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THE LINC-PIN

Issue No. 7 - September 1997
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In Memory of Diana, Princess of Wales,
who died this day 31st August 1997

LANGUAGE thou art too narrow, and too weake
To ease us now ; great sorrow cannot speake ;
If we could sigh out accents, and weepe words,
Griefe weares, and lessens, that tears breath affords.

John Donne 1572 - 1631
LincsPPN Website

I am standing upon the seashore.
A ship at my side spreads her white sails to the morning breeze and starts for the blue ocean.
She is an object of beauty and strength.
I stand and watch her until at length she hangs like a speck of white cloud
just where the sea and sky come to mingle with each other.
Then someone at my side says: "There, she is gone!"
"Gone where?"
Gone from my sight. That is all.
She is just as large in mast and hull and spar as she was when she left my side
and she is just as able to bear her load of living freight to her destined port.
Her diminished size is in me, not in her.
And just at the moment when someone at my side says: "There, she is gone!"
There are other eyes watching her coming,
and other voices ready to take up the glad shout:
"Here she comes!"
And that is dying.

Anonymous

Rev. Karen Utz, Polio Survivor in the United States of America.

More messages to us from Polio Survivors from around the World.

Why?

We don't know what we had until we loose it, I'll never understand. This lady was a symbol of caring, not perfect, but an inspiration to all of us.

Karen, your story said it perfectly. The fact she is gone from our sight doesn't mean she isn't still doing a marvelous job, somewhere else. Her happy, uplifting spirit will be here forever. Yes there was glitz and glamour, but the kindness for a disadvantaged world shined through.

The Monarchy will never be the same. Church today will be special and inspirational, because of one strong spirit lingering over us. This spirit will be permanently entrenched in the Palace of unbending souls, to change, yes gradually, old hardened ideas.

My thoughts are with you,
This Sunday of shaken dreams.
Kane Basie in Anchorage, Alaska.

I am so sorry to hear about Princess Diana...I knew before going to bed last night that she had been injured, but not until retrieving the morning paper did I learn she did not survive the crash. My heartfelt prayers and sympathy to you and to all the UK...

I remember getting up in the wee hours of the morning to watch her wedding, and following the ups and downs of her life since then. She coped with the good and the bad, grew strong and finally seemed to be finding happiness again. I admired her love for children...not only her own, but all children of the human family. She will be missed.
hugs & love **Ginger Hastings, Portland OR, U.S.A.**

I am also saddened by the death of Princess Diana. This is a true tragedy. As you said, she had just begun to reach her potential and was so special to so many people. The world will have a void without her.
Hugs, **Helen Ferguson, Georgia, USA.**

I just want to offer my prayers up for Princess Diana and her family. This is such a sad occasion in the UK - love her or hate her, she was never ignored. God bless her and those who died with her. We have lost someone who will not be replaced easily. Republicanism is looking even more certain - a sad day for a Monarchist.
Pam Vogt, Bournemouth, Hants.

I would like to send my condolences to Princess Diane's Family and to the families of those who died with her.
Bobbie Foster, USA.

Diane had really begun to find her footing and realize how much good she could do for humanity. I too was hoping she had finally found someone to give her some happiness in her private life. My heart is with her children and family. The world has lost a spokesperson that held up a mirror to remind the leaders and those that have power, what real people in the streets are dealing with, that illnesses and bombs do not descriminate or care if you are old, young, rich or poor. A sad day Britain and the world.
Marilynn Biermann, California, USA.

I have felt sad all day about Princess Diana's death. It is a tragedy. The whole world will miss her.
Carol Meyer, Massachusetts, USA.

I also am one not to get maudlin about these things either but the case of Princess Di is a special one to all of us. I believe like a lot of us she had so much hardship in her life that sometimes she must have felt that the world dealt her a bad hand.

Yes she was special, we will miss her and grieve for her family. To our British members, my sympathy at this time.
Ross Cornwill, Australia.

I had my tele tuned to CNN all evening and heard about the crash from the first. I was awake most of the night following reports of this tragedy. The Princess was an absolute exceptional person, through her very humanness, more able to relate to the average person than I believe any of the other royals can. She was delt a hard hand to play and she came out on top. I believe she truely cared about others.

My sympathy to you and your countrymen. Diana will be missed by the world.
Love & prayers, **Susan Yakima WA, U.S.A.**

She was loved in the US almost as much as in England.
Margaret Sessions, Florida, USA.

For one person to become so well known - and loved - by the world is probably the highest of achievements a human can attain.

All you needed to say was "Di", or "Diana" and everyone KNEW to whom you were referring.

This lady was one who did good works - really good works. I believe she would rather have done them without fanfare, but she knew (or was advised) how to use the media to call attention to those human needs that she worked toward solving. She did this knowing the media would follow her wherever she went - even though it was not something she wanted for herself.

This kind of person, in my book, qualifies as one of the greats of history - and should take her place alongside people such as Churchill, Mother Theresa, Gandhi and others. Unfortunately, she didn't live long enough to attain the full measure of her potential.

It is the rare person about whom one can say, "This person will TRULY be missed by many millions of people.
Jim Sutton, Graham, WA, USA.

My prayers also go out to Diana and her children. Maybe now the press will stop stalking.
Bob, U.S.A.

My sincere condolences on the death of the Princess of Wales. I know her loss is felt around the World. Please know that we in America are most sorry that this great lady and her extraordinary humanitarianism are forever gone. God bless her, her family and all of you in her homeland.
D. E. Hall, Minneapolia, Minnesota, U.S.A.

Please pardon this personal reflection.

I was awake Saturday night when the news broke. It felt like a serpent uncoiling in slow motion, striking at the life in me. Although, I was raised as an African American, my ancestry is of British origin and influence. My Father's family date from the 1600's in the Bahamas, which was under British rule for many years. The documented history starts with two brothers from Spain via Cuba, and an English gentleman from London. These individuals arrive in the Bahamas in the 16th Century and married the native Indians present there. Thus settling the island known as Long Key which is in the Exuma Keys.

When I met my family in the Bahamas for the first time, I was shocked at how British they remain. Today's Bahamian government is Independent. In fact, the current Prime Minister, Sir Hubert Ingmam happens to be married to my second cousin, Delores. It was my honor to visit their lovely home and be welcomed into the family. In addition, there are two cousins in Parliament.

