



The LincPIN

**The Lincolnshire Post-Polio Information Newsletter
Volume 2 - Issue No. 10 - April 2000**

**This issue is Dedicated to the Memory of two Polio Survivors
Mrs. Marjorie Hotham who died aged 77 on 21.3.2000.**

Her brother Bernard Shillitoe has sent us a donation of £127 in lieu of florals in her memory and tells us that Marjorie was born in 1922 and caught polio in 1926. Despite having one paralysed arm and another weak arm and legs she married and worked for Remploy in Wakefield until she was 30. She then started to use an electric chair and in the last 20 years had to use this all the time. He remembers her mostly for her sense of humour, strong minded attitude to life and the summer evenings when they drove out to the Woolley Edge Car Park and took in the wonderful view overlooking the Pennines.

and

**Ian Dury who died aged 57 on 27.3.2000
'Reasons to be Cheerful' his attitude to life and a
Number One Hit in the UK for Ian Dury and the Blockheads**

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*Remember the opinions expressed are those of the individual writer(s) and do not necessarily constitute an endorsement or approval by the Lincolnshire Post-Polio Network. **ALWAYS** consult your doctor before trying anything recommended in this or any other publication.*

Editorial by Hilary Hallam

A very busy two months with much happening and at last with the new Millennium the light at the end of the tunnel appears to be closer. Of significant importance are:

The Lincolnshire Post-Polio Library article [Non Paralytic Polio and PPS](#) by Marcia Falconer PhD and Eddie Bollenbach MA published in January 1999 has now been referenced in Dr. Halstead and Dr Silver's article *Non Paralytic Polio and Post-Polio Syndrome* in the Special Feature of the American Journal of Physical Medicine and Rehabilitation January/February 2000. Also in this feature is another article by Marcia Falconer and Eddie Bollenbach, *Late Functional Loss in Non Paralytic Polio* and Richard L Bruno PhD *Paralytic vs "Non Paralytic" Polio Distinction without a Difference*. It is now accepted that the criteria for PPS of just paralytic polio is not correct. Polio is one line and as the level of damage increases the diagnostic name changes. Less than 45% damage and no weakness was clinically evident and if polio was diagnosed from a lumbar puncture/spinal tap then the diagnosis was 'sub clinical polio'. Between 46% and 59% damage weakness was clinically evident and the diagnosis was 'non paralytic polio'. Over 60% damage and the diagnosis was 'paralytic polio'. Most of our body was affected but to differing degrees. The comment in articles 'also having problems in areas not thought to have been affected' is now explained. Remember Dr. Perry's MMT chart for a Polio Muscle. A tested 5 is only functioning at 53 to 59%. These muscles with 'unknown to us weakness' had and have to work harder compensating for our known weak and weakening limbs but are weak themselves.

If you go back to my article in the June 99 LincPIN, [pages 3 - 11](#), *Polio Survivors need Holistic Multi-Disciplinary Assessment because the Standard Physical Assessment is not Adequate*. It does not show Substitution of Muscles or test repetitive or sustaining power, reporting that Manual Muscle Testing (MMT) alone was not showing our true muscle ability. **Our Latest article *Polio Biology X - In PPS Manual Muscle Testing Problems Arise from Judgement and Biology* by Polio Survivor Professor Eddie Bollenbach** (Page 4) explains that Manual Muscle Testing tests instant strength and does not show the muscle fatigue that we are reporting.

It is essential that a multi-disciplinary holistic approach when assessing Polio Survivors becomes the 'norm' in the UK with immediate effect. Walking across an office, pulling against their effort, will not show the muscle fatigue we are reporting that sets in as we repeat or sustain our movements. We must be seen to do actions, walk the corridor, climb a flight of stairs, peel potatoes,

lift a saucepan of water across a room, get into and out of a chair or up off the floor, show how we wash our hair, etc. See the weird and wonderful ways we have developed to achieve tasks. We only have 10 energy tokens a day, 70 a week, we have to plan how we use them depending on what we have to do. For example, a doctors physical assessment could take 15, 20 or more energy tokens leaving nothing for the rest of the day, and less than 'normal' for days afterwards. Whilst we might be able to achieve a task once, it is still muscle fatiguing and takes up energy tokens and we have to decide what's important today. We are proud people and want to achieve and not give in, but we have limited energy for each day. We need aids and assistive devices and the correct benefits to effectively manage our lives. Many of us now need to employ cleaners, gardeners and people to cook us meals; swap our mobility allowance for a vehicle with hoist or use disabled accessible taxis to get out with our electric wheelchairs or scooters. If we continually overstrain and overdo then we manage less each day, have more pain and fatigue and can deteriorate faster. So many of us have already deteriorated at an unnecessary speed due to lack of knowledge of the condition. We want to do as much as possible for ourselves for as long as possible but realise that this has to be within new and ever challenging limitations. We need the help of the medical profession and government agencies to assess us correctly and quickly, advise us and provide us with the wherewithal to effectively manage our lives. Please reduce the continual worsening of our condition due to the stress we are being put under as we struggle up the 'Everest' of Post Polio.

Dept. of Social Security and Medical Advisory Panel for the Benefits Agency. Because of the continual problems our members are having when applying for benefits we have again been in correspondence with these organisations. Problems reported to us are, not being awarded the right level of benefit and having to appeal and attend Tribunals and even appeal at Tribunal level; having benefits suddenly withdrawn for no apparent reason; and that most approved doctors who visit admit a lack of knowledge of polio and its late effects. They do not understand the way we have to live our lives juggling energy tokens to get some quality of life. Hugh Bayley MP sent us the two pages on poliomyelitis and its late effects from the Disability Handbook which he believed covered our condition adequately. As can be imagined these two pages are not up to date and contain little about the late effects of polio as we know them. We have sent in an appraisal of the document with medical references with a request for this section to be rewritten. We have just been told that the British Polio Fellowship have also requested this and they will be publishing an article on post polio syndrome in one of their future updates. We have stressed the urgency of this.

New Committee Members Wendy and Frank Grimmitt have been co-opted onto the Committee and we must express our thanks to them and friends for helping with the total reorganisation of the office area - new longer working surfaces, new cupboards and easily movable extra working tables.

Membership Fees - Details of all membership fees are on the [back cover](#). We look forward to receiving renewal fees that are due. We are adding your renewal date to the envelope but the office renovation has delayed cross-checking this. If it's wrong please ring. Please do not hesitate to contact us if you do not receive an expected newsletter or information requested. We endeavour to provide an excellent service but are not infallible - new systems being set up should eliminate errors. The earlier you tell us the earlier we can ensure that any error is corrected.

Medical Complaints - We have many calls and letters expressing dissatisfaction with assessments by doctors. Our advice has been to make an official complaint. However, on checking with members - and being honest ourselves - we have realised that when you visit doctors, ring and write and are still struggling to get your PPS symptoms addressed, that an official complaint is more stress than you are prepared to take on board. There is also the fear of being struck off that hospitals list. This leaves the hospital unaware of the level of complaints. To improve the situation we must address this both personally and as an organisation. If you would like help with this then please contact the office.



Charity Aid Foundation (CAF). Donations can now be made to the Lincolnshire Post-Polio Network via Charity Cards and online at www.charitycard.org. If you are an existing CAF CharityCard™ holders go to CAF™ secure online donations to the Lincolnshire Post-Polio. See also www.CAFonline.org.

Long-Term Medical Conditions Alliance (LMCA). We have joined this umbrella organisation made up of over 110 voluntary organisations working to meet the needs of people with long-term medical conditions. LMCA works to ensure that the voices of people with long-term medical conditions are heard, valued and acted upon, and to provide effective support for its member organisations. Its strength comes from members' commitment to work collaboratively on issues of common concern. It is distinct in that it focuses on long-term conditions for which there is generally no cure.

Neuroscience Forum with the Lincolnshire Health Authority (LHA) - The February meeting was another step forward with many concerns being discussed. I asked that all groups put forward their ten top gripes as I believed them to be at least 80% the same. I have already heard from Deborah Jaines (LHA) that I am right and the top two will be on the agenda for the next meeting on May 18th 2000. At this meeting the Parkinson's representative and I are talking for 5 minutes each about our conditions. Glenys Sanders - Guillain-Barré Syndrome and Jan Limback - ME (page 14 - 15) spoke about their conditions in February.

