



## THE LINK-PIN

### Lincolnshire's Post-Polio Informative Newsletter No. 2 - November 1996



### To Medical Professionals from the Polio Survivors of the World

**'75% of Polio Survivors are non visible.'**

**1.63 million in the USA - Over 1.7 million in China - 50,000 in the UK**

**How many in the World ?**

There is overwhelming evidence that Polio Survivors are experiencing new problems. Polio Surviving Doctors, Nurses, Teachers, Engineers, Scientists, Authors, Managers, the list is endless. So please spend time with us, talk with us, listen to us. We are not trying to dupe you.

Why would we want to give up our jobs and trade economic prosperity for poverty? Why would we not want to do things with our children? Why would we want to deny our goals and aspirations? Why would we want to throw all the years of training away? Why would we want to sit on the sidelines watching when just a short time ago we were playing?

Be careful of locking yourself into one theory and one way of thinking. Don't restrict diagnosis to **THE** test. Be expansive and ever enquiring, stretch boundaries.

Recognize and encourage our wholeness. We know our own bodies, we have lived in them for many years. We have pushed them to the limit and beyond, over and over again. We know what they were capable of when we were at our best recovery, and if we listen to our bodies, we can see the changes. Understand where we are coming from. Listen to the stories of our experiences in hospital, if we can remember them. Counsel us and ask how we coped with being 'less able' than others, what did we do to succeed. Trust us, and work with us. Help us to redefine our lives.

**Remember we are counting on you.**

## **Editorial**

Two months have passed since our first newsletter, where did the time go? Welcome to all those now reading this newsletter, we do hope that you find the articles interesting and informative. Feedback is imperative for us to improve on this newsletter and the post-polio support that we can give. This newsletter is being read by polio survivors and medical professionals in this country and via the Internet by many others. It is not an easy task choosing what to include from the many hundreds of articles we now have copies of, but we hope that over a few issues we will be able to cover many different topics. Professor Peter Behan has let us know that in a few weeks time he will be writing an article on post-polio for publication in a British Medical Journal. As other Post-Polio Support Groups Newsletters we have added a few jokes which we hope will make you laugh - always the best medicine.

We really want to hear from you regarding anything you have read in here or elsewhere on post-polio. Come round and see all the information, help us with the work.

What do you think about what you are reading?

How can we best help you personally, more information, more stories, etc.,?

Would you like a Post-Polio Clinic in Lincoln?

Who would you like to see working in this clinic,  
and how do you think they could help you,  
with the symptoms you are having problems with?

Have you any tips to pass on to others about how you manage to do certain tasks. I can remember back about ten years when I went windsurfing and the instructor said 'I have never seen anyone stand up on a board like that before'. How do you get up from the floor; from a chair onto a consulting couch - that is if it is wide enough - carry things from kitchen to dining room, get the washing downstairs etc. If you have any tips on anything that you think others might find interesting, it does not have to be just on polio, it can be cooking, craft, anything that you think might be of benefit to others, please write and tell us.

May I take this opportunity of thanking Shaun very much for writing his [story](#) for this newsletter. Can I also thank all those in this country and on the Internet, far too many to mention each one byname, who have offered help to us as a Network. But special thanks to Jimmy and Jin from China, a wonderful [story](#) and something to look into. Jimmy is to be congratulated on his command of english after just three months, and thankyou for allowing me to publish this.

May we take this opportunity of passing on

**SEASONS GREETINGS TO YOU ALL.  
WE WISH YOU ALL THE VERY BEST FOR  
A HEALTHY AND PROSPEROUS NEW YEAR**

**ARTICLES PUBLISHED IN THE LINK-PIN.** *Remember the opinions expressed are those of the individual writer(s) and do not necessarily constitute an endorsement or approval by the Lincolnshire Polio Network. Although it does not provide an endorsement, it is provided as a service for those seeking such information. Always consult your doctor before trying anything recommended in this information or any other publication.*



## COMING HOME

Travelling in an ambulance was not unusual, but this trip was special. I had been isolated from my four older sisters and big brother for 366 days, yes one year and a day.

It must be the middle to late September, a bit chilly outside, the ambulance men wrap a red blanket over me, which seems to have been woven from barbed wire, and was nowhere as comfy as the cream ones with the holes in.