It was four o'clock in the afternoon when my cousin appeared with tea and crumpets. Having been raised in the USA, I very seldom drink hot tea, except for colds. It was one of the most proper moments in my life. Pinkie out, slip not slurp :-)

These are the memories that makes me feel like a Brit today. Lady Di was also my Princess and her life now resembles a Greek Tragedy. It is clear, she lived a life of private, isolated pain. Didn't we hear the lady crying? Didn't we hear her silent wails? Too suddenly, the fairy tale ends not happily forever.

@-',--'-- A rose for you Lady Di.
Kioni, Florida, U.S.A.

Dear PPS Friends' Round the World, I too, am saddened by the death of Princess Di. We all are.
Eileen in Sunny San Diego.

I too send my prayers for the family, especially the beloved sons, of Princess Diana. We lost a marvelous Lady!
Joan in Florida USA.

The world has lost a grand lady. Sorry, but I feel Princess Di was disgracefully treated within the family. I loved reading about the way she was raising her sons. They wouldn't be the stiff leader that their father will be, if he ever gets the chance to be King. When Princess Di took them shopping, she saw to it that they were treated just like any other customer. They stood in line, with the regular folk, and payed for themselves. She wanted to be sure that they knew all the things her husband never knew. There was life beyond the palace. Hopefully, William, the older son, in line to be King one day, learned her values and responsibilities in his young life.

I know Heads of State are not being invited to her funeral but it would be a great wake up call to the occupants of the palace if most of the Heads of State decided to attend the funeral. Bill and Hillary had become some of her many good friends in America. I'm extremely disappointed to hear "he" doesn't plan on attending. I wrote him of my feelings, I just wish others feel as I do.

The outpouring of love, for the Princess, has the simple folks waiting in lines for more than four hours, with small children, just for a chance to write their messages to her. She is a symbol of good for all people of the world. The nicest thing that I heard her being referred to was an "icon".

May she and her new love rest in peace.
Bunny in the States.

I'd like to tell you how truly sorry I am about Diana. We heard about 7:00 P.M. Saturday night, and stayed with CNN for about 3-4 hours. What a thing to wake up to and get hit right between the eyes with it. I think that she was the "Queen of our Hearts" over here, also. She knew that love was the most important thing on this planet. I think that she truly cared about the charities she was involved with - and that's why everyone wholeheartedly returned her love back. This one's going to hurt for a long time.

Wordsworth said it best:

There was a time when meadow,
grove, and stream,
The earth, and every common sight,
To me did seem
Apparelled in celestial light,
The glory and the freshness of a dream.
It is not now as it hath been of yore;
Turn wheresoe'r I may,
By night or day,
The things which I have seen
I now can see no more.

The rainbow comes and goes,
And lovely is the Rose,
The moon doth with delight

Look round her when the heavens are bare,
Waters on a starry night
Are beautiful and fair;
The sunshine is a glorious birth;
But yet I know, where'er I go,
That there hath passed away
a glory from the earth.

Sincerely, **Kathy, United States of America.**

Now, the whole world is focused on Britain because of the Princess Di tragedy. What a sad life - what a sad death. She will be a legend in the years to come.
Viola Pahl, Vancouver, Canada.

Just wanted you to know how deeply saddened I was to hear of the death of England's beautiful young "Queen of Hearts." She was a very special woman, whose kindness toward all people, and whose grace under the most horrendous conditions imaginable, will be anenduring source of inspiration to women the world over. Your American sisters share your loss, and mourn with you today...
Love,
Marcia Bedard, PhD, U.S.A.

The death of this beautiful young woman is truly tragic and sorrowful. She was the light in her sons lives. I wonder who will be there now to provide that light. It is obvious that their Dad doesn't enjoy the types of things that Diana did with them. Also I can't help but ponder on why she was so hounded by the reporters. It was because of the type of person she was - certainly not just because she was a royal - none of the others are so hounded. She was a beautiful caring person and I don't think it was an act.

I think she was real. I have to agree about censorship - I am not in favor of that but I do believe laws could be enacted to prevent such harrassment.

Just thoughts,
Betty in Tennessee, U.S.A.

My sincerest sympathy to those who suffer with the Spencer and Royal families in this most tragic loss, a legacy of beautiful life has been so quickly taken. May we all cherish the grand moments and forever keep her memory alive and pray for the children.
Angel of Northern Lights,
Linda, Nova Scotia, Canada.

A sad day for the world, not just Great Britain. I heard this afternoon that the driver of the car had a really high blood alcohol level. And yes, those poor boys will probably be raised just as their father was. The world of children will suffer the most, but the whole world will have lost a real lady who was treated so badly. My condolences to all the UK gangstars.
Love, **Sheila Tohn, USA.**

Our hearts are greatly saddened by the death of your princess. We, in America, loved her very much. The entire world has suffered a tremendous loss. Please accept our condolances.
Sincerely, **Dema Lunsford, Olney, TX. 7637**

I want to share something that was in the newspaper yesterday: "Two things stand like stone," a young Princess Diana said prophetically in a speech in the 1980s. "Kindness in another's trouble; courage in your own." To me, this exemplifies what she was all about and it reminds me of what happens in this group. The world has lost a great lady.
Helen, U.S.A.

Dear Linc-Pin

Hi, I have MS and PPS and for me the losses continue, and I'm simply angry and at a loss for words or thoughts. Princess Diana was a very real and tangible hope for so many. Her life was that of which " fairy tales" seem to be based on, yet so many of us realized, was NOT a fairy tale which ended with "and they lived happily ever after." It WAS her warmth, intelligence, her humor, her sharing and caring, and her commitment and devotion not only to her children but to the "masses" that glistened. Her being and her life drew me toward her in ways that few have ever been able to do..What a tragedy for any loss....what a shattering of dreams and hope. Perhaps the expectations were overwhelming.....but she seemed to indeed possessed the ability and willingness to assume such responsibility in her short life. How could these wonderful qualities ever be overlooked or denied? She found her way through many trials and tribulations and became such an inspiration to so many. What a splendid, humanitarian and caring person in spite of her "royal" inheritance. For the UK and the world...such a loss...such grief.....a beautiful memory and inspiration for all.
Love to all..... **Jane Bercier, Louisiana.**

Dear Linc Pin Members

I was channel surfing last night and came across the news that Princess Diana had been injured in a car accident. I continued to watch thinking that they would come back on any minute and say she was all right, that she had a broken arm but would recover nicely. As the hours passed and I waited for news of her condition, I kept praying the damage was only minor. Then they showed the condition of the car and I was so afraid. 'Dear God, Please do not let her young sons see this broadcast on television. Please let their mother be OK." Then they announced that she had died. Such a terrible waste of a life that was making such a difference in this cold world. She will be missed. She was a truly good person.
Shirley in Kansas, USA

ODE TO AN ENGLISH GARDEN : FLEETING AS FLOWERS

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Sincerest symphathy, from LaVonne Schoneman Seattle, Washington USA
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Fleeting as flowers
Photinia
Phlox
Pinks and such
Freesias
with tight
white
frilled
ruffs

The summer
the garden
the life
of one man
enjoy them
whenever
you possibily can

Who is to blame
when such lives
end
the flowers
the garden
the woman
the friend?