GINI Conference - trip to America - I am flying into Florida and travelling by car with US member Richard Boone stopping for breaks with Polio Survivors en route. (As on earlier trips without their generosity this trip would be impossible). First stop is Trenton, Florida to meet with Art Coburn. Then to the Roosevelt Warm Springs Institute for Rehab Post Polio Clinic to meet with Dr. Anne Gawne and her PPS Clinic Team and new PPS Support Group. Via the east of Atlanta to meet US Member Nancy Vandyke and Myrna Whittington. North via Knoxville up the I75 and then west at Lexington stopping at Mount Vernon Illinois. Then to St Louis for the 8th GINI Polio and Independent Living Conference where I am doing a 12 minute summary of my presentation '*Assessing our activities to more effectively manage our lives*' on 8th June following the presentation by Dr. Gawne and her team. Richard and I share the whole presentation on the 10th June at the same time as Peter Jay (UK LincsPPN Member) and Welfare Visitor for the British Polio Fellowship gives his presentation on Self Management of Chronic Conditions. Sample cost before the 1st May for a polio survivor is registration \$160, meal package \$105, hotel rooms \$119 per night. (Our speakers reduced cost is \$800 (£500), registration, meals and hotel). Then **South to Branson Missouri for the 2nd Internet Reunion (June 10 - 13)** see page 15. This is a friendly get together (about 50 so far) with a Conference Room available for getting together. Craft made by Polio Survivors attending will be on display and for sale. Dorothea & Michael Nudelman and Richard and I will be doing our talks again for those not able to go to GINI. A tv interview and visit to Silver Dollar City (wheelers go free) has been arranged. South via Mobile Alabama to meet Charles Gollot (US Member) and his PPS Group and back to the Tampa area. If time, finances and energy levels allow then we will be meeting with other Polio Survivors, PPS Specialists and PPS Groups. This trip will not be possible without sponsorship and donations and I am still waiting with trepidation for reply letters to requests. I would like to thank 5 Polio Survivors, 3 in the US, who have already given cheques totalling £240 towards the trip expenses. If you would like to contribute please write on the back of the cheque 'Trip to America'. We do not have enough funds to support attendance at conferences.

Mail and the LincsPPN phone number will be diverted to other committee members whilst I am away. I will be keeping in regular contact via email.

Office Days. Every Wednesday and the third Saturday in a month will be Office Days starting in July. If you would like to visit then please give us a ring.



Polio Biology X

In PPS Manual Muscle Testing Problems Arise From Judgement and Biology

Eddie Bollenbach

A Lincolnshire Post-Polio Library Publication - 18th March 2000

When acute polio struck it was essential to measure the extent of paralysis quickly. One of the techniques used was manual muscle testing. There isn't too much to it really. The physician holds a hand against a patient's limb and coaches the patient to push as hard as possible. Depending on the judgement of the tester the patient's muscle strength is graded from 1, (Trace Strength), to 5, (Normal Strength). This assessment was very valuable because it provided a clinician with enough resolution in measurement to quickly evaluate the extent of neuromuscular paralysis from acute polio in one session.

From the standpoint of muscle biology these tests made sense too. During acute polio, motor nerves, and all their branches to muscle fibers, die. The muscle fibers are then unable to receive motor stimuli from the brain and spinal cord to induce voluntary movement. A manual muscle test would quickly show that many or all muscle fibers were orphaned and had no ability to do work. Appropriate therapy could then be initiated.

The biology of Post-Polio Syndrome is distinct from that of acute polio. In PPS end fibers of motor nerves begin to lose function. This is a slow process which involves fatigue more often than muscle incompetence. Let me explain. If a normal person is standing it is possible that 30% of the muscle fibers in his leg are contracted to maintain his upright position and posture. When those 30% get tired they automatically rest (switch off) -- isn't the human body an ingenious creation? -- and another different 30% of fibers contract to allow the first group to recoup. This can go on for hours. Someone with PPS may have only 40% of his original muscle fibers. When he or she stands they have only 10% in reserve, so in a short while there are no substitutes to take the load off. The result is fatigue of contracting muscles.

In the case described above what would show on manual muscle testing? On contraction against a clinician's hand strength may show normal (5). But this is instant strength, which is what manual muscle testing measures. Many people with PPS are not down in the (1) trace range, especially if they recovered well from their acute polio. They are in the 5,4,3, and 2 ranges.

Dr. Sharrard in 1953[[1](#)] found that in order to identify any weakness, by this kind of testing, more than half the anterior horn cells had to have been destroyed during the original polio infection. Other clinicians have also demonstrated the problems with manual muscle testing in grading PPS involvement.[[2,3](#)]

The biology of PPS explains the problem. What we should be looking for is fatigue in previously involved muscles, or less frequently in uninvolved muscles. Manual muscle testing just doesn't do that. The PPS health professional should be clear about what is being measured by manual muscle testing. It may be, for many, that what is being measured is the original weakness and not the new loss.

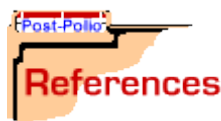
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1. Sharrard, W. J. W.: Correlations between the changes in the spinal cord and muscular paralysis in poliomyelitis. Proc. R. Soc. Lond. 40:346, 1953.
2. Perry, J.; Barnes, G.; and Gronley, J. K.: The postpolio syndrome. An overuse phenomenon. Clin. Orthop., 233: 145-162, 1988. [[Lincolnshire Library Full Text](#)]
3. Grading For Manual Muscle Testing (attributed to Dr. Perry - Rancho Polio Clinic). [[Polio Survivors' Page](#)] <URL:<http://www.eskimo.com/~dempt/grading.htm>>

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Lincolnshire Post-Polio Library - [Copy of above article](#) with links to referenced full text and abstracts where available. For the complete list of Eddie's Polio Biology articles including links to recent additions see the [Polio Biology Catalogue](#).



POST-POLIO SYNDROME AND LOCAL AUTHORITY SUPPORT

The Lincolnshire Post Polio Network contacted me to talk about difficulties people with Post Polio Syndrome (PPS) have been having in obtaining support from their various local authorities. This short article is designed to outline local authority's obligations and some of the steps individuals who are having problems might take to enforce them.

The law - The basic position is that local authorities social services departments (SSDs) - often working together with health authorities - have an obligation to assess the needs for community care services. A wide variety of things may be covered by such an assessment, including the need for accommodation, adaptations and extensions to accommodation, carers, respite care, assistance in the home and special equipment.

The SSD has a wide discretion as to how comprehensive a needs assessment should be but it should be tailored to the individual concerned. Medical advice will often be necessary. Carers (including other family members) should usually be consulted as well as the person being assessed.

There should usually be a written record of the results of the assessment, and if the authority decides to provide services then there will be a care plan which sets out what these services will be. There is detailed guidance on what care plans should contain. Look for descriptions of the service to be provided and by whom, objectives, costings, any areas of unmet need, procedures and timescales for review and complaint. It may be a fairly lengthy document depending on a person's level of need. There should be a separate assessment included of the carers' ability to care for the service user.

Once the assessment has been carried out there is some debate over the obligations of SSDs to meet the needs that have been identified. In some cases, notably services in the home for disabled people and residential accommodation, the SSD must make arrangements to meet a person's needs. In other cases the SSD will have a wide discretion as to whether to provide a service or not (for example, people who need help simply because of their old age). In addition, in all cases once the SSD has gone a step further and decided to provide the service in question they must do so. The failure to do so, or the withdrawal of those services later on, can be challenged in the courts.

SSDs are not entitled to "means test" when deciding whether to provide a person with services. However, once a decision to provide the service has been taken then the SSD can charge a user for that service an amount it is reasonably practicable for the user to pay.

Common problems - The following are common problems that arise with SSDs, together with suggestions as to what you might do about it:

1. The local authority has not carried out an assessment or you do not know whether they have formally done so. Request an assessment or a copy of it. So long as you are someone who appears to need community care services you are entitled to be assessed .
2. You are being or have been assessed but the SSD does not agree you need the services. You need to ensure that the widest possible assessment is carried out, and that the SSD has as

much favourable evidence as possible. Try to get your GP and any other medical staff helping you to produce letters. Ask carers and other witnesses to prepare statements. Put this information to the SSD and if they ignore it, ask why and what evidence they rely upon that contradicts it.