I am delivered home. Home, this can't be home. It's about the size of a biscuit tin, contains all manner of things, a table and six chairs, a side board, a piano (upright), a three piece suite, a dog, now that's different I haven't seen one of those before, but best of all an open fire, roaring away in the grate, that's why they call it great, because it is. The fireguard seems to be made out of solid brass, but upon closer inspection has tiny holes left between the weave; I swear you could have watched an eclipse of the sun through it without any damage to your eyes; and my bed placed under the window, not in front of..... but next to the fire.

Home! This is the woman who came to see me each night, but where's my mum? I begin to cry for her, the woman tells me it's all right and that she's my mum, I know she's not, she doesn't wear a hat or uniform like my mum.

Unbeknowingly to me, my eldest sister, Dawn, had seen the ambulance arrive and had hastily asked the teacher if she could pop home to see me (we lived opposite the school), she arrived almost as soon as the ambulance men left. A young woman wearing a uniform, 'I want to go home, please let me go home nurse'. She looked taken aback, tears flooded her eyes, we were all crying. Dawn gave me a cuddle and said, 'You are home Shaun'.

**Shaun Hardy then aged two and a half.**



The following article '[Bouncing Back Without Guilt](#)' by Wendy Clyne PsyD. is long. We tried to use only the first part of it, offering the rest if you wanted to read more, but each paragraph added more information that we felt has great relevance to our situation. Please remember that we are only choosing articles to publish each time, we are not medical professionals in any way, we are just passing onto you those articles that we feel have helped us gain more knowledge and understanding about Post-Polio. ( made available on the Internet with the permission of the Easter Seal Society of Washington). The opinions expressed are those of the individual writer and do not necessarily constitute an endorsement or approval by the Easter Seal Society or Polio Outreach Advisory Council. Please read [our endorsement](#) on the bottom of page 2.

We now have a bibliography of the copies of the medical articles and other support group newsletters that we hold - over 200 items and growing daily. If you would like a copy then please send an sae, 6 pages of A4. There is much to read, many different opinions, from many different medical professionals around the World. If you would like to have a look at the articles or any special ones then please contact Hilary to arrange this.

# **BOUNCING BACK WITHOUT GUILT**

**Wendy Clyne PsyD.**

**Transcribed from the Colorado 1993 Educational Conference.**

Today, I'm going to be talking about some of the factors that may hinder you from becoming your own medical advocate. Some factors may be related to your experience of having polio, or to anyone attempting to cope with medical problems, such as chronic pain, fatigue, weakness, loss of function.

Even though there's an attempt now to educate professionals and the general public about the existence of post-polio syndrome, many of you began to have your symptoms at a time when there wasn't much information about this condition. Not only did you not understand it yourself, but the symptoms often went unrecognized by the health professionals working with you. Or they may have been misdiagnosed as depression, as hypochondriasis, or as frightening diseases such as ALS.

When you were recovering from polio no one said to you, 'You're doing a great job but down the road, twenty, thirty, forty years from now you might have some problems'. To have to deal with the unpredictability of having symptoms returning or other symptoms coming back is extremely unsettling. Whenever someone feels like they've gotten sideswiped in life like this, feelings of being helpless, feelings of being out of control, feelings of vulnerability are very normal. Feelings of denial, anger, and frustration are also normal in these situations.

It's important to check if the intensity of your reaction to your physical limitations may not seem to match the level of physical problems that you're experiencing. This can be a source of self-criticism for people because they are thinking, 'Why am I having such a reaction, it's not that big of a deal, I'm just having some weakness'. But your reactions are coloured not only by the physical limitations that you have, they're also coloured by your memories from the past. They're coloured by how much interference those physical limitations caused in your lifestyle, in your sense of self, and in your coping strategies.

Intense emotional reactions are a normal response to remembering catastrophic illnesses such as polio. Even if you've made a very good recovery, some of the things you had to go through to make that recovery were anxiety producing and stressful.