I rather
believe
God calls the shots
the garden's reseeded
with perennials
plots
of flowers
to bloom
for another day

The woman, too, will fade and die each blooms for a moment as with Lady Di	In God's lovely garden not one fades away the resplendent people comprise His bouquet.

Pinks double = Woman's Love - Pinks single = Always lovely - Phlox = Unanimity - according to Kate Greenaway's Language of Flowers

For Karen and her family

Sparkie Lujan, Montana, U.S.A. wrote this on 2nd September for Karen's mum (popette), one of our PPS Pals on the Internet whose mum died today. Our thoughts are with you Karen and your family.

Also for Prince Wiliam and Prince Harry - know that the whole world's thoughts are with you.

Thank you all so much for the condolences and love you have so freely expressed! Sparkie - the poem was so beautiful! What a lovely thing for you to do! When I read it, I keep hearing it sung in my mind to the tune of "Bless This House," - one of my mom's favorite songs. Thank you , thank you all, sweet friends!
Love - popette

Lift my mom, oh Lord I pray
Take her home to rest on this day
Hold her close as I once did
I remember her arms around me as a kid

Her warm smile, made me glad she was my mom
I will miss you, now that your gone
Know I loved you, and will hold you close
I love you mom, and this I boast

God will care for you these days
I know his love, and his ways
So rest in peace dear mom of mine
As the almighty God loves you, he is simply devine

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This issue includes an article from our online library (our newsletter is distributed by post to many subscribers who do not have Internet access). Rather than duplicate the article in this online edition of the newsletter, I have instead just included a link to the library article. I have assumed that those of you who already have the article would prefer not to have to print it again if you wish to print this newsletter for your own use. However, if you are printing copies for further distribution we would ask you to print copies of the article as well.

Online Reading Navigation Tip - Selecting Cathedral logo will return you to the above contents.

Editorial

The Committee would like to express Our Sincere Condolences to all the family and friends of Diana, Princess of Wales, and Dodi al Fayed.

We, the LincsPPN, have been overwhelmed with the number of messages pouring in to us. We felt that you would like to read these, if we have left any out then we do apologise.

This has been a week for news. Sad news about our lovely Peoples Princess and Dodi Al Fayed, and then glad news as we heard today that we were granted Charity Status on the 29th August 1997. We feel sure that Diana would be pleased for us and knowing of her wonderful sense of humour have decided to leave the remainder of this newsletter as planned.

This newsletter is shorter than normal, and has some planned articles held over as events of the last few days have taken over. By the time you read this I will be in the U.S.A. I am going to attend the

Atlanta Post Polio Conference
Been There, Done That, Movin' On
A post-polio conference focusing on quality of life.

Our next newsletter will be a special issue, full of information, facts, medical articles, funnies, information from the Conference, and from other Post-Polio Support Groups from around the World - to celebrate our achieving Charity Status. Please help us make this special, send us your stories, letters, we really do want to hear from you.

Since our last newsleter we have had **more new members.....** We need to hear from you, please tell us your stories of the past and present. You will be surprised how much reading them will help other members. We are all different, and have different problems, but many problems overlap.

Generous Donations - we have been overwhelmed in the last couple of weeks by two donations received with membership fees. One from Florida in the States, and the other from Hong Kong... Thank you gentlemen, your letters telling us how the information we provide on our Website enabled you to get medical help for your condition was a great boost, the enclosed cheques brightened our day considerably. This has been an enormous boost to the Committee and we can now relax just a little...... Our Website is growing and we have many ideas to improve on the service that we provide, as soon as we have funds available.

A meeting with the Director of Public Health in Lincolnshire, was held a few days ago and we are pleased to say that this was informative and helpful and we look forward to working with them to improve services for our members in Lincolnshire. Please do not hesitate to let us know of the good or bad side of your foray into the medical world with your PPS. We need to know who is interested and ready to work with us, as well as those who still believe that it doesn't exist. We know not all our problems are Polio related, or PPS, all we are asking is to take the enormous amount of information that is out there in the World into the equation.

I would now like to welcome Shirley and let her introduce herself to you.

> **Hello:** I would like to take a moment to introduce myself to everyone. My name is Shirley and I live in Kansas (United States of America). I have volunteered to proof read the articles for the "Linc Pin" as Hilary writes them. I volunteered to do this because I know how hard it is to proof read something you wrote yourself and I thought it would be fun as well. This is all in the spirit of international goodwill and cooperation. Sounds pretty "Noble", huh? I do realize that some of your words are spelled differently than in the U.S. of A, so hope that is not too much of a problem. May this effort bring us closer together, as people and as friends.
> Shirley in Kansas
> swhisman@earthlink.net

Hilary's Trip to the States

Thanks to the generosity of some of the Polio Survivors on the Internet for offering me hospitality - and to my parents for paying for my air tickets - I will be in the States by the time that you read this.

After a few days to settle in, I leave Tennessee for Atlanta Georgia, to go to the Conference. From there, with CarolAnn, Millie and Sparkie, I leave for a trip of a lifetime. Lafayette near New Orleans on the Gulf of Mexico, and to Houston, Texas. To Pineville and then Birmingham and back to Loudon to meet Miss M. Then to Joilet near Chicago, and then to CarolAnn's house near Niagara Falls in Canada. Along the way, we stay with other Polio Survivors we talk to on the Internet, and meet others who are driving in to meet us. All represent different Post Polio Support Groups in their areas.

Many real time hugs will take place, and an enormous exchange of information, ideas and plans for the future. I look forward to telling you all about it in the next newsletter.