3. The SSD appears to be doing nothing. Failure to do anything at all, or within a reasonable time frame, is a failure to carry out statutory obligations. It may be that you need to make a social services complaint but it may also mean that you have to take legal action. At this stage, consider consulting solicitors.
4. You were assessed as not needing services but your needs have changed. Request a reassessment.
5. The SSD agrees you need services but says they have exhausted their budget, that you can pay for them yourself or that there is some other alternative source of funding. They may be entitled to do this but it depends at what stage of their decision making process they are taking financial considerations into account. Again, consider consulting solicitors.
6. The SSD tells you it is their policy not to provide for people with your type of disability or they do not, as matter of policy, provide a particular kind of service. Unless they are considering each individual case on its own merits this may well be unlawful and so consult solicitors.
7. The SSD initially agreed to provide services and began to do so but it has now been withdrawn. Whatever the reason, this may also be unlawful so consult solicitors.
8. You have been charged for the service but can't afford it. You can ask for a review of the charge.

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HAVE I or HAVE I NOT GOT IT???

Member John Richardson, Wetherby, Yorkshire.

I was born on 8th June 1923 (77 years ago), I was a relatively healthy child, although I did seem to have childhood ailments worse than my siblings. At the age of seven I suddenly found one day that when playing a game indoors I could not get my breath, I was diagnosed as being asthmatic but I still managed to live a reasonably normal life. My mother was a great believer in "old wives remedies". I had to sleep on a flock pillow with my head to the north and I had to have the first interior sprung mattress in our house. She even sent me off to boarding school with an amber necklace round my neck (this lasted until my first bedtime). I was pretty healthy at school except for blinding hay fever in the summer and excema in the winter that prevented me from holding a pen.

I left school at the outbreak of war and at eighteen joined the army (Medically A1). I had a very active service career during which I took an engineering degree. Towards the end in '47 I did have a recurrence of asthma and had to have adrenalin injections in order to do half a days work as messing officer. I was discharged in late '47 still A1.

Having fallen in love with my wife to be and finding myself out of a job I obtained work as a lorry driver for an ex-girlfriends father. During the next three years I learnt the cabinet making trade and also studied interior decor by helping a first class designer in his late sixties.

One day he said to me "It is high time you started on your own". We found a local shop, which we

bought, and worked night and day to get the business started in the spring of 1950 and at the end of that year we got married.

Life was pretty hard in a small maisonette and harder still when our first son arrived in '52 so my wife could not help in the business.

Our second son was born in 1954. He was inoculated against POLIO we think in late '57 and was very poorly indeed. That year we had managed to have our first real holiday with my parents who lived in the midlands. David was off colour all through our stay. On our return home on the Sunday, after a long drive, I did the usual chores, cutting lawns etc. On Monday morning when we awoke I said to my wife "I do not feel like going to work I can not lift my head off the pillow". Her answer was that she felt the same but we had a living to earn, no sympathy! However I could not get out of bed, it was then decided to call the doctor. He came twice within a few hours and on his second visit announced that the ambulance was on its way. I arrived at Seacroft Hospital in the late afternoon and had to have a lumbar puncture before being admitted to the POLIO ward.

My brother a G.P., came to see me and brought me an opinion from his best friend, who was John Fitton, the Orthopaedic specialist at Pinderfields. Their theory was that if the muscles were not stretched whilst infected they would not be harmed. I literally did not move for three weeks and although I was told several times that it was doubtful if I would walk again I insisted that I should leave the hospital on my own legs.

I was eventually transferred to Pinderfields and as John Fitton was on sabbatical I came under the control of Mr. Clark who was, at first very pessimistic. I eventually announced that I was going to walk to the 'loo' and did. I was then allowed to go home with a wheelchair.

I returned to my business, which had suffered badly despite the brave efforts of our staff of one lady. I found that the only way to cope was on hands and knees, but I had to get out to clients and start getting orders and after a few weeks I managed to drive and pick up threads again.

Although I was able to hang curtains after several weeks it was some months before I could lay a carpet single handed. However I was eventually back to normal, except if I put my back out which in our business everyone does periodically. I could lift as heavy loads as anyone and I could work a 10 or 12 hour day.

I was very active in the Chamber of Trade and in Rotary International when I founded the Leeds branch of the British Polio Fellowship and eventually became the Chairman. Unfortunately our Rotary Club changed to an evening club which was the same night as the Polios which made attendance at both impossible.

I was fully active in all walks of life. I tripled the size of our shop, doing all my own shop fitting. I continued to hang curtains and lay carpets until I had two operations for ulcers in one year. I walked and swam as often as I had time and I did exercises every morning.

I retired when I was sixty and handed the business over to the two boys, although I did help with the books for some time. I still had a very active retirement because we had a large garden and I did all our home maintenance. I then became very involved with The William Merritt Disabled Living Centre and got the job of 'publicity'. I would go all over the north giving slide shows telling people what we do.

Seven years ago we moved to a lovely flat on the banks of the river Wharfe in Wetherby so I then took up Crown Green Bowls. I became besotted and played nearly every day and several evenings, also took over the maintenance of the surrounds, fences and pavilion so I was never idle.

Then in May 1999 I started with an aggravating ache in my right leg on the outside of my calf muscle just below the knee. I took very little notice, at 76 I was lucky to have nothing worse, but as the season wore on I found that it was getting worse and was spreading up my leg. Every time I put my weight on it the pain went up my thigh. I can not say that it is agony all the time but it is always uncomfortable. I had a session with a physio who thought it might have something to do with the

polio and suggested I use a stick. I now find that I need a hot wheat bag on it in bed to get some relief. I have also developed an area about the size of a half crown on the outside of my thigh which feels as if it had had all the skin grazed off but there is nothing to see.

At Christmas I started to be very short of breath and could hardly speak, the Doctor sent me to Harrogate Hospital for x-ray because he could not find any congestion, neither could the Dr. at Harrogate and the x-ray was clear. I was then put on Becotide which has helped my breathing.

SO WHAT ARE THE SYMPTOMS.

My right leg feels uncomfortable, at times it is very painful with stabbing ache shooting up to my hip when ever I put my weight on it. I feel that it is going to give way under me, particularly when I get out of bed or stand up but so far I have managed not to fall. I also have a raw spot on my thigh with nothing visible.

I still want to do all the things that I have been used to doing but I do not seem to have the energy or the inclination. I have to force myself (I do not even know if I am looking forward to the bowling season).

I have not slept well for several years and spend a lot of the night listening to the radio or reading. I am beginning to feel an 'old man' (which I suppose I am) but I have never felt so before.

WHAT IS THE DIAGNOSIS?

My doctors do not seem to believe in PPS and even my wife thinks it is all in the mind having read your newsletters.

What I would like to know is:

- Is this just a case of old age, arthritis or rheumatics that I must learn to endure,
- or are my troubles related in any way to having had Polio, in which case can anything be done to help me improve the quality of my life?

WHAT IS THE ANSWER - WHO DO I CONSULT?



IS THIS PPS? and FITTERS

Member Sheila Crampton, Newark, Nottinghamshire.

I started having new pains and more discomfort from the polio damage I had as an infant. I had mentioned it to my GP on a number of occasions; however he made nothing of it. It was affecting me quite a lot, I was having a lot of pain especially at night. I saw another GP and I explained to her about the pains I was having and I would like to see an Orthopaedic consultant to see what was happening. She said to me 'What do you say if we had your whole body x-rayed.' I said 'Yes, I would agree to that.' Thinking she was going to get to the bottom of my new pains. I was also in need of a new caliper so I asked her if she would get me changed to a Grantham fitter because where I was registered they were closing down which was Harlow Wood Orthopaedic Hospital. She said she would write and get me an appointment.

My Orthopaedic appointment came but there was quite a long wait. So after a while I rang Grantham hospital to see if they had a cancellation. I was given an earlier appointment which I gratefully accepted. When I saw the consultant he hadn't any information about the new pains and told me 'your GP has only asked for you to have a new caliper made and change to the Grantham fitter.' He hadn't got my history notes which were at Newark Hospital. He was arrogant. I have never heard anyone so rude.