There is a condition called Post Traumatic Stress Disorder, which includes flashbacks, nightmares and feelings of re-experiencing the trauma. Many of you first heard of this disorder with Vietnam veterans. Returning veterans did not have the opportunity to talk about their experiences. From that experience psychologists have gained knowledge covering the problems related to not being able to talk about and work through a traumatic experience. Today however, there's a real recognition of the need, the importance, of having an opportunity to talk about what people go through (like plane crashes or earthquakes). Talking about feeling wasn't acceptable or 'in' until the late 60's or early 70's and that was a long time after most of you went through your illness.

The people who seem to have the most difficulty with emotionally letting go of a traumatic event are the ones who either don't have an opportunity to talk to other people about what they've gone through, or even if they have someone there they feel like they aren't able to regain a sense of control about their experience.

PTSD symptoms can be set off by a lot of things; by sensory input, by thoughts, by feelings. Some people walk into a hospital and they smell the odour that reminds them of the things they smelled as kids when they were in hospital, and they start getting rattled. They start thinking about what they went through, they start thinking about the doctors. Actually smell is one of the strongest triggers for memory because it has got the shortest route to the brain. Smells are very powerful and

sometimes we don't always recognize that it's setting off some memories.

Flashbacks and re-experiencing the trauma can happen on a couple of different levels. Sometimes very concrete; you have a visual memory, you can see the doctors, you can see the hospital, you're very clear on the memories you are having. But sometimes the memories are more unconscious, something called emotional memories or physical memories. Going back to the example of the breathing problem, you might start having trouble breathing and start to panic; you're not reacting just to the current situation of breathing trouble, you're reacting to that situation plus being flooded with memories of having trouble breathing and wondering if you were going to survive when you were a child. You may not be aware of it, it may be happening unconsciously.

Another example is sometimes people may experience some pain in their legs. They know it's not a huge pain but they have this intense sense of anxiety and panic. They are asked, 'Why are you getting so upset? You say it's not bad pain.' But there's this intense emotional reaction. Part of what may be going on is an unconscious remembering of all the feelings that went with that particular pain. This is especially true for people who experienced their polio when they were very young. Real young kids remember more on an emotional level or kinaesthetic level. They don't have the words to encode their memories on a verbal level. For those who had polio at ages, one two and three you might have more emotional reactions that are hard to make sense out of.

During the 30's, 40's 50's most people did not talk about feelings; doctors didn't want to hear it and our parents said 'Just be quiet and do what the doctor says'. Intellectually, people understand that it's good to talk about their feelings, but when it comes to talking about post-polio syndrome this big wall comes up and they beat themselves up about the thought they can't talk about polio. Other people criticize by saying, 'Why can't you talk about it? You can talk about everything else'. But that pervasive feeling of 'I'm not supposed to talk about it' comes up. You're dealing with strong prohibitions that you grew up with.

Another experience on a behavioural level is that many of you were quite young or young adults when you had your polio. Even though you may be 60, old enough to be the parent or grandparent of this doctor that you're talking to, you're dealing with your polio, you're experiencing being young again, in the sense you're supposed to be quiet, you're supposed to listen., be good and do what the doctor says.

How do you confront or disagree with a doctor when you are feeling like a kid and he is the adult and you are supposed to listen and do what he says? A lot of this occurs on a more unconscious level so the more conscious you can be of this process, the more you can say, 'I'm not just reacting because I think I'm not supposed to question him.' The more conscious you can be of that process the more in control you can be and make choices about how you want to have it.

At the time you were experiencing polio there was not a glimmer of an accessible world. People who were disabled were not out in public, you did not see them around. So, as you're re-experiencing symptoms, there may be a sense of shame that seems totally out of context with what you're going through now. There might be a feeling that people won't want to be around me, I shouldn't be out there. The daily living begins to feel monumental as you worry about how you're going to get around. How you will be accepted.

Many of you were separated from your families. If you were out in the country, a long way from a medical establishment, your family had to stay where they lived while you were shipped off to a hospital. Some hospitals didn't allow visiting. That sense of isolation, of being cut off from your family, can also come up now even if it's not realistic for our current situation. The more you are aware of his process the more you're going to be able to manage those feelings.

