are comfortably rested.

Try using all the above positions to see which one you prefer. Lying positions give a great deal more rest than sitting positions. Remember that rest is giving the brain minimal information from the body or from the mind. When you sit, your balance reactions are constantly sending information to the brain. When you lie down, the amount of information coming from the mechanism is greatly reduced. Remember that closing your eyes reduces the amount of information being sent to the brain.

Do not allow yourself to fall asleep whilst resting, rest and sleep are very different activities as regards the nervous system.

Attributable to the CFS Team, Havering Hospital NHS Trust & BUPA Hartswood Hospital.



PPS MENTIONED AT EUROPEAN HEALTH SUMMIT

Post-Polio Belgium met with the Belgian federal minister for public health, Mrs. Magda Aelvoet, and briefed her about the problems facing polio survivors and how these should be approached in Belgium and the rest of Europe.

Mrs. Aelvoet presided over the European summit for the fifteen EU ministers of public health on the 15th November 2001. As promised she added PPS as a miscellaneous item to the Agenda.

As requested by Post-Polio Belgium we made strenuous efforts to ensure Ministers attending from the UK were aware of PPS from a UK perspective. Here is the official report from that meeting.

Title: Health Council 15/11: Minister Aelvoet satisfied with results.

Category: Press Releases by the Belgian EU Presidency

Description: The Federal Minister for Public Health, Magda Aelvoet, is satisfied with the results achieved by the Health Council held today.

1. Agreement was reached on quality and safety standards for the collection, testing, processing, storage and distribution of blood and blood products. A large number of ministers were able to identify with the text in which the Member States undertook to encourage the voluntary and free donation of blood. Member States are entitled to refuse blood imports that do not meet their requirements regarding free and voluntary donation.

2. Agreement was also obtained on the recommendations relating to the prudent use of antibiotics in human medicine. Member States pledged to adopt measures to combat resistance to antibiotics, to inform their citizens of this problem and to ensure that it was not ignored. As of tomorrow Belgium is launching its second information and awareness-raising campaign on this issue. A European conference on antibiotics also started today. The outcome of this conference, the Council recommendations and the campaign will be presented at a press conference tomorrow (15.00 hours at the Métropole Hotel, Brussels).

3. The third important matter on which the Ministers agreed was the fight against problems connected with stress and depression. The conclusions of the Conference held on 25 October were unanimously adopted. They concerned the adoption of measures to improve mental health, thus preventing stress and depression. To this end Member States will collate and exchange data, and will also cooperate with the

WHO.

Minister Aelvoet asked the European Public Health Ministers to turn their attention in their countries to post-polio patients. People who had survived polio were now affected by post-polio symptoms that were disrupting their lives once again.

At the proposal of Minister Maréchal from the French Community and of Minister Vogels from the Flemish Community, the conclusions of the Conference on "The role of health promotion in tackling inequalities in health" were adopted by the Council. They concern socio-economic indicators likely to have an influence on health.

The ministers also agreed on the approach to be adopted to biological terrorism. They demonstrated the necessary political will, based on efficient and rapid cooperation, to find a response to problems that could emerge for European citizens. Existing networks will be used for this purpose, adapting them where necessary.

CONTINENCE AWARENESS WEEK 2002

Continence Awareness Week 2002 will be September 16-22. The theme is "functional incontinence" i.e. about people who have some impairment which leads to their being incontinent e.g. for physical reasons they can't get to the loo in time or have difficulty undoing their clothes, or they don't remember to go. As you can see from this vague statement, it is difficult to define in common language -- we have clinical advisors who can do it in medical language.

We would like to involve as many as possible of the Neurological Alliance members in helping to define the theme in more detail and suggesting people who could have input to the leaflet that will accompany the week. There is a committee of continence charities which prepare for the week and anything sent to me will be circulated to them. One of these charities, Promocon, specialises in continence products and also adaptations to clothing, so we have considerable knowledge for that side of the theme.

Dr. Judith Wardle, Director
The Continence Foundation
307 Hatton Square
16 Baldwins Gardens
London EC1N 7RJ
Tel: +44 (0) 20 7404 6875
Fax: +44 (0) 20 7404 6876

Recent Events

WHAT A SHOCK!