I went and saw my GP telling her that the consultant she had sent me to hadn't got my notes from Newark hospital and was very rude to me. She told me they don't have to have them. I told her he

said he only had a request for a new caliper. She made nothing of it. I wasn't very pleased with what had happened to me so I asked to see a private Orthopaedic consultant and pay for it. My GP made the arrangement and I saw another consultant whose secretary told me over the phone that he had said it was important he had my history notes as well as my GP's letter.

He examined me but told me there was nothing they could do. He did say he would have liked an x-ray of my spine but I wasn't sure how much would run up his bill so did not agree to it at this time. The consultant sent my GP a letter. I have a copy of this, so I know they do and did know of my detailed handicap. My GP was on holiday so I asked the other partner GP if I could have an x-ray on my back, as the consultant had requested, but the GP said 'No the NHS does not pay for information.' So asked how much it would cost if I paid privately and he rang the x-ray department and they said £30. I said, 'I will pay that can you arrange it for me?' but he then said 'Wait till my partner gets back off holiday and she will let you have one on the NHS.'

I was x-rayed and shown them - all three - and I arranged for the consultant to see them, but he said there was nothing he could do, but it was interesting viewing and that's where my question 'Is it PPS?' has stopped. It seems very unfair that a person who has lived with a disability from childhood and has made a success of her life should have her new problems dismissed. I think that the NHS should tell GP's that when Polio Survivors have new problems they must be sent to someone who does understand Polio and its late effects and tell them who the specialists are?

I move on to Fitters.

Through my experiences I have noticed that there is a need that Fitter's should all have medical knowledge about different conditions because every disability varies.

Many years ago I had to be referred back to see a consultant because the knee bend caliper that had been ordered for me wasn't any good for my type of disability. It was a registrar that I saw. My caliper was stood up against the wall. I was not asked why I said it was unsuitable, he just told me in a very cocky manner that I was ungrateful. At that time I did not know what to do.

Therefore I went years without a knee bend caliper. Then one day I sat thinking about the confusions I had been through with fitters. I decided to write and tell my saga to Harlow Wood Orthopaedic Hospital. They wrote back and told me I could get fitted by them.

I kept the appointment and I went to great length to explain the type of knee bend caliper that would be right for me. The fitter took my measurements. I could tell he hadn't taken any notice at all of what I had said to him. He said 'We are trying to get patients out of ring top callipers because they are very painful.' I saw another fitter when I went back and he proudly carried my new knee bend caliper and said 'We have had a long talk about you.' My heart sank. I knew it wouldn't be any good for me, but he insisted that I put it on. He asked me to stand up. It did not support my hip, but he insisted that I would get used to it and that I should take it home. He even forced me to sign for it. I was so mixed up I signed. I was afraid of trouble.

During the following week I rang the firm where the caliper had been made and explained the problems I was having. They told me to take it back a week later which I did, and I took with me a drawing of the sort of caliper I needed. I also pointed out that I need a very lightweight caliper because of my small height and weight. I noted:

- The corset top knee bend caliper has no support for a damaged hip.
- The ring top knee bend caliper with a calf bar obstructs a person putting on their shoes. This is even more difficult if you are wearing a raise shoe like I do. You have to put your leg through the ring first and which ever way the shoe is put on the calf bar obstructs this procedure.

I got the design I asked for but had to sign to say that I would be responsible for it. These inconveniences would not happen if we had medically trained fitters and they were given medical information on each patients needs. In fairness to fitters it must be as frustrating for them

sometimes.

Surgical shoes are another pain. Shoe fitters should be surgical shoe fitters not someone from off the shop floor of a factory. They should also understand balance. I have experienced different heights in the raise shoe I have to wear, and when it's wrong I fall. I had to find my own surgical shoe fitter.

Why do **WE** have to search for people who will do the job properly?

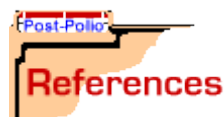
Editor's Note - Personally I have had four AFO's given me by Lincoln Hospital, one 'off the peg' and three 'made to measure'. The 'off the peg' version idea was right but I had terrible pain under the ball of my foot and asked for one to be made to measure. Number 2 was cut off behind the ball of my foot because I had complained of pain but this split the skin open when walked and it was at least two inches too large round my calf and therefore totally unsuitable. [I then had one made in Canada in three hours that fitted beautifully and 95% of my problems of swelling and pain went, and I could now walk better and drive longer.] In December 1999 I was fitted on my left leg with the Utx Swing from Ambroise UK Limited and I asked about a new AFO for my right leg so that I was covered on my records in this country. Number 3 was cast but the inside was flat and my heel slid up and down in it. There was no recess for the big toe joint like the one I was wearing - and although the Orthotist tried to alter it with a hair dryer - it was not suitable, so he cast me again. Number 4 arrived and had six things wrong with it. It was two inches longer than my foot!! The underneath was shaped correctly but not the back of the heel, the sides were at least an inch too high, when I stood up in it the sides splayed open, it was cast at 95 degrees allowing my knee to hyperextend, instead of the 85 degrees I had asked for having had that explained to me by the Canadian Orthotist; I had asked for it to be 2" higher but it was at least 4" higher and cut into the back of my knee and the strap was at least 3" too short. It was agreed that I should go to where they are made, but I have heard nothing.

Shoes - Another member simply wants flat soled inside and out soft flexible leather tie up shoes. She purchased these for many years from Marks & Spencers but their new version has a slight heel and she cannot wear a shoe like this. She visited the Orthotist at her hospital and explained fully what she needs and why, but has been given shoes that are too rigid and told to try them for a month. She cannot wear them even in the house and so has to go back again. [The LincsPPN made contact with a specialist shoe company but was horrified to be told that the price of specially made shoes is in the region of £400 and that does not compare with the £25 from M & S.]

Tell us your story - good as well as bad.

Utx swing from Ambroise UK Limited - More and more members are being fitted with this and the reports coming back are that there is a huge difference in walking and standing ability. Consultants and Orthotists are also reported to be surprised at the difference it is making. Please note that their offices have moved and the contact details are now:

October 2005 Update. Ken Spooner and Ambroise UK Ltd are no longer the UK contact. The UK supplier for UTX is RSLSteeper and their [web site](#) has full details of the UTX. According to their web site "for information on our range of orthotic services and products, please contact Mark Tomlinson on 0113 2070435 or email mark.tomlinson@rslsteeper.com". The Dutch manufacturer's web site can be found [here](#) (primarily Dutch language).



1. Update on members using Ambroise UK Limited orthoses. [[LincPIN Volume 2 - Issue No. 9 - February 2000](#)]
2. Have you heard about the revolutionary new callipers now available in the UK? [[LincPIN Volume 2 - Issue No. 8 - December 1999](#)]
3. Len's Story. [[LincPIN Volume 2 - Issue No. 8 - December 1999](#)]

Easter Traditions

Hot Cross Buns.

At the feast of Easter, the Saxon fertility Goddess, an ox was sacrificed. The ox's horns became a symbol for the feast. They were carved into the ritual bread. Thus originated "Hot cross buns". The word "buns" is derived from the Saxon word "boun" which means "sacred ox." Later, the symbol of a symmetrical cross was used to decorate the buns; the cross represents the moon, the heavenly body associated with the Goddess and its four quarters.

Easter Rabbit and Eggs.

The symbols of the Norse Goddess Ostara were the hare and the egg. Both represented fertility. From these, we have inherited the customs and symbols of the Easter egg and Easter rabbit. Eggs were sacred to many ancient civilizations and formed an integral part of religious ceremonies in Egypt and the Orient. Dyed eggs were hung in Egyptian temples.

Easter Sunrise Service.

This custom can be traced back to the ancient Pagan custom of well-coming the sun God at the vernal equinox when daytime is about to exceed the length of the night time. It was a time to celebrate the return of life and reproduction to animal and plant life as well.

When is Easter?

Easter Sunday falls on the first Sunday after the first full moon after March 20, the nominal date of the Spring Equinox. Easter Sunday can fall on any date from March 22 to April 25. The year-to-year sequences are so complicated that it takes 5.7 million years to repeat.

Rick Martinek from Milwaukee, Wisconsin

Home <http://home.earthlink.net/~polioinfo/>

⚠ *Currently Unavailable* ⚠

Home page revised on: 4/2/00



Fighting all the Way

Member Alec Mackinnon.