I then go back to Tennessee for a rest - but I have agreed to work with the North Middle School in Lenoir City not far from Knoxville in Tennessee on a project on Lincolnshire and England. I also talk to all 450 in the school, and if the email questions that I have received are anything to go by, this will be real fun, a daunting prospect but fun. I must thank the many organisations in Lincolnshire for the information, videos, booklets etc., that I have to take with me.

Hilary Hallam

Jane's Story

In 1955 at the age of 5 years I was stricken by Infantile Paralysis (in short Polio). For the first eight days of my illness I was at home with what the doctor thought was Pneumonia. The doctor decided after this period that it might be more serious so he sent me to the School Clinic for further investigations and from there I was sent to Lincoln County Hospital to see Mr. Thomas. He took five hours to come and see me (after his clinic) in a small room and he said it was Polio and sent me by ambulance to the Lincoln City Isolation Hospital. Upon arriving a Ward Sister came and took me from my father and as she did he asked if I would walk again and she said 'No'. He replied, 'if she is my daughter she will'. On the first night in hospital I was put in the men's ward and next to me in a cot was a little boy about 15 months old from Dorrington who cried most of the night so I played beep bo with him and at this time I decided that I wanted to work with children. My mother said I would change my mind.

The next day I was moved to the women's ward. In this ward was a girl called Christine Roebuck aged 12 years who was in an iron lung and who sadly died just after I came out of Hospital. Another girl was called Ann Crow who used a walking frame to get around and a lady called Mrs. Minnitt [with] a baby which she had had whilst in an iron lung. While I was in this ward they put a plaster boot on my right foot and ankle and made one for my left leg but it was left on the radiator and never fitted. If I got my right leg on top of my left I could not lift it off by myself and had to call the nurses to lift it off.

I could only get around on my bottom but if I had something to hold onto I could manage to walk. I found that I could use the port hole handles to the Iron lung and could get things out of Christine's locker. Also I found that I could use Ann's walking frame but the staff kept telling me off because they had been told that rest was best for my recovery. I don't know if the fact that I used the aids available to help me walk aided my recovery but I walked out of the hospital six weeks later like an old walkie talkie doll. Stiff legged from the hips downwards and by all accounts took 20 minutes to climb down the 22 steps that led up to the hospital main door. I then attended physio three times a week at Lincoln County Hospital.

In addition to the physic at the hospital I had to do my exercises at home every day and if I tried to give up my parents would push me to continue. Due to this I made a full recovery to the outside world, but I have had weaknesses in my right leg, especially the calf muscle is not as well developed as the left and tires easily if I walk far. My back is also weak and over the last few years I have had problems with my breathing and tests for angina which proved negative. My hands are also getting weak but I did achieve my ambition to work with children and qualified in 1966 as an NNEB. I also have two children of my own who are now 22 and 21 years old. I am at present looking after two boys aged 5 and 2 years and have been with the family for four years and six months.

Sadly I lost my father in 1963 in an accident at work, but during the period from 1956 to 1963 he worked to help the British Polio Fellowship, Lincoln Branch, especially the selling of Christmas cards.

Some of the other things I remember from this Club are...

Garden Parties at Stones Place with Major and Mrs. Walker - President.

Going to Worthing, after my father died, for a holiday.

Swimming at RAF Cranwell.

Some of the names I recall and positions held in 1964 at the Lincoln Branch are...

- Mike Key the Vice President,
- Eddie Wing from the Lincolnshire Echo
- Dr. and Mrs. Stiall the Chairman (sadly died 1964)
- Miss Hall from the Red Cross
- Barbara Bell (Stokes) and her dad
- Mrs. Button and her daughter Pam the Hon Sec

- Nancy Crow the Press Secretary
- Dorothy Roberts the Editor of the Newsletter
- Mrs. Bear
- Mr and Mrs Cave, Tony and Steven
- Wendy Maddan and Wendy Taylor.

At present I am waiting to go the Papworth Hospital Sleep Unit to have tests for Post Polio Syndrome (PPS for short). In the past I have said I had Polio believing that it was all in the past ..... and it has come as quite a shock to read that in some cases it is not all in the past.

Jane now in Cambridgeshire.

* * *

Nature Notes from the Pen of the 'Lunatic Fringe'

Harlow Wood Revisited.

Wandering around the woods surrounding the old Harlow Wood Hospital one warm September Day I paused to admire a 'Jay', a rarely seen bird with such beautiful plumage. Further on I cam across the red spotted MyAgaric (the toadstool of fairy tales) shaded by golden fronds of bracken. I smell the many scents of a wood in autumn.

But then what is this coming towards me through the trees? An apparition? A Zombie? A ferocious Monster? A thing to terrify horses, encased in a hard white shell up the body, round the head and neck and down own arm to the elbow. This being set at right angles to the body and the arm below the elbow hanging down like a wet flag. It is wearing a black cape with red ties (obviously stolen from a nurse) baggy pyjama bottoms and slippers. It lumbers towards me, crushing the beautiful red toadstool under one of its big flat feet. I look into what is visible of the face and see that the two front teeth stick out like chapel hat pegs. Teeth Dracula would kill for. I also see the fierce brown eyes, and read the message in them. You may laugh if you want to, but don't pity me. I realised I was looking into my own eyes forty years ago.

Editors note: The Lunatic Fringe is the pen name of a member living in Lincolnshire, she will be writing each newsletter.

Medical Funnies

My old lady neighbour - 'Yes, Duck, my son in law was never much good, don't know why my daughter married him. He died in a mental hospital.

Lunatic fringe - 'Oh I *am* sorry, what did he suffer from?'

Old Neighbour - 'Well duck, he had athletic fits.'

from the States...........

The following quotes were taken from actual medical records as dictated by physicians ...

By the time he was admitted, his rapid heart had stopped, and he was feeling better.

On the second day the knee was better and on the third day it had completely disappeared. She has had no rigors or shaking chills, but her husband states she was very hot in bed last night.

The patient has been depressed ever since she began seeing me in 1983.

The patient is tearful and crying constantly. She also appears to be depressed.

Healthy appearing decrepit 69 year-old male, mentally alert but forgetful.

The patient refused an autopsy.

The patient has no past history of suicides.

Patient has left his white blood cells at another hospital.

She slipped on the ice and apparently her legs went in separate directions in early December.

The patient was in his usual state of good health until his airplane ran out of gas and crashed.

She is numb from her toes down.

The skin was moist and dry.

Occasional, constant, infrequent headaches.

From a member in Bournemouth, Hants.