Another area that I think is complicated for people with post-polio syndrome is coping strategies. Now the line is 'No pain, no gain'; back then what was pounded into you by physical therapists was 'use it or lose it' or 'push till it hurts - then push a little harder'. The way you learned to cope after polio was to push hard, to have a hard work ethic. The statistics show folks with polio have a higher

level of education than the general population and are four times more likely to be employed than any other disability group in the United States. This is a hardworking, highly motivated group of people.

You've worked very hard to get where you are. Now suddenly, people are telling you to slow down, don't push so hard, don't work so hard. This goes against everything you've learned to do to overcome your disability. It's stressful. People tell me they worry because if they don't push they will feel like they are giving up.

The absolute worst time to try to change your coping strategy is when you're worried and stressed. That is the worst time to find another way to deal with what's going on, and that's exactly what people are telling you to do. You have symptoms, you don't know what's ahead for you. There's no way you cannot be worried and stressed.

Another complication, for those of you who had minor residual physical problems, success meant hiding your limitations. Suddenly you no longer hide your limitations so there is the feeling of re-experiencing those limitations and that can add to the stress. Your whole way of coping has been built on hiding your limitations. Overcoming your physical limitations has become a strong source of pride and personal gratification. When you overcame all the troubles related to polio and then see the things you've accomplished start to crumble it can be devastating.

One of the things I need to say to spouses or professionals; unless you are also experiencing polio pain and fatigue, you don't know what it's like. Even if you have a chronic pain syndrome where you are dealing with arthritis, back injury etc., you don't have all the memories, all the old stuff that's coloring your experience with the pain. For those of you who are experiencing the pain and fatigue it's important for you to understand that, when someone says, 'Oh, yes I understand what you are going through', you can say, 'No, you do not understand what I'm going through, you may have some ideas about that, but you don't really know what it's like.'

When I talk about pain I'm not talking about ten on a scale of one to ten, which is the most intense pain you can have. People who experience the two, three, four levels of pain still experience the problems that go with chronic pain. In some ways some of those folks are more self-critical because they think they should toughen up and get past that. Sometimes the pain is always there so they can't quite get comfortable and are unaware why they are feeling irritable and uncomfortable.

I've never met a person who has chronic pain who also doesn't have sleep deprivation. They go hand in hand; you cannot sleep well if you have chronic pain. Most of us learn to live with the chronic levels of sleep deprivation, even though we can cope we pay a price. There's a lot of research literature in psychology about the consequences of chronic pain and sleep deprivation in terms of our cognitive functioning such as; Attention and Concentration; Memory; Problem Solving. There is something called information processing - speed and capacity. One of the things that happens with pain and sleep problems are both speed and capacity of information processing go down. Even if you were someone who could always take in a lot of information, now you might take in less information and process it slower. For some it's more noticeable than for others.

Other things commonly seen in people with pain and sleep deprivation, especially with post-polio problems, is staying awake - it's hard to take in information when you're having a hard time staying alert. Thinking clearly, even word finding can be affected by chronic pain and sleep deprivation.

Going back to the statistics, the level of formal education for people experiencing polio is higher than the general population. That means many people with polio took jobs that involved thinking, using your brain, being on top of things, being able to problem solve. Suddenly those capacities may not be working so well. Maybe subtle difference other people don't notice, but you do. Even if you function in the normal range, if you're not where you're used to functioning, it's a loss. A loss not supported by other people who when you say 'I just can't remember names anymore', they say, 'Ah I do the same thing,' but their situation may be a lot different than yours.

If you've used your mind to cope and live with the world, then on top of losing physical function there's also the sense of losing cognitive function. This adds to the stress. Sometimes people try to attribute pain to anxiety or depression. Anxiety does not cause pain. It can increase it by being tense. Tensing your muscles can increase pain. Depression does not cause pain. It can make it more difficult to deal with the pain. Stress does not cause pain. Many doctors don't like to say, 'I don't know', so they might attribute your symptoms to being depressed.

One of the difficulties with ruling out depression is that when a psychiatrist, a psychologist or social worker is trying to do an assessment as to whether you are depressed or not, most of the symptoms are things that are common in post-polio syndrome and very common in chronic pain and sleep deprivation.