Christine Mackinnon is £17.00 week better off and that is official. On Friday 3rd September 1999 the Disability Appeals Tribunal struck a blow for justice and overturned a previous decision by the DSS to reduce her Disability Living Allowance to the middle rate for care. Under the now disgraced Benefits Integrity Project, which even the Social Security Minister Andrew Darling branded as unfair and unworkable, Christine had been Bipped, to coin a new verb. (My dictionary, incidentally, defines the word integrity as "adherence to moral principles", but of course the one thing that this current government would not recognise, if it came up and peed on its collective leg, is adherence to moral principles.) However, I digress.

The whole sorry saga of Christine's Bipping, began in 1998 with a very polite letter asking her if

she would allow a visitor to call on her to make sure that she was receiving all the DLA she was entitled to. A little strange, since she was already on the higher rate care component and the highest rate mobility component, which had been granted to her for life in 1987. Christine decided to see this visitor. Well, actually, she read the veiled threat to the effect that if she did not her money would be stopped anyway.

A polite woman arrived on the doorstep and was invited in and plied with tea and pleasantries. She asked her apparently innocuous questions, such as how many times Christine went to the loo and how she turned over in bed and other minor details designed to make the disabled person feel like a freak, logged the answers and asked Christine to sign the form. Off she went, rejoicing no doubt in the knowledge that she had probably earned her money that day, having been able to claw back a few miserable pounds from another disabled person who tried to answer her questions honestly. After all, if this visitor called on 100 disabled people per month and snatched back £17.00 per week from just half of them it would save the DSS around £44,200 per annum. Nice work if you can get it.

Christine thought no more of it, until about five months later she was notified that a doctor would be visiting to interview her on behalf of the DLA office. Strangely enough, the alarm bells didn't ring; she invited him in and answered all his questions honestly and off he went. A month later the letter asking for the return of her book arrived and she was told her benefit was to be reduced by £17.00 a week. The injury which was added to the insult was that they said that she would have to refund the overpayment since the re-assessment had been made, about four weeks.

A review was asked for and undertaken by the adjudication officer, but the decision was not changed and then a second review was asked for and that didn't change anything either, surprise, surprise. The only course left open to Christine was an appeal to a Disability Appeals Tribunal and with that in mind, she sent for the file on the case. If it hadn't been so serious, it would have been laughable.

Basically, the decision was that because Christine was able to take tablets in the night without assistance and could *turn over in bed by the use of a monkey pole and satin underwear* and by virtue of the fact that she was *independent in her toileting needs at night* she was only entitled to the middle rate care component of Disability Living Allowance. Of course, how she could be independent in her toileting needs at night when she is wheelchair bound and needs assistance into and out of her wheelchair escaped her, too. The satin underwear thing came about as the result of her trying to inject a little levity into the proceedings at the first interview. The visitor asked how Christine managed to turn over in bed and something along the lines of it not being too difficult "when I wear my slippery knickers" was said. The DSS has now got a note somewhere in its files about "specialised underwear for night-times". That should get someone scanning the catalogues of disability aids!

The day arrived for the Tribunal and Christine attended. One of the bones of contention between the DSS and Christine was that the report indicated that she only ever visited the toilet once a night, whereas Christine maintained that that was not so, since pain killers, of which she takes about 8 a day, dry her up and she drinks more and when one drinks more one goes to the loo more and so on and so forth... the old vicious circle of drug taking. The chair of the Tribunal asked at one point whether Christine had seen her doctor to get some more drugs to dry her up so that she did not need to go to the loo quite so often. A crass and ill-informed question to say the least and Christine more or less said so.

Well, Christine won her fight, but she should never have been put into that situation in the first place just because she is disabled. Her message to all the disabled people out there who may be targeted by this Government in an attempt to cut their benefits, no matter what they call the next round of intrusions, is simple. "If they say they are reviewing your benefits," says Christine, "seek legal advice or assistance from one of the disability rights organisations at once, preferably before you fill in any forms or see any visitor. If they cut your benefits anyway, appeal as far as you can

go. It isn't our fault we are disabled and we should not be treated like spongers or second-class citizens. Fight them all the way."

Alec & Christine Mackinnon

[<earthborne@CABLEINET.CO.UK>](mailto:earthborne@CABLEINET.CO.UK)



The APS Machine

Joy Witheridge, West Sussex.

I first read about the APS (Action Potential Simulation) Therapy in Autumn 1999 in the Daily Mail which gained my interest, and sent the cutting to Anthony Warren for his advice. He was a Veterinary Surgeon and later went into Scientific Research after contracting polio. He did say that he did not know if the therapy could help the late effects of polio, but it maybe will help with inflammatory and circulatory damage. I did nothing further about it. [Sadly Anthony died earlier this year with his problems mostly unaddressed. I miss my polio penfriend.]

Some months later, December 1999, I heard the machine mentioned at the Hydrotherapy Pool by Mrs. Anthea Frank, the Chairlady of the local Osteoporosis Group. She spoke very highly of the machine's capabilities to which I listened with interest. I asked her for more information and she gave me photocopies of the description of the Action Potential Simulation Therapy device. Anthea says 'I no longer have to take the cocktail of drugs and I take the machine wherever I go.'

Feeling that this machine might assist me in my plight with the deteriorating physical condition of my upper body, relieving aches, pain and stress, I contacted the Company requesting a free demonstration. It was explained to me that the machine would not cure the late effects of the polio but it could help with some of my symptoms. It has been primarily developed for use in pain management and is used in 38 countries.

I received the machine in February 2000 for a trial period. I was fully assessed as to where my problems were and a treatment plan was written out for me and they arranged follow up sessions to see how you are getting on and to modify the areas. This covers on a rolling plan the areas of my body where I am having the most problems, with 8 or 16 minute sessions (totalling 24 minutes a day) depending on the plan. To date I have experienced pain and stress relief in my upper body, and reduced my intake of anti-inflammatory drugs and pain killers.

In conclusion I feel that I want to do more but I have learned a great deal from being a member of the Lincolnshire Post-Polio Network. I know from trial and error that to overdo on a good day causes problems for many days afterwards. Caution therefore prevails and I keep within my worked out limitations. The APS device does not in my experience lift one out of the quagmire of the 'Post-Polio Syndrome' but has certainly helped reduce my pain levels and drug intake and I 'feel better' in myself and that has to be a plus.

Editor's note. I contacted the company - AMC Limited the sole UK distributors [<http://www.apstherapy.net>](http://www.apstherapy.net) - for more information and have been visited twice by the Regional Manager Colin

It has been demonstrated in a number of published clinical trials, that APS Therapy is successful in the reduction of pain and inflammation. This is due to the decrease in Beta-endorphin and increase in both Leucine Enkephalin and Melatonin secretion due to the APS device.

APS Therapy will decrease swelling and increase flexion and mobility due to improved circulation (Thermography). This increases the rate of antibodies, enzymes, neurotransmitters and hormones to the treated area, which will increase the rate of

removal of metabolic wastes from the treated areas.

This research indicates that chronic disease often requires protracted treatment management. Therefore, with correct use over a period of time (this period varies depending on the individuals personal state of health) real benefits and improvements can be maintained.

I was given a demonstration on the machine and it is not unpleasant to use - a sort of tingling feeling - and the time goes very quickly. I have provided them with some medical articles and their medical team have downloaded more from our site and others. The company have offered four of our members - all with very different levels of pain - a six week trial of this machine which their medical team will monitor closely. The results of this will be used to arrange further extensive hospital based trials on Polio Survivors. We will put an initial report in the next newsletter.

Colin Pearce can be contacted on his home business phone/ansaphone 01763 263305 or mobile 0378 769051.

N.B. As with any medical or holistic treatment, advice, drugs, aids and equipment etc, that Polio Survivors are being offered or undertaken, what works for one may not necessarily work for another and everything should be discussed with your primary care physician prior to starting it.



A Novel Approach to Breathing

Mary Clare Schlesinger.

This is a story about the essence of my life: polio, breathing, and the medical care that gave me some of the "best breathing years" of my life. Three months before the birth of my daughter, I had the opportunity to meet Dr. Kenneth Moser (1929-1997), and reaped the benefits of his excellent medical expertise along with the benefits of a lasting relationship. Dr. Moser was the founding director of the University of California San Diego (UCSD) Department of Medicine's Pulmonary and Critical Care Division. Dr. William R. Auger described Dr. Moser as "always very good at pinpointing what is novel about pulmonary disease and pulmonary medicine and getting people to develop novel approaches in care that you just don't see elsewhere."