On Sunday 28th October 2001 Frank and I had just returned from Birmingham with my friend who was staying with us for a week's break. We got home about 3.30 in the afternoon.

I decided to go into the bedroom and put some of my clothes away as we had also been staying with my grandchildren for the week-end.

Suddenly there was a huge bang and wobble and I thought either a car had hit the house or, as we live close to a lot of military airfields, a plane had crashed. Frank thought I had fallen over in the bedroom which I am prone to do. I know I am a bit heavy, but really!!!

We all went outside to see if there was anything about and all the neighbours were coming out of their houses, like rabbits out of the warren, all wondering what had happened. I think we all stood there waiting to see if there would be another one.

We discovered later on the TV news that we had had an earthquake with the epicentre being about 15 miles away, the first report was a 3.8 but apparently it measured 4.1 on the Richter scale.

Believe me, this was scary, so the really big ones must be horrendous. I have experienced earth tremors before, in England, but nothing on the scale of this one and believe me I do not want to experience another one - but who knows. What with serious floods, gales and now an earthquake, I wonder sometimes what mother nature has in line for us next. The only thing we seem to be missing is good old sunshine. Even the birds and flowers do not seem to know what season it is. I suppose these are the joys of the unexpected.

Wendy Grimmitt (Hon Sec)
<wendy.grimmitt@lincolnshirepostpolio.org.uk>

IS IT OK TO LAUGH NOW?

As you know, humor is my "thing." With the events of the last months, I find that I feel a little bit guilty about continuing to laugh and enjoy my life when so many have died. However, I've given it a lot of thought and here's what I decided.

Terrorists live to induce terror. If I refuse to live my life in a state of terror, they cannot win. Terrorists want to divide us, to say to us. Look, that person is different from you, you hate him, don't you? I say to them. We are all different, none of us is identical to

any other. In my case, my two legs don't even match. Terrorists want to disrupt our lives to the fullest possible extent. By going about our business every day, we win a small part back from them.

It saddens me so much to think of all those victims but I refuse to be a victim myself. The firemen, the policemen, and indeed the people who died in the attack, were all going about their business, doing what they did best. It would be a dishonor to them to let the humorless terrorists win even one small part of my day.

Laughter is such good medicine for us. Most of us cannot exercise to keep our bodies in shape and depression makes limp noodles of all its victims. I read somewhere that 100 belly laughs is as good as a 45 minute workout for our entire body. What a concept. The thought of working out for that length of time is pretty scary to me. However, watching a really funny movie or reading one of Dave Barry's or Erma Bombeck's columns is a much more pleasant prospect. One lunch spent with my sisters or friends usually generates enough laughter to cancel out the calories of the lunch itself, so think of laughter as a diet aid, if you will.

Laughter releases a chemical in our brains that is a natural pain killer. It's free, too, which, in my usual state of financial distress is also a pain killer. And guess what? Laughter is a lot more contagious than Anthrax. Think about it...remember the school bully? The best defense against him was to get others to laugh at him. You cannot feel pain while you are laughing.

Let's stay informed, but let us also spend as much time each day watching a child at play, or kittens, or funny movies as we do watching the news. Give your best buddy a phone call, say a pleasant word to your neighbor, hug your Mom. We cannot bear arms, but we can do better than that. We can bare our teeth in a hearty laugh and thus defeat terrorism in our own small way.

Millie Malone
GLEANINGS - Nebraska Polio Survivor Association.

[Editors note - Chris Salter and I were speaking on the phone when the events of September 11th appeared on our tv screens. We just could not believe what we were seeing. We were concerned for our American members families and friends and are pleased to report that all are O.K. Last January I met PPSer Jo and husband Kevin Kelly - a NY City Fireman - on their way home from The Keys. They were on holiday in Crete on the 11th but managed a flight back four days later so Kevin could return to work. He lost many colleagues. Our thoughts are with

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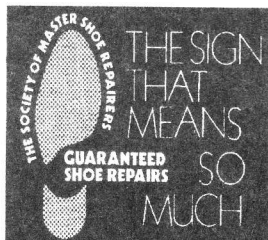
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Visiting the British Museum

Not only is this a wonderful museum to visit they provide some free parking for the disabled in the grounds of the museum by prior arrangement. This can be arranged by telephoning the Information Desk on 0207 323 8299; Please have your vehicle details ready and the times you wish to be at the museum. When you arrive they open the main gates and direct you to an area in front of the building close to a lift to take you up to the level of the top of a large flight of stairs at the front entrance. There is no entrance fee to the main museum although there can be special exhibitions with a cost. There is so much to see that you really need more than one visit.