A 29-year-old woman was arrested and accused of attempting to murder her husband by spreading peanut butter over his face, knowing he is diagnosed with severe allergy to nuts. The husband escaped serious injury by immediately injecting himself with a remedy medicine. [Montreal, Canada, La Presse, 07-20]

Was she arrested for "assaulted peanut and buttery"!

Pam Vogt

What It Means to Be Adopted

Teacher Debbie Moon's first graders were discussing a picture of a family. One little boy in the picture had a different color hair than the other family members. One child suggested that he was adopted and a little girl named Jocelynn Jay said, "I know all about adoptions because I was adopte." "What does it mean to be adopted?" asked another child. "It means," said Jocelynn, "that you grew in your mommy's heart instead of her tummy."

Sent by Popette........

Letters to the Linc-Pin

Luv the Book... Dorothea's book, 'Healing the Blues' made me think especially about the hospital. Realised that I spent most of the time hiding under the covers, petrified. No-one told me anything, just lots of interns standing round discussing me. In a ward with older people, dark and gloomy, are my impressions. It was the National Childrens Hospital in London.

Visiting was once a week, but my parents only came once, and brought one sister, just before Christmas. I can't blame them, it was a long way, and my father was working and they had three other children. I spent Christmas alone. I had no help with the pain.

I made a fuss, and I still believe that one of the nurses 'took' my large parcel. I also had a 3' teddy, been with me for years, but it also got 'lost' when I was discharged.

This book has brought out so many buried memories, they are still coming out. I do feel so much better for having visited you and talked more about this. Releasing the blocked memories is lightening my load. I was still awake at 02.00 last night reading, I can relate to so much that she talks about, I will drop her a line and thank her myself.

Jean near Boston - am on the Phone Pal list.

To Pam in the UK, your story sounds sooo familiar, could it be me? Yes, it is! with the addition to the plot. I now am having more and more pain. I suspect we can only beat these fried nerves and muscles to death for so long before they start screaming at us. I drug on through the tiredness and exhaustion... getting worse almost daily... for about 15 years before found out what was wrong. Always told by doctors to (of course) exercise!!! So I added insult to injury very well, thank you (^_^) VBG! I, too, had very young children to care for by my lonesome so just kept pushing.

I still keep plodding on more than I should....hard not to with little ones around (mine now are twin grand daughters 10 months old and their mother and 17 year old son). Difference now is that with what I've learned from this list, I know I have to Pace and NOT fry what's left. The more I do the more the pain comes. I don't get to take any meds (allergic to most) so try to keep it down which isn't always possible.

The friends you make on the Internet will help you leaps and bounds. When I was told what was going on it was "You have post polio syndrome, unless you have something else come up I don't need to see you again. This will not get better, only worse, so rest as much as possible to maybe slow a down" (Thank you very much, pay on your way out, etc.!!!)

Everything I know about PPS, I've learned from the folks on the internet. AREN'T they great!!!

Love, Mary-Lou
"Tootings From My Place Alongside the Railroad"
Kuna (Pronounce Q'na), Idaho

Editors Note: When typing to each other on the Intemet, it is easy to possibly misunderstand the exact tone that the words are sent with. So we use letters like VBG - meaning very big grin, and LOL - laughing out loud..... We also use Smileys to convey meaning.

:-) is a Smile
;-) is a Wink - meaning it is a joke
:'-) is Tears

There are many many more, but they do help us convey more of the meaning in our words. With the difference in our 'English' we need these, you would not believe the misunderstandings, mostly very funny, that take place.

We now have a link with the Post Polio Support Group of Far North Queensland, Australia

We have just received their June newsletter in which we were thanked for allowing them to use information from our Website..... and in return I think you will agree that the following article from this newsletter shows that we have similar problems all over the World..... and that we can support each other no matter how far apart we are.

David Hurse writes...........As a starting point for our discussion Ned Kelly has contributed a very moving paper which we print here with his kind permission. The sentiments that he expresses are echoed by many polio survivors.

"SUCH IS LIFE"

Born 26.10.56 in Melbourne..
Polio at age 5 years....

Lived with thoughts and little memory of the experience

In my early teens I had difficulties with my left arm and leg. Was always asked questions and never realised how a would affect me until later.

In my early thirties I noticed small things were not working well - breathing, movement, aches and pains in all parts of the body - good bits and worn bits. In 1992 things started to go wrong - knees, back, arm and shoulder, neck pains, headaches, stiffness, lack of breath etc.

1993 - Time to start asking questions from the medical profession. Well I really believed what they told me. For example my age factor; work and life had caused minor problems - my cramps and pinched nerves in the back, loose knee joints; arthritis, maybe viral infections.

SOLUTION - "TAKE THESE PILLS"

In the middle of 1993 I was told I had stress and anxiety and forced to take time off work. Twelve months later many different doctors and diagnoses later finished off my working career.

Pension time.... Now I was lost. I had been working 20 odd years. Should still be at work 6 a.m., home at 5 30 pm. This is the time I started to hate myself and dislike life eg. I am no good anymore. But I was lucky. I had a beautiful caring wife, who put a lot of hours and effort into giving some life and happiness back to me.

Now we are in 1997.... and I have started to fight. I know now that life is worth while and there are people who care. I am still seeking medical advice and asking questions. This is in the hope that through my pain and experiences this will not be wasted and someone out there will gain some benefit and help in their life. I've joined a support group and through the people associated with it I have learned and gained so much. But one of the most important facts are that I gain important new friends and family, so to speak.

This is a strong part of my life and thoughts. I hope that someone will read this, smile and maybe join a support group or write their story and share what we all have in common.

Always remember you are not alone and you can always ask questions, listen to advice, and learn more to better your life.

Bye for now
Ned Kelly

Editors note: Thank you Ned for writing this and I hope that by adding this to our newsletter, that your wishes of it being read by someone will now increase to many, many more all over the World.
If anyone would like to write to this Group their address is
44 Miles Street, Cairns, Queensland 4870, Australia....

Roles And How We Play Them

Whenever I'm disappointed with my spot in my life, I stop and think about little Jamie Scott. Jamie was trying out for a part in a school play. His mother told me that he'd set his heart on being in it, though she feared he would not be chosen. On the day the parts were awarded, I went with her to collect him after school. Jamie rushed up to her, eyes shining with pride and excitement. "Guess what Mum," he shouted, and then said those words that will remain a lesson to me: "I've been chosen to clap and cheer."