Polio found its way to me in 1952 when I was three years old in the small town of Sylvania, Ohio where I lived with my loving parents, my sister and five brothers. An ambulance rushed me to Toledo Hospital on the day that my legs refused to walk. I was in an iron lung for a while then transferred to Children's Hospital where I stayed for four months. My left side was permanently damaged and weakened by polio. In an effort to correct scoliosis, Dr. Fred Hawkins performed a spinal fusion when I was 13 years. The surgery left me in a full body cast for a year and then braces and a wheelchair. However, I taught myself to walk in private, without professional help. While I was away at college I noticed the first signs of shortness of breath. A doctor at the Cleveland Clinic diagnosed my condition as "anxiety" and prescribed the tranquilizer, Librium. Several years later and several episodes of bronchitis later, I found myself in West Penn Hospital in Pittsburgh, PA with oxygen tubes wrapped around my face, painful tests for blood gases and EKGs. I recovered with a strong determination to live in a climate with less extremes.

The temperate climate of San Diego, CA was perfect for easier breathing. My husband, Steve, and I left our families in the East and moved to the West coast to start our own family. However, at 24 I developed complications during my pregnancy and the local medical establishment shunned my condition as "too risky." Fortunately, I met Dr. Moser who welcomed me with his expertise.

Unlike many doctors today, Dr. Moser was very familiar with polio. His wealth of knowledge and gentle positive attitude emanated hope. He explained the physiology of my condition with words I could understand along with words that were easy to hear. The weakened muscles on the left side of

my chest gave way to severe scoliosis, thereby compressing my lung and reducing its capacity. The inflexibility of my rib cage combined with my weak chest muscles only compounded my breathing difficulty. And, in order to expand my lungs, I used extra effort. In simplified terms, Dr Moser proposed a treatment plan for the best breathing possible with my limited capacity.

Although I don't have asthma, Dr. Moser prescribed bronchial dilator medications when I was in my mid-20s. At the same time, I learned breathing exercises with the focus on deep, slow breaths that I continue to do 10 to 15 minutes twice a day. I also acquired an ultrasonic nebulizer (USN) that I use with a saline solution two times a day. The USN treatment is followed by postural drainage and "tapping" on four sides. Steve learned the "art of tapping" from a Respiratory Therapist. Dr. Moser explained that the purpose of the USN is to keep my lungs clean and clear of secretions to reduce the risk of infections. He explained further that the mechanics of my breathing caused more than the usual amount of bronchial secretions which are a breeding ground for bacteria. The USN thins the secretions and makes it easier to clear my lungs with my reduced ability to cough. I'm able to breathe more efficiently with the least amount of congestion. These exercises are a part of my routine twice a day. When more sophisticated bronchial inhalers came on the market, Dr. Moser added them to my daily repertoire.

I enjoyed 10 years of easy breathing before polio found its way to me again as Post Polio Syndrome (PPS). With the gradual onset of PPS, Dr. Moser increased or changed some of the bronchial dilator medications. He also found that some inhalers required more frequency, and new or different combinations, to make my breathing easier.

I became Dr. Moser's "student" and gradually learned the intricacies of my own pulmonary function. Extensive testing revealed that I had the most difficulty breathing IN rather than exhaling. Every episode of bronchitis was treated quickly and aggressively, Fortunately, I've never had to use a ventilator.

While Dr. Kenneth Moser pioneered the surgical removal of blood clots from the lung and was a world renowned leader in pulmonary medicine, he continued to follow my condition for many years. Although he had to discontinue his private practice, I was fortunate to benefit from his expertise as his patient until 1993. Dr. Moser consulted with my doctors even when he was recovering from heart surgery and later, fighting lung cancer. He often commented to me or to his colleagues, "There's nothing about you that follows a textbook."

On several occasions I related to Dr. Moser the frustration of trying to explain polio and its after-effects to doctors who are unfamiliar with it. I shared many stories from fellow polio survivors whose lives were unnecessarily complicated by the medical profession. I was especially appreciative of our unique relationship, as a patient and a friend, along with the rare opportunity to know a truly great man, Dr. Kenneth Moser.

Dr. Andrew L. Ries thoughtfully described Dr. Moser, "What set Dr. Moser apart was his concern for people... both the patients he cared for and the people he worked with." Before Dr. Moser passed away, I was thankful for the opportunity to express my deep gratitude, "I know my life has been fuller because of you and your excellent care. I'm especially grateful to you... you made it possible for me to have the 'best of life'."

Pulmonary Medications: theophylline, albuterol, metaproterenol (inhaler), triamcinolone (inhaler), salmeterol (inhaler).

Mary Clare Schlesinger, San Diego, California.

<sschlesinger@home.com> - DOB 1949

Height 4 ft. 11 in. (150 cm) - Weight 90 lbs. (41 kg)

http://sandiego_polio.tripod.com

Editor's Note - More and more people are contacting us and mentioning they have respiratory problems or recurrent coughs, wheezing, difficulties sleeping, waking with a headache, choking

when laughing etc., who are being examined and told their chests are clear - x-rays if done are clear - and it's nothing to worry about. We would advise that you start diarying your days, record what you do, what symptoms you have and what effect it has on your pain, fatigue and functioning ability. Take this to your GP and ask if he thinks its advisable that you be referred to a PPS respiratory specialist for an assessment.

Forrest Gump dies and goes to Heaven. He is met at the Pearly Gate by St. Peter himself. The gates are closed, however, and Forrest approaches the gatekeeper. St. Peter says "Well, Forrest, it's certainly good to see you. We have heard so many good things about you. I must inform you that the place is filling up fast, and we've been giving an entrance quiz for everyone. The tests are short, but you need to pass before you can get into Heaven.

Forrest responds "It sure is good to be here, St. Peter. I was looking forward to this. Nobody ever told me about any entrance exam. Sure hope the test ain't too hard; Life was a big enough test as it was.

St. Peter goes on, "I know, Forrest, but the test is only three questions:

1. What days of the week begin with the letter T?
2. How many seconds are there in a year?
3. What is God's first name?"

Forrest goes away to think the questions over. He returns the next day and goes up to St.. Peter to try to answer the exam questions. St. Peter waves him up and says, "Now that you have had a chance to think the questions over, tell me your answers".

Forrest says, "Well, the first one how many days of the week begin with the letter "T?" "Shucks, that one's easy. That'd be Today and Tomorrow."

The Saint's eyes open wide and he exclaims "Forrest! That's not what I was thinking, but..., you do have a point though, and I guess I didn't specify, so I will give you credit for that answer." "How about the next one?" "How many seconds in a year?"

"Now that one's harder" says Forrest, "but I thought and thought about that and I guess the only answer can be twelve." Astounded, St. Peter says "Twelve! Twelve! Forrest, how in Heaven's name could you come up with twelve seconds in a year?"

Forest says "Aw, come on, St Peter, there's gotta be twelve. January second, February second, March second... "

"Hold it" interrupts St. Peter. "I see where you're going with it. I guess I see your point, though that wasn't quite what I had in mind, but I'll give you credit for that one too. Let's go on with the next and final question. Can you tell me God's first name?"

Forrest replied, "Andy."

When St. Peter asked how in the world he came up with the name Andy, Forrest replied, "You know, St. Peter, that song we sing in church: "Andy walks with me, Andy talks with me."

The lesson:

THERE IS ALWAYS ANOTHER POINT OF VIEW, and just because another person doesn't see things the same way or understand the same way that you do, does not mean that it's wrong. It's just different. Not good, not bad, not right, not wrong; just different, and where would we be without our differences!

Mary-Lou Whitaker, Kuma (pron. Q'na) Idaho.

Mary-Lou.Whitaker@kinfolk.org



M.E.

Jan Limback, Bourne & Spalding ME Support Group, Myalgic Encaphalitis Association.