Let me go through the list of things a psychiatrist might check out if she/he were checking for depression; Social withdrawal - if you have a lot of pain, not functioning well, and you're not sleeping well, you tend not to be as active. Social withdrawal often goes with PPS. Eating disturbance - if you hurt and don't feel well you don't have the energy to eat, especially if you must fix it. Depressed or irritable mood - not enough sleep can make you irritable. Diminished interest or pleasure - it's hard to get excited about anything when anything you do takes effort. Insomnia or hypersomnia - meaning you're trying to sleep all the time or you're not sleeping enough. Fatigue and loss of energy - again very common in PPS. Diminished ability to think and concentrate.

You can see how difficult it is for people to rule out depression or rule in depression. There's a significant overlap in terms of some symptoms of depression and symptoms of PPS. People will come in and ask me 'Am I depressed?' I don't know if we can sort that out. We can take care of some of the stresses and see if that helps, but the reality is that so much of this can be part of depression and part of what you're going through as a result of your post-polio. To sort it out may not be that important.

What do you do about the problems that go with experiencing PPS? How do you get on with your life? One of the ways is to get started grieving and getting rid of the loss. Unfortunately, for some [people] that means going back and dealing with 'junk' you didn't have time, or opportunity, or permission for dealing with when you first had polio. I'm not saying to feel sorry for yourself, be down all the time, or blame the world. That's not grieving and loss. Everybody deals with it in a different way. For some it means getting angry, for everybody it means acknowledging that your life has changed - not changes you're happy about but changes you must deal with.

A piece of grieving and loss is trying to redefine your sense of self, regaining your sense of self-esteem. If you were praised and recognized for overcoming your obstacles and for your productivity and suddenly you're no longer able to produce, many people start to devalue themselves. You need to value yourself outside your accomplishments. Recognize that you are loved for who you are and not for what you do. Focus on what you can get done, not what you can't get done. Not constantly compare yourself and evaluate yourself based on what you were able to do ten or fifteen years ago.

How do you do this? Write down the tasks you've accomplished that day. You might think you've accomplished nothing until you write it down and see what you've done. Simple tasks can feel monumental when you're dealing with chronic pain and fatigue. It's important to give yourself recognition for what you accomplish. Give yourself credit for your rest time. You're taking care of yourself - a novel concept for those who are always pushing themselves hard. Nurturing yourself one day maybe a greater accomplishment than getting the dishes done.

To regain a sense of control, learn to monitor yourself. The biggest key to that is having realistic expectations for yourself. Dr. Frederick Maynard said that folks with post-polio may take two to ten times longer to recover than someone not experiencing PPS from things like fractures, flu, - which creates a ripe opportunity for self criticism. Be realistic about how long it takes you to bounce back and you'll not cause so much stress for yourself. You have to have health care specialists who also have realistic expectations. Ideally find health care specialists who know about PPS - who

understand the medical condition. If that's not possible because of insurance or location, find health care specialists who are willing to learn from you. You need people who'll remind you 'Remember this is going to take longer than you expect'. When you have realistic expectations for yourself, you have more opportunity to feel successful. Unrealistic expectations are a guarantee to make you feel like you're falling.

Other ways to increase your sense of self control are through choices; predictability, and information. One of the strengths of support groups is the information sharing. If somebody is a little further along in the process and can help you understand what he's going through, you can then prepare yourself for what might be ahead. Pay attention to your thinking. Everybody has little voices, little tape recorders in their head (things you've heard your parents say that you thought you'd never say) saying things like 'I'm not working hard enough, I should be over this'. You're buying into 'old tapes'. It's important to stop that thinking and say, 'Wait a minute! That was before, it's not true now and I need to let go of that.' The more you're aware of your thinking the more you can deal with the things coming your way.

Psychotherapy can be helpful. It's not for everybody and it's another area where it's important to be a good consumer. You need to see if it fits with everything I'm saying today, see if the pieces fit with your experience; some pieces will and some won't. If you're looking for a psychologist or a psychiatrist find someone you feel comfortable with, someone who's trustworthy, treats you with respect and seems to really listen to what you have to say. Sometimes people benefit from short term marital or family therapy just to help those people you are living with understand better what you're going through and improve some of the communications.. Learning to cope with PPS is a process. Things begin to get clearer as you go along.