Letter from Marilynn

Dear Polio Surrivors

Surgery was one of the many subjects covered at the GINI conference. The truth is that NONE of us are really good candidates for surgery and should avoid it as much as possible. Your friend is absolutely right, there goes any thoughts of an all inclusive face and body lift...oh well, if someone decides to love this person it's going to have to be an "as is" deal.

The amount of good muscles needed to support and hold a joint replacement anywhere in our beautiful bod's is substantial. I don't know how many of the rest of the polio survivors have given any serious thought to the dilema we are in, but because of the way my twisted mind works and the research I have had to do for friend's that are not on computers, I have looked at what my own options might be if I were faced with the problem. The most difficult information I have had to digest from reading the articles and information during the last two years was that every muscle in our bodies was affected to some extent by the Polio virus, no matter how "normal" we were able to function up until we hit the PPS wall. In my particular case, I have had muscle losses from my eyes down since PPS first reared it's ugly head. As strange as this may sound to some of those that are new to this whole thing, the eye muscle problems were diagnosed as part and parcel of the PPS thing happening with me by my last eye doctor. I thought I was just dumping the problem on PPS in my head and never spoke about it to anyone until he spoke those words "You started having this focusing problem when the PPS hit, didn't you?" I almost fell out of his chair.

For those of you that are newly diagnosed or just finding out about PPS, DON'T PANIC. It affects all of us differently, but you have an opportunity I didn't have when I was finally diagnosed in 1985, which was about 10 years after it had already started stealing my lifestyle and ability to be an independent, self sufficient female who thought nothing of painting, wallpapering, doing electrical and plumbing repairs, paneling walls by myself....in general if a mountain was in my way I would find a way to move it by myself. I would plan very involved charity projects as well, that were supposed to be handled by a committee but marilynn couldn't wait for others to get their butt's in gear, so no matter what it was, I would get it up and running before anyone realized what was happening. NOT SMART!!! NO ONE TOLD me the information I got from people like Connie and Sheila who were the first ones to scrape me off their computer screens when I found the St. Johns University Polio List and was on the verge of doing something really stupid to myself if I couldn't find anyone that understood what I was talking about and believe me. I needed tools to help me cope until I could find a way to lower the outrageous pain levels I had been dealing with as well as so many new problems doing anything. I had been diagnosed with 5 different medical problems in 5 years. I needed help to change my perception of the dreaded symbols I had spent my life hating, dreading,....why did I have these warped feelings about things that were really only tools to help me accomplish a task??? We all know the answers to that, because it was drummed into our heads that they were to be avoided because if you used them you had failed to recover etc., etc. etc.

One of the wonderful things that happens when you finally find others that do believe you, do care about you and will be there for you when you cry and scream your anger and frustration at the powers that be with the questions "Why me??? what is happening??? My whole world has fallen apart. Why??? is that you are heard and understood . You will not get flip answers like the doctor's give from anyone here. There are things you can do to help preserve what you have and work with your body instead of running it into the ground. Will you have to make changes about how you might have done something last year and can't seem to do it now??? Yes...so what?? If you really look at TAB's (TEMPORARILY Abled Bodied or sometimes also refered to as AB's) you will see them look for ways to get out of doing some of the stuff we take on or finding easier ways to do something, not because they can't do it with the blood, sweat and maybe tears we might tackle something with, but because they are not being driven within themselves to do anything regardless of the toll it would take just to prove how worthy they are to anyone else (especially themselves). They were never told that it is not ok to ask for help from others, so they do. Most of us choke on those words....I need help, or could you take care of something, or I want.... I am still working on saying the words I need or I want.

We all need support at different times. When you have others to help you carry the load that we sometimes think will bury us, it all becomes somehow more manageable.

LISTEN AND LEARN BEFORE you cause damage that no one and nothing can repair or replace. YOU do NOT have to outdo any 5 or 10 other people to be worthy of love and respect. This is where you can unscrew your smiley masks. You won't need them here. Many of us will trip on dust bunnies so toss the darn mask into a corner so that no one trips on it. I know it will take you time to believe that, but the faster you reach out, the more we can help you past the shock of not having to straighten or screw that mask in place. We all have them but have gotten to the point where when we are together, we don't need them. We love and respect each other as we really are....warts and all.

Much <3 (luv)

Marilynn, U.S.A.
Miriasha@aol.com

Article from our Online Library

The following article is reprinted in full in the edition of this newsletter distributed via the postal services. If you are printing this web edition for further distribution, please print the library article as well and attach it to the newsletter.

Experiences Adapting To BiPAP+Mask Technology

FULL TEXT HERE

Author: David Ronfeldt
The following memorandum was prepared by David Ronfeldt at Joan Headley's request for a recent GINI conference.
At your request, this memo elaborates on my difficulties adapting to the BiPAP+mask technology, and offers some points that may be useful for other people to read who are concerned about adapting with difficulty.

NOTES FROM ERIKA

Erika
c/o Neurological Resource Centre
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Unley SA 5061
AUSTRALIA

This week I received a Disability Pension Review form from the Government - it was unexpected due to the type of disability I have, The Post Polio Syndrome, and let's face it, we all know, there isn't a 'cure', and it doesn't 'get better'. It's management, 24 hours a day, 7 days a week management. ..

You know, I'm sure there are many people who are quite content to survive on a government subsidy of some sort, and probably get by quite comfortably with a little, perhaps 'on the side' finance. I know there are people who go to great lengths to cheat Workcover or insurance companies. I can assure you that there are a larger number of people who need help from the Govemment to 'survive'.

Disability, in whatever form it takes, can be and is for many people intolerable; able bodied people whose minds are not sound, either from disease or brain injury or some unfortunate genetic disorder.

The polio virus affected me at the age of three; I was taken from my family and deposited at what was in the 1950's, the Northfield Infectious Diseases Hospital. Because of quarantine, no one but over worked, tired and in many cases helpless staff were all the company we had. All ages, all sexes, immobilised, on frames, rocking beds, sand bagged unable to move, unable to feed ourselves, toilet ourselves, move nothing, not even to lift our heads off the bed, hard, board beds. The pain, fever, fear, loneliness, frustration and uncertain futures.

Some, like me, spent months in frames, on wheel beds, in painful, unrelenting physiotherapy, and still ended up in body braces, callipers, on crutches. Different, reserved; quiet; in pain; missing out on life, on playing; on learning to socialise and missing out on valuable school work; often becoming solitary adults.