Presentation given at the Lincolnshire Neurosciences Forum on 10.2.2000

M.E. is a somewhat complicated illness - we don't understand what causes it, we don't know how to cure it and we can't even agree on what to call it! It stands for Myalgic Encephalomyelitis, of which

myalgic - of the muscles

encephalo - of the brain

myel - of the nerves

itis - inflammation

and its the 'itis' that causes the problem as there is no actual physical evidence of inflammation although the symptoms suggest it. C.F.S. (Chronic Fatigue Syndrome) and P.V.F.S. (Post-Viral Fatigue Syndrome) are currently being used, but neither term conveys either the complexity and severity of the symptoms or the degree of disability they can cause.

Although the Government now recognises M.E. as a disease of neurological origin, a section of the medical community still insists that the causes are psychological. Despite a clear directive from the Chief Medical Officer last year some doctors still refuse to accept that M.E. exists at all. Clearly because of this situation patient care is being adversely affected, with many being given wrong advice and/or wrong diagnosis. We wish to make it clear that M.E. is in the brain, NOT in the mind!

Diagnosis is not easy - there is as yet no definitive test, and all the standard tests at GP level usually come back with 'normal' results. The sufferer often seems inarticulate, especially in the early stages of the illness. A Government Task Force is currently working on a new set of diagnostic criteria, which hopefully will improve the situation.

M.E. has been around for a long time, and historical figures such as Florence Nightingale are thought to have suffered from it. It is becoming more prevalent in recent years, particularly among children. It appears mainly in temperate regions with modern standards of hygiene - Britain, Europe, North America, New Zealand and parts of Australia.

It can affect anyone, but after puberty it affects more women than men (a ratio of about 3:1), probably due to the hormonal difference. The main age of onset is between the ages of 20 and 40. Prognosis is very variable both in severity of symptoms and length of illness, and the way it is treated especially in the early stages can influence outcome.

Symptoms are many and varied, and no two sufferers ever seem to be the same! They include:-

- Disabling exertion-induced muscle fatigue, both immediate and delayed by hours or even next day. This delayed reaction may last for days or even weeks in severe cases.
- Neurological problems, including loss of memory and concentration, problems with balance

and spatial awareness, and problems with speech, vision and hearing. The brain seems to have 'input overload' and is unable to interpret some of the information it receives.

- Periods of inability to reason, plan or think clearly, often referred to as 'brain fog' (but I call it 'total gumption failure').
- Muscle and/or joint pain, often unresponsive to analgesics and may be very severe.
- Headache, often severe and long-lasting, may respond to migraine medication.
- Immune dysfunction. May be overactive, with frequent swollen glands, sore throat and 'flu-like' symptoms, or underactive, with continual infections.
- Hormonal imbalances.
- Allergies and intolerances to food and environment (particularly alcohol).
- Digestive dysfunction, including slow movement of food through the gut (causing wind and discomfort), poor absorption of nutrients, and sometimes severe pain and irritable bowel symptoms. Some people attribute this to Candida infection, but it is not proven.
- Sleep disturbances, often sleeping too much (particularly in the early stages) or not enough, or at the wrong time. Sleep is often unrefreshing and with dreams of nightmares.
- Inability to regulate body temperature.
- Night sweats, palpitations, panic attacks.
- Marked weight gain or loss.
- Mood swings, period of depression.

Whatever the combination of symptoms they tend to fluctuate, both during the course of the day and from one day to another. The illness often follows a fluctuating course with periods of remission followed by relapse.

Treatment of M.E. is also not easy, as often what helps one patient may even make another worse. The only advice that is universally applicable is to learn to listen to your own body, rest when it tells you to, and pace yourself to get a balance between resting and periods of mental and physical activity. Medications can do more harm than good, and should be introduced at the smallest possible dose. Alternative therapies can be helpful but are often costly (beware of unscrupulous practitioners).

Average length of illness is said to be 2-4 years, but many are ill for much longer and there is a tendency for the illness to become chronic. Approximately 25% of sufferers become very severely affected, to the extent of being bed-bound, partially paralysed (sometimes unable to swallow) and unable to tolerate light or noise. People in this state are not often seen by the medical profession.

M.E. may not be life-threatening, but it is certain a life-altering and disabling condition.

Editor's note - The more we hear the symptoms of other neurological conditions the more we realise that there is a huge overlap, not only with the symptoms but also with the difficulty of getting an assessment, diagnosis, advice, treatment and management of the condition.

Strength ~Author unknown~

We don't always have to be strong to be strong. Sometimes our strength is expressed in being vulnerable. Sometimes we need to fall apart to regroup and stay on track. We all have days when we cannot push any harder, cannot hold back self-doubt, cannot stop focusing on fear, cannot be strong.

There are days when we cannot focus on being responsible. Occasionally, we don't want to get out of our pajamas. Sometimes we cry in front of people. We expose our tiredness, irritability, or anger. Those days are okay. They are just okay.

Part of taking care of ourselves means we give ourselves permission to "fall apart" when we need to. We do not need to be perpetual towers of strength. We ARE strong. We have proven that.

Our strength will continue if we allow ourselves the courage to feel scared, weak, and vulnerable when we need to experience those feelings. Today, help me to know that is it okay to allow myself to be human. Help me not to feel guilty or punish myself when I need to "fall apart."

Sent in by Tommy Conrad <tlcon@WEBOUND.COM>
<http://homepages.msn.com/SpiritSt/tlc57/PPSersandJesus.html>

2nd BRANSON POLIO SURVIVORS INTERNET REUNION

Branson, Missouri, USA. June 10 - 13th 2000 (Immediately following the GINI Conference)

Staying at the Lawrence Welk Resort - Rooms \$55

Meet, chat and laugh with Polio Survivors - Visit Silver Dollar City - See the sights of Branson

Email Tommy <tlcon@WEBOUND.COM> for more information.



Stop chasing the holy grail of medical care and take charge of your life.

Do we get discouraged? Yes, we do. Are we depressed? Yes, much of the time. Are we depressing? **NEVAH!** "But," you say, "I have PPS and there's no cure, no hope and precious little help." Are we wimps that lay down and become doormats? Maybe, but even a polio-wimp can take charge of his life. After all, most of us were Type A's, weren't we? So, dear friends, gird up your loins and, **"CHARGE!"**

"Just as there was no cure for acute poliomyelitis, there is no cure for post-polio syndrome (PPS). The most successful treatment program for PPS is survivor and family education, which teaches the survivors the principles of, and methods for, self-management of their bodies."

Laura K. Smith [[1](#)]

Did you catch that? Smith writes that *"The most successful treatment program for PPS is... self-management of their bodies."* In other words, we alone are best suited for taking care of ourselves. When King Arthur's knights quested for the Holy Grail, they did not find it. Neither will we, if we look only to the medical establishment.

I am writing this article NOT to be offensive, but to provoke your thinking about this debilitation, will we or nil we, that has overtaken us. So please don't get mad at me, which won't do any good, but DO think about this statement, which will do you some good:

Even though most of us may not be, nor ever have been, like the "Prodigal Son" spoken of in the Bible, we waste our substance, not on the riotous living of a wastrel, but in chasing the Holy Grail of medical care.

When I use the words, "our substance" above, I am taking the systemic and holistic view of what "I" am. Money is just a small part of my substance, but energy and strength are a very large part of what is "me;" and need even tighter budgeting.

A rut is an open-ended grave, and that's where you and I often find ourselves: in dead-end thinking and actions, until someone or somewhat jerks us up short, and forces us to stop and think for a minute, or even three. I admit these statements below are between generalizations and hyperbole, but do think about them:

- We get a pain and run to the doctor, expecting a magic cure in a little bottle from the drugstore.
- Only in the last *fifty years* or so has this been true. In the previous *fifty centuries* we ignored the pain, or fixed it ourselves - there wasn't a doctor on every street corner.
- Before WWII, Mommy was the family doctor when we were non-adults, but when we became adults we became responsible for ourselves or developed the unenviable reputation of being hypochondriac, or even a whiner.
- "Kiss and make it better, Mommy," is still heard today, and sometimes it works! But Mommy had a certain amount of experience with various owee's and knew what to do, and did it.
- Sometimes Mommy had to think about it, perhaps even remember what Grandmama had done in such a case. She had to THINK! And so do we.

Years ago I went to the doctor once, and told him, "Doc, it hurts when I do *this* (whatever "*this*" was)." He said, "Don't do '*this*.' \$5 please! Next!" Now that may be a small chuckle, but the common sense of the doctor's instruction is not. Today if I went to my doctor and said that, I'd have an MRI and a sonogram scheduled before I could blink twice, right?