A lot of folks are labelled 'non compliant'. It's difficult for individuals who have experienced polio and are now experiencing PPS to be encouraged to do things differently from the way you learned to cope with them.. You're asked to use a walker, or use a brace (you proudly discarded years ago); to shirt (sic.) the way you are dealing with your situation. This brings up a lot of old polio memories. When you are stressed and anxious is the worst time to make big changes. A better way is to make changes with minor interventions at first. A way of gaining a sense of control is by being aware of your own reactions and trying to understand them. When someone is saying to you that you need to do something very differently, you'll be able to have more ability to advocate for yourself, deal with health care professionals and not be labelled as non compliant.

Some other things to help with the treatment of some of the symptoms of post-polio are antidepressants - even if you're not clear if you are depressed. Make sure you take it in appropriate doses. Folks with post-polio syndrome often require small doses to receive the positive effects without the negative side effects. Other helpful thing; Relaxation, Biofeedback, Meditation, Self-Hypnosis, Holistic approaches can be helpful as an adjunct, not replacement for our medical therapy. Acupressure, Acupuncture, Massage, Healing Touch. Ways of gaining a sense of control; social activism; getting involved in a support group network; distractions - such as music crafts and hobbies, reading or listening to books-on-tape; humor is a very adaptive way of coping with stress.

**Lastly take care of yourself as you would someone you very much love,  
Be nurturing and accepting of yourself.**



### **The Best Medicine?**

Why isn't phonetic spelled the way it sounds?  
How does the guy who drives the snowplough get to work in the morning?  
If nothing ever sticks to Teflon, how do they make Teflon stick to the pan?  
Why is it when you transport something by car it is called a shipment,

but when you transport it by ship its called cargo?  
When your pet bird sees you reading the newspaper,  
does he wonder why you're just sitting there, staring at carpeting?  
Why isn't there mouse flavoured cat food?  
Why do they report power outages on TV?  
Is there any other word for synonym?  
Isn't it a bit unnerving that doctors call what they do 'practice'?

### **Interesting headlines.**

Grandmother of eight makes hole in one.  
Two convicts evade noose, jury hung.  
Queen Mary having bottom scraped.  
Panda mating fails - veterinarian takes over.  
Eye drops off shelf.  
Squad helps dog bite victim.  
Enraged cow injures farmer with axe.  
Lawmen from Mexico barbecue guests.  
Two sisters reunite after eighteen years at check out counter.  
Something went wrong in jet crash, experts say.

### **The Christian and the Lion**

In the time of the gladiators, a Christian had been thrown into the lion pit. He was sure these were to be his last moments on earth when he spied an opening in the enclosure. He bolted for it and was free.

Unfortunately, a lion spotted the same opening and followed him through. Realizing he was being chased by the lion, the Christian ran as fast as he could up and down the streets of the village. Suddenly, he came to a dead end. The Christian knew that soon the lion would devour him, so he dropped to his knees, clasped his hands in prayer and looking heavenward said, "Lord, I've been Your faithful servant since birth, and I've never asked anything from You. But now, I beg of You, please make this lion a Christian.

At that exact moment, the lion stopped dead in his tracks, dropped to his knees, clasped his paws in prayer, looked heavenward and said, "For what I am about to receive, the Lord make me truly grateful.

Moral of the Story. Be careful what you ask for, you might just get it.

Some days you're the pigeon and some days the statue.



### **Snippets from the Post Polio Family of the World.**

**Tom McKeever - Merritt Island. Florida. USA. - <http://spacecon.net> (Disability Home page)**

I was a Principle Design Engineer here at Kennedy Space Centre, responsible for the Guidance, Power and Communications Systems of Space Station, as well as equivalent systems in the Space Station Processing Facility and was badly 'screwing up' presentations to NASA Management on these systems I knew so intimately!! - Lost the concepts and processes in mid stream - just GONE - resorted to the old 'I don't have the latest information here with me today, but I'll get back to you' gambit, so I could rush back to my 'Cube' and look it up again! Heck I was in my early 50's then, but didn't think senility was an option in my Family seeing as my Dad was sharp as a tack until age 91 when he passed on. But the PPS factor SEEMS to be an interesting and PLAUSIBLE reason.