The callipers may have been discarded, but bodies now twisted, limbs wasted, legs and feet difference, uneven, deformed and life viewed from a completely different perspective. We were told to get on with life.

'You had polio but you're over it now, so forget it'.

School work suffered, for me, my incessant physiotherapy sessions were always at the same time every week. I still can't cope with figures, maths, algebra, physics & chemistry etc. I was never there.

For many months, I could not hold a pen to write and still find I get pain and fatigue in my hand when I write, as I do now, after only a single page.

I was 'protected' by my parents, 'for my own good'. I had dreams; architecture, medicine, science. I was dissuaded due to my lack of endurance and concentration. I had dreams, an 'air hostess' - not with a disability. A hairdresser, but could not stand on my feet for very long.

My dreams faded. I was not a good student. I was socially reclusive, my self image and esteem became lower as the years went by. I was a shop assistant, a cook, a barmaid, a domestic; all things I could give up when my pain, weakness and fatigue made the effort of the work and hours became too much and I had to take a couple of months off. Not much chance to save money for my future, but jobs I could go back to when my pain and energy level recovered.

In all those years, I never considered myself disabled, just unfortunate, and I got on with life the best I could. No sport, no high heels, no short skirts, no dancing and always with a limp, that I could ignore, but others could not.

I never admitted that I had polio, I always blamed uncomfortable shoes, blisters, sprains everything but polio. In the mid 1980's, "things" began to go wrong. I couldn't walk as far or as fast; my right leg would give way, and I would fall losing control of my ankle. I was embarrassed and became wary of social and work situations. I felt unfeminine because of my "sensible" shoes and "camouflage" clothes. I was in my 30's, I wanted so much, but afraid to expect even a little.

Relationships failed, jobs came and went; I couldn't "keep up". I was often tired, and in pain, and always worried about it. I'd cancel social situations at the last minute, and so the invitations got less. I looked for acceptance, but the problem was I couldn't accept myself. I sought medical advice and was referred to a neurologist who was adamant that I'd never even had polio. I got my records from the Children's Hospital.

No one was ever going to deny me my medical history again, even though I hated it. In the early 1990's, while working very hard as a domestic, things really began to go wrong. I became ill - severe neck pain and headaches. My gait became unstable; my arms became weak; I dropped things; doing my hair became a chore. I got cramps in my legs and shoulders - the fatigue and the pain became unbearable. I'll get fit I thought, after all, another neurologist told me I was just being lazy and should exercise more. I got an exercise bike, ankle weights, dumb bells - 5 kg & 10 kg. I was the dumb bell I just didn't know it!! I felt as though I could help myself to get and stay fit. I was destroying nerves and muscle fibres beyond repair- muscle atropism began to set in. My left hamstring disappeared; my right calf muscles; both quads. I developed foot drop in both feet and as the tendons shortened, my feet began to curl up. Neck muscles began to deteriorate after a minor car accident. My right arm had already become thinner and weaker. Next my shoulders, left arm, neck & pectoral muscles, back and abdominal muscles; and still I exercised; firm in my belief that it was simply being over forty and unfit. It wasn't. Alcohol became a great muscle relaxant. It helped me forget what I was, what I could have been, what I could never be, what I might become. Specialists told me it was "family problems" and I was simply depressed and emotional - DAMN right I was.

Then I found a doctor who had another patient who'd had polio and actually knew what the Post Polio Syndrome was, and what it would lead to if it wasn't properly managed; what it could do if I kept on working as I was, and believe me, the worse I got, the harder I worked - I had to prove to myself that I could, that I was capable, that I measured up.

He suggested that I apply for what was in my mind still the INVALID PENSION - Invalid?!! Me?!! Invalid, unnecessary, unworthy, useless, irrelevant!!! For months I refused to fill in the forms, while on sickness benefits. I took analgesics, muscle relaxants for the spasm; sleeping pills to help with pain, numbness and pressure spots, the crawling skin sensation, and stiffness because I did not move in bed as normal sleepers do. I was afraid I also stopped dreaming. Finally, my doctor filled in the forms and sent them off. I was interviewed, questioned, prodded, probed, emotionally degraded and made to feel like a "bludger". I cried for three days after my assessment. I was devastated. Then it came, a decree stating that after being interviewed, psychologically assessed and physically tested and diagnosed, I was now on a DISABILITY SUPPORT PENSION - AN INVALID PERSON. I was forty-three!!

Myself esteem, my future, my plans, my dreams, my security, my life had all changed. I had bills, debts and expenses. They went on - a good income did not. At first I spent like a fool, mostly on credit. I was angry, then I stopped. I became sad, I cut corners, made changes, recycled clothes, sold jewellery and artwork, had a garage sale and sold many of the things that had represented my independence. I was resentful. I sold things I loved, nice things, my home, my sports car. Well, after all, I couldn't get any more out of it without destroying my left shoulder. I lost a lot of money and I lost a lot more. I sold all my exercise equipment. I got splints for my feeble legs, an abdominal support, a back brace, a cervical collar for my neck. I bought a sensible car, that I could fit a wheelchair into. My life had changed, I had not. I still haven't. I still don't consider myself disabled - I can't. I push myself to exhaustion, the early "use it or lose it" is still embedded firmly in my psyche.

But I am getting there, slowly and I do mean slowly. And I'm angry all over again. Tired eyes at the end of the day, a tongue that won't get around the words I want to say, a voice that becomes thin and broken, a body that aches, fatigue that is all encompassing, a solitariness, a loneliness that I still prefer to think of as self sufficiency and independence. A shelf full of vitamins, supplements, and homeopathy. A chiropractor, physiotherapist, massage therapist, relaxation tapes and a cheap bottle of wine in the fridge. In the words of Mr Spock in "Star Trek", "it's life Jim, but not as we know it".

PS Now I have to reviewed for my Pension all over again!!

Editors Note:

Erika, thank you for allowing us to print this. I also felt exactly like you, to receive the certificate 'It has been decided you are unfit for work'. It's like being put out to grass. It is bad enough getting this, but I also had a Doctor suggest that I wanted to be like this, that I did not want to work, to walk miles with friends, to disco dance all night long, to decorate my house, garden, etc. Why on earth do they think that we want to be like this, such a change from our 'not given up done everything pasts'. I never stopped. I took the challenge every time anyone said 'She would not be able to do this' and I tried and tried and most often succeeded. I now have had to change my lifestyle, it was not easy, it has taken many months to come to terms with the fact that this change was necessary but it has beneftted me.