Disabled toilets are easily found. Mostly there is plenty of room to get about - school children sitting on the floor drawing specific items can make life a little difficult at times, although we learned to go the opposite way. The best part of the visit was later in the day when you see the envious looks at your wheels and seat... and the bubble coming out of their head 'I wish I had one of those my feet are killing me'.

Whilst at the museum I enquired about a Stela showing an Egyptian with possible polio. I had seen this used at a Post Polio Conference a few years ago and seeing all the ancient Egyptian items remembered it. Marcel Maree, the Curator of Ancient Egypt and Sudan provided me with a photocopy of the Stela which is in a museum in Copenhagen, Denmark. He also told me about another possible piece of evidence of polio during those times. They had a scan of a mummy of King Siptah and it shows a club foot, although he said there are two schools of thought, one says its just a club foot and the other says its definite evidence of polio.

A book that we might find interesting is J. Filer, *Disease*, British Museum Press 1995. It deals specifically with disease in ancient Egypt, and in several places touches on instances of poliomyelitis.

Marcel Maree
Curator of Ancient Egypt and Sudan
British Museum
Great Russell Street,
London.WC1B 3DG
<http://www.thebritishmuseum.ac.uk/>

Whilst researching on King Siptah I found the following two pieces about the first known records of polio in the UK.

Sir Walter Scott (1771-1832):

"I showed every sign of health and strength until I was about 18 months old. One night, I have been often told, I showed great reluctance to be caught and put to bed, and after being chased about the room, was apprehended and consigned to my dormitory with some difficulty. It was the last time I was to show much personal agility. In the morning I was discovered to be affected with the fever which often accompanies the cutting of large teeth. It held me for three days. On the fourth, when they went to bathe me as usual, they discovered that I had lost the power of my right leg ... when the efforts of regular physicians had been exhausted, without the slightest success ... the impatience of a child soon inclined me to struggle with my infirmity, and I began by degrees to stand, walk, and to run. Although the limb affected was much shrunk and contracted, my general health, which was of more importance, was much strengthened by being frequently in the open air, and, in a word, I who in a city had probably been condemned to helpless and hopeless decrepitude, was now a healthy, high-spirited, and, my lameness apart, a sturdy child."

First known published clinical description of polio from a British doctor, Michael Underwood, in 1789.

"Debility of the Lower Extremities"

"The disorder intended here is not noticed by any medical writer within the compass of my reading, or is not a common disorder, I believe, and it seems to occur seldomer in London than in some parts. Nor am I enough acquainted with it to be fully satisfied, either, in regard to the true cause or seat of the disease, either by my own observation, or that of others; and I myself have never had the opportunity of examining the body of any child who has died of the complaint. I shall, therefore, only describe its symptoms, and mention the several means attempted for its cure, on order to induce other practitioners to pay attention to it. It seems to arise from debility, and usually attacks children previously reduced by fever; seldom those under one, or more than four or five years old. The Palsy ... sometimes seizes the upper, and sometimes the lower extremities; in some instances, it takes away the entire use of the limb, and in others, only weakens them."

Polio in Ancient Egypt.

The stela on the front cover is from the reign of King Amenhotep III, i.e. from the first half of the 14th Century BC. (18th Dynasty). The depicted man seems to be unknown from other sources.

King Siptah was a Pharaoh who reigned at a somewhat later age, during the start of the 12th Century BC (19th Dynasty).

Siptah was born in Egypt and his mother was Queen Twosre, widow of Amenmesse. When he was a boy, he was struck with a terrible disease. When he recovered he was left with a withered left leg and foot was rigidly extended like a horse's hoof.

Searching on the Internet on Siptah produced some very interesting information, although sometimes the dates differ. However it appears that he reigned for only six years, dying at about 18, that his mother was co-regent and after his death became Mistress of Upper and Lower Egypt. King Siptah was buried eventually in the

Valley of the Kings and his tomb remained undisturbed until 1905 when the the tomb was excavated.



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