**Mary-Lou Whitaker - Idaho** - Started really noticing problems in early 80's, by late 80's just could not function on a day to day basis.... went to work, came home and collapsed (in my clothes on the couch) back to work, ditto. This was horrific as had children still small enough they needed my care and am a single mum. Anyway I started going to docs, they told me out of shape, EXERCISE! I tried that, got up to walking 5 - 10 miles a day with a great deal of difficulty and fatigue, just getting worse, then crashed. Took until '95 to find out that the trouble is..... all the time being told to exercise, building up slowly to walking AT LEAST 2 miles a day.

**Florence Lunde** - I also recently started the retirement business (June 96). It took me four years after my MD advised me to retire to make the final decision. After the adjustment of realizing that I am not the six million dollar woman, and that I have limitations which I must admit, I would like to encourage you and say that I feel 1 million times better in the following ways: My fatigue has lessened, My joint pain has lessened, I can concentrate again, I can absorb and retain what I read and It was the best thing that I have done for myself.

**Jimmy and Jin - China** - I'm a new comer to the Internet. After three months of studying English, I was asked to join the net by my polio sister, Jin, I found this group with the net. Thanks to the group people. As my sister, Jin, can not speak/write English, I must 'work' three nights a week for her, writing e-mail and translating. Jin is an active and kind nice girl. She wants me to tell her story to the people like her and hear. She wants to know what's happen out of her city, whether they are happy and what they are thinking about post-polio situations. Jin was contracted polio at age 18 months in 1973. After isolation and five months treatment in the hospital, Jin backed to family. The doc said to my parents "Jin's legs are fully paralyzed, her muscles are unbalanced, you have to find some methods to prevent her from deformities, specially in ankles, knees, and spinal column". Before age seven, Jin can not sit up and move body without help. she had to look cartoons and listened to the radio in bed. At that time, her child friends gone to school but she can't, so she began to do exercise in order to go to school, but failure. As many years of 'unused' legs, the doc's words become truth, she got muscle atrophy in legs and feet drop, the joints of knee become weak and soft. Jin can not move a small step even wore hip-to-toe braces. She had to do household works in bed. My kind mother quited her job in order to care of Jin. At Jin's age of ten, I began to learn Chinese traditional medicine, acupuncture and moxibustion, meridian point massage, which are very useful and effective in home care of polio. After one year of learning, I applied to Jin with my parents encourages. The miracle things happened three months after, Jin's legs became warm, the muscle atrophy stopped through eight months of treatment with meridian points massage, Jin's skin of legs become smooth, the pain of knee joints disappeared. Jin never be afraid of cold weather. And deformities are stable. At age of 15 years old, Jin can walk with hip braces, and now with two crutches. I also applied to Jin's friends, over ten people and get good feedbacks. In the theory, acupuncture and moxibustion can stimulate nerve cells, meridian points can increase the situations of blood circling. If you want to get some consultations about simple different massage methods for home care, please e-mail the following material in order to determine the key points for massage or simple finger-press:

A. simple describe about pain and deformity B. picture(s) before age 25-30 yrs C. picture(s) of standing without brace but clear looking D. Picture(s) of sitting, back is better. After five years education Jin now works for a branch of the foundation of people with disability as a volunteer specially in the three kind of rehabilitation: polio, blind and deaf. In China, there are over 1,700,000 polio survivors, most of them work well in the society, some of them should get proper rehabilitation, training and back to family and society. Jin takes care of the 'heavy' survivors, how are they living well, is there any new method to apply for polio survivors, what will happen on survivor's body about this progressive matter in the future. Jin wants the answer. Any response/opinion will be appreciated, Jin's still active.



## Tips for Physiotherapists.

Thanks to Sandra Walline in London for sending me the Mount Diablo Post Polio Network Newsletters in which I found this article. Her physio from when she had polio is a member of this group and she is still in touch.