Learning about PPS, taking the advice that is out here, and putting it into practice really does make a difference. Pacing allows one to do much more than without it. Using the aids and assistive devices does work. How many of our members have said the same as I did 'I don't need that yet'. I would not give up my electric scooter now. I can do so much more by using it.

I also have had to re-apply, and then the letter arrived a few days ago. Four pages and lots of ticked boxes, and I had to read it four times to work out what it really said. It was good news, but it took about ten minutes to realise it.

The Most Caring Child

Author and lecturer Leo Buscaglia once talked about a contest he was asked to judge. The purpose of the contest was to find the most caring child. The winner was a four year old child whose next door neighbor was an elderly gentleman who had recently lost his wife. Upon seeing the man cry, the little boy went into the old gentleman's yard, climbed onto his lap, and just sat there. When his mother asked him what he had said to the neighbor, the little boy said, "Nothing, I just helped him cry."

Practice Your ABC's

Act silly
Believe in magic
Create adventures
Daydream every chance you get
Enjoy the little things
Find time for FUN
Go to unexplored places
Hang upside down from trees
Imagine....
Join clubs
Keep it simple
Love all creatures
Make time for friends
Nap when you can
Open your mind to new ideas!
Play with a child
Question the answers
Run with the wind
Sing favorite songs
Take days off
Uncover your talents
Venture out
Walk on the wild side
X-pect the BEST
Yield to the moment
Zzzz peacefully at night

Barney

A four year old was at the pediatrician for a check up. As the doctor looked down her ears with an otoscope, he asked, "Do you think I'll find Big Bird in here?" The little girl stayed silent.

Next, the doctor took a tongue depressor and looked down her throat. He asked, "Do you think I'll find the Cookie Monster down there?" Again, the little girl was silent.

Then the doctor put a stethoscope to her chest. As he listened to her heart beat, he asked, "Do you think I'll hear Barney in there?"

"Oh, no!" the little girl replied. "Jesus is in my heart. Barney's on my underpants."

Pace Come Home

In a small town in Spain, a man named Jorge had a bitter argument with his young son, Pace. The next day Jorge discovered that Pace's bed was empty - he had run away from home.

Overcome with remorse, Jorge searched his soul and realized that his son was the most important to him than anything else. He wanted to start over.

Jorge went to a well-known store in the center or town and posted a large sign that read, "Pace, come home. I love you. Meet me here tomorrow morning."

The next morning Jorge went to the store, where he found no less than seven young boys named Pace who had also run away from home. They were all answering the call for love, hoping it was their father inviting them home with open arms.

RESPIRATORY QUESTIONS

Ask Wayne - Registered Respiratory Therapist.

Firstly may I say how sorry I was to hear the news about Diana, Princess of Wales. My thoughts go to her sons and the rest of her family and friends. A sad loss, she was such a beautiful and caring lady, one that will be sorely missed.

Secondly, I am sorry that this is a short article, but I have had to work 12 hours shifts in the last few days and have only had time to answer the questions asked privately. I do understand how difficult it is to ask questions, especially when we ask to publish your letters. However, we do understand that the questions you are asking have not been easy ones to ask, and have respected your requests to just have private replies.

Today however, I received a plea to answer the following,......

> "Why do I feel so bad at the moment, so out of breath. I want to breathe in like, sighing or yawning, but I just can't. I am very tired. I want to know would it help me to have oxygen, or do I need respiratory support to improve things. I can't go on like I feel at the moment, it is a struggle. I remember in the past that if I hoovered that I got very out of breath. I put this down to the way I hoovered and the energy I used. My chest and arms are affected by the polio. I did hoover up a couple of bits a day or two ago as the hoover was nearby, but only this. However, my cleaner now does not use one of the proprietary brands of polish as this affected me, and also cleans whilst I am out of the room, and I wondered if I may be allergic to something, or asthmatic."
>
> "I do so need some advice, I need to know what to say to the Doctor, after all I have been backwards and forwards to Doctors and recently to Hospitals and still have not been offered respiratory help. Which I am sure I need".

Without examining you, and without more information, and living as we do in different countries and with different medical systems, this is not easy to answer. It would be wise to visit your family physician or Pulmonary Specialist who might do the following. However, it sounds like it very well could be a series of respiratory complications, running from

1. A simple need for oxygen....particularly when you exert yourself
2. Based on your reactivity to the polish, I'm assuming the odours of chemicals, this might be Reactive Airways Disease.....A form of Asthma
3. At the worst, nocturnal hypoventilation...The inability to maintain normal levels of oxygen or ventilation during sleep and/or a host of other related respiratory problems in between.
4. Can't rule out sleep, or obstructive sleep apnoea.
5. Here's the confusing part...It could be, a combination of more than one of these things.

Differential diagnosis can be obtained by the following, but these are aggressive testing measures, and will most likely require a Pulmonary specialist to interpret. Try to find one who is familiar with PPS, because there are so many ways that respiratory problems differ in you and the average chronic pulmonary patients.

Pulmonary Function tests

1. Will rule out or in, the reactive airways disease with tests specific to your flowrates
2. This next one is superb for PPS'ers, the test normally done sitting in chair, should be done while laying on one side, and repeated on the other. This is because PPS'ers often have a paralysis of one dome of diaphragm, which can be picked up with this type test (right side down testing, then same study repeated on left side). If the results are markedly different, problems relating to diaphragmatic excursion can then be pinpointed.
3. Arterial Blood Gases....Both at rest, and after exertion.....This will be the key in factoring out the fatigue thing... Arterial Blood Gases gives information about one's ability to ventilate normally, at rest, and then under exertion. This test is momentarily painful, because it requires sampling of arterial blood, usually but not always from the radial artery... In other words it hurts like hell. This test is done to check the adequacy of ventilation. In other words, oxygenation is not the important thing here........
4. In order to rule out oxygen deficiency, simpler oxygen saturation measurements can be recorded. But again they should be done at rest...and then after exertion.
5. Finally, I would recommend a sleep study, but at a bona fide sleep center with holistic knowledge of PPS.

In conclusion:

- Peak FlowTests sitting, and repeated on both sides.
- Oxygen saturation at rest and following exertion.
- Arterial Blood Gases, both at rest and after exertion.
- And finally, a full blown sleep study connected to an EEG machine to check frequency of REM sleep, or lack thereof.

Should pin point any and/or all of these components which could be your problem.

* * *

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