### Taken from the South Alberta PPSG Newsletter - PP Echoes

- Most polio survivors are over achievers.
- With the onset of the late effects of Polio, they are having to cope with new feelings and conditions from the renewed pain, muscle fatigue etc.,
- Case histories are very important as 75% of all Polio Survivors are non visible. Unless asked, a history of Polio may not be taken under consideration and could lead to unexplained problems that could be avoided.
- 'No pain, no gain' is out. 'Conserve it to preserve it' is in.
- Therapy must be individualized. Even from day to day, as study has shown, Polio Survivors have unexplained day to day fluctuations in strength. Overuse may not show up until the next day. Periodic rests are needed to avoid fatigue.
- Polio Survivors do not like the cold. Their muscles do not perform as well in a cold room versus a warm one.
- If a patient requires therapy three days a week, Monday, Wednesday and Friday are best with rest periods on the days in between. Morning appointments may be better than afternoon.
- Try to schedule testing for the same period of the day or document the time and the results.
- Polio muscles fatigue easily. Stronger on the first repetitions, weaker after five or six tries. Grades should be assigned after the first or second try or document that you had to do it six times to assess the patient's strength.
- Surgical procedures are common in Polio Survivors, i.e. joint fusion, muscle-tendon transfers. Therapists should be familiar with these procedures so the muscle that they want to be testing is the right one. A muscle that should be doing one movement may be doing another.
- Video taping the patient's gait allows the therapist to review and examine without fatiguing the patient.
- Remember that any physical change is accompanied by emotional change and some patients with the late effects of Polio may have difficulties adapting to new disabilities.



### Some of the Conferences in 1997

April 12	Tucson, Arizona, USA	Southern Arizona PPS Conference.
April 18-19	London, Ontario, Canada	'I have something to say'
May 28-31	St. Louis, Missouri, USA	7th International PPS & Independent Living Conference.
Sep 12-14	Atlanta, Georgia, USA	Been There, Done That, Movin' On A Post-Polio Conference focusing on quality of life.



## INFORMATION FROM ANOTHER POST POLIO CLINIC

### Roosevelt Warm Springs Institute for Rehabilitation Post-Polio Clinical Services

Outpatient Services. Roosevelt Insititue. PO Box 1000, Warm Spings, GA 31830-0268, USA  
Tel. (706) 655-5300

Our Polio Clinic serves former polio patients and provides a comprehensive array of services to assess any new medical problems they may be having.

Some former polio patients are experiencing increasing difficulty in maintaining their usual daily activities. Some symptoms include increasing weakness, increasing fatigue, decreasing endurance, muscle pain and joint pain.

Sometimes, but not always, these symptoms are due to a syndrome which has been named the Late Effects of Polio. In other instances, the symptoms may be due to other causes.

A complete evaluation consists of two days of outpatient services in Warm Springs. Each patient is examined by a physician specializing in the management of post-polio problems, a physical therapist, a certified orthotist and a respiratory therapist.

Referral to the Institute's occupational therapists and psychologist may be also made. Other studies that may be done include eletrodiagnostic studies and sleep studies when certain patterns of sleep disturbances have been noted.

*Physical therapy* - detailed manual muscle tests, gait evaluation, posture assessment, instructions in individual home exercise programs, therapy sessions for relief of symptoms in appropriate instances.

*Orthotics* - evaluation of current bracing, fabrication of individualized bracing and corsets and provision of manual and motorized assistive devices.

*Occupational therapy* - evaluation of upper extremity function, evaluation of need for orthotics and home support systems to maintain or enhance daily living.

*Psychology* - evaluation and recommendations for appropriate follow-up when significant coping strains are noted.

*Medical* - evaluation of specific complaints and problems. Referral may be made for additional medical services or to other physician specialists, including cardiologists, pulmonologists, neurologists or orthopaedists.

Electrodiagnostic studies - electromyography, nerve conduction studies, evoked potentials.

Electroencephalography (EEG)

Radiology.



**Articles for publication by January 11th please.  
Publicity date anticipated about 20th January 1997**

**Bibliography of all articles and newsletters we hold now available please send sae if you want a copy. About six pages of A4. Please remember that we are running on a shoe string whilst we apply for grants. Any donations will be gratefully received.**

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*Original map graphic courtesy of [www.graphicmaps.com](http://www.graphicmaps.com)*

Document Reference: <URL:<http://www.zynet.co.uk/ott/polio/lincolnshire/linkpin/linkpin962.html>>

Last modification: 10th April 2009.