Granted, the debilitations, aches, constant pains, frustrations, flusterations and general malaise that we polios entertain daily, are NOT funny, but I want to advance the proposition that sometimes we make them much worse by stressing out with continuous doctor visits.

"Now come on Docs... time you learned to doctor... listen to your patients... listen to what they say... If they say they cannot walk upstairs now but could five years ago.. something must have changed. ...Rest (after the examination) and muscles will recover somewhat. Depends on how much straining you have done and how much energy level you have. We all know how we feel after a full physical by a doc/etc. Totally and utterly shattered... Takes at least one day of doing nothing to come back to anywhere near what we were before they started."

Hilary Hallam [[2](#)] in an email in 1997.

A couple of years ago we visited my blood pressure and primary care doctor, whose clinic is connected with the University of Florida's teaching hospital. As usual, one of the students came to me first for the preliminary examination -- and I love these visits! I get to train a new doctor on the ins and outs of PPS and my other assorted problems! For some reason our appointment was in the afternoon, and therein lay the learning experience: the young lady student examined me, checked my heart - breathe this way, breathe that way, my reflexes, my throat, et al, and then she left to consult with the doctor. The two of them came in a few minutes later, and I was a basket case, almost. Even my wife, Nancy, said that I looked awful, and we all agreed then and there that I would always have an early morning appointment Lesson Number 1. The doctor and the student were very surprised at my condition, and what the simple examination had done to me, as were Nancy and I, though I should have expected it.

Today, any doctoral appointment, whether medical, chiropractic or masseuse, is always early to mid-morning. Anything else is simply unacceptable.

About twenty years ago, I wrote a letter to a doctor in the city who was recommended by a friend, and detailed my problems. I did this because my allergist wasn't helping particularly nor was my GP, who'd been our family physician for nearly twenty-five years. The city doctor responded that he could help and we set up an appointment. I went. He examined me. He said he could *NOT* help; \$150 please. If I'd had any sense, I would have whipped out his letter and refused to pay! I still get angry thinking of it.

That was the last time I went chasing the holy grail of medical care. I came to understand that since I live with myself 24 hours a day, but only occasionally see an "*expert*" for ten minutes or less, the primary responsibility for my well-being is mine. No one else's. *Mine!* And that is the way I still work it.

Should we abdicate the management of our physical well-being to some "*expert*" whom we see for ten minutes after significant lapses in time? I do not think so, so don't you do it! Look at the energy you'll save to play with those precious kids! Laugh all the way to the bank with the gas money you save not going all over creation chasing this specialist and that therapist. Be happy thinking of all the stress and frustrations you've given the pass to. Take time to enjoy the sunset, the birds, and even the weeds in their season.

Art Coburn - Trenton, Florida.

You may freely vent your opinions of this article to me at: [<artinfla@afn.org>](mailto:artinfla@afn.org) or by writing do the LincPIN, address on [back page](#).

1. Laura K. Smith, Ph.D., P.T. Consultant, The Institute for Rehabilitation and Research, Houston, TX, pp 84-85, Managing Post-Polio, Lauro S. Halstead, M.D., 1998.
[\[Lincolnshire Library Book Catalogue\]](#)
2. Hilary Hallam, Lincolnshire Post-Polio Network -
<http://www.zynet.co.uk/ott/polio/lincolnshire/>

All I need to know I learned from Noah's Ark!

1. Don't miss the boat.
2. Remember that we are all in the same boat.
3. Plan ahead. It wasn't raining when Noah built the Ark.
4. Stay fit. When you're 600 years old, someone may ask you to do something really big.
5. Don't listen to critics, just get on with the job that needs to be done.
6. Build your future on high ground.
7. For safety's sake, travel in pairs.
8. Speed isn't always an advantage. The snails were on board with the cheetahs.
9. When you're stressed, float awhile.
10. Remember, the Ark was built by amateurs, the Titanic by professionals.
11. No matter the storm, when you are with God, there's always a rainbow waiting.

sent in by Rick Martinek from Milwaukee, Wisconsin

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Mousemat

Christine Ayre.

Things have changed for me in many ways since I have had PPS. The obvious changes many of you will also have experienced. The changes of lifestyle, maybe retirement, giving up the hobbies you once enjoyed and a general scaling down of things you have taken for granted for so much of your life. This is hard for all of us, but being polio survivors we don't give up, instead we look for pastimes we can do well using less energy.

So it was with me. When I retired I planned to take up painting and reading, and with my dogs to look after and a bit of gentle weeding of the garden, I thought my days would be full enough.

I had reckoned without technology and never thought to be dragged into all the paraphernalia of the computer age. The nearest I had come to technology was when I bought a wheelbarrow and looked for nothing more. Catley Abbey never has been at the cutting edge of the modern age and we still look on an exciting day out as visiting the nearby village shop, to watch the bacon slicer.

A friend I was visiting one fateful day suggested I go with her to computer college. Oh no! I said, I'm not interested in those things: in fact I think they are more trouble than they are worth and if I had my way they would all be gathered up and dumped in the sea. "Go on" she said, "what else do you have to do? It will do you good, get you out to meet people." I said I would try it once, to see if I liked it but, no promises.

I attended the college for six months before I bought my own computer, by which time I was completely hooked. I was by this time doing word processing, spreadsheets, databases and desk top publishing. It took me another few months to get on line and since then I have made many friends across the World.

As with any hobby there are a lot of things one has to buy, these in computer speak are known as peripherals, so since the computer took over a corner of my sitting room other little things I could not possibly live without have been appearing at regular intervals. First the computer demands its own workspace, in the form of a custom made set of shelves. The printer needed a shelf, then the scanner arrived and needed a shelf. Then came the boxes for the CD ROM's and the floppy discs, the reams of paper, plain and photo quality, by this time I had a digital camera, then it needed a lead to plug it into the mains electricity.

I have spare batteries for the camera, spare internal fan for the computer, retractable keyboard brush, inks for the printer, files to hold all the paperwork I now generate. A spare lead to plug the modem into the phone socket, books on how to do things when my one brain cell overheats and goes on the blink. They all require shelves, as do the the increasing number of computer magazines which arrive at regular intervals and I dare not throw away, just in case I have a problem which one of the magazines is able to solve.

There is also a certain pleasurable time consuming side to the computer in the form of games, also things like the pet dogz CD ROM. where one can adopt a dog and watch it grow from puppyhood into an adult dog, fall in love with another dog and produce a puppy. The puppies are very sweet and fluffy, and one is able to interact with the dogs, play ball, scratch their backs etc. Not that I know much about that sort of childish thing of course. There is also one with cats. I don't have that one... yet.

I must admit having a computer is rather like having a superior friend. Smugly reminding me when bills are due and telling me that it has changed its own clock in line with British Summer Time. Unlike me it never forgets.

With technology making great strides almost daily, the time will soon come when computers will not only think for themselves but also talk. I dread the day when I sit in front of my computer and it says something like, 'nice legs, pity about the face'.

Well that has given you an insight into the computer situation at Catley Abbey. I'm just about to set out and drive with Ben boxer riding shotgun, to PC World, there I hope to purchase a new talking mouse mat. I saw it advertised in my computer magazine this week, it has a limited vocabulary but, just right for me, it says, "Greetings oh enlightened one-ohhhhh" and features a picture of green aliens, sounds nice. Also I fancy one of the furry monitor covers, I think one like a zebra will look nice in my room. Oh and I must look at the camera to fit on my monitor, then people I talk to on the net will be able to see me, that should put them off for life. Then I've seen some screensavers that look like a tank of tropical fish. There are also some slim line monitors, I'll look at them while I'm there. If I had one of them it would free up a bit of space on the shelves, that's tempting.

I did also want a Shorn the Sheep mouse pad. Maybe I'll end up with two mouse pads. Decisions decisions.

Christine Ayre

Chairperson. Lincolnshire Post-Polio Network.

A Nippy Ventilator User.

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My Private War

by June Millard 1.4.26 - 8.8.92

[Part 2 - continued from [last newsletter](#)].

This article was written by the late June Millard whose sister is Wendy Grimmitt, a new member from Grantham who caught polio at the same time as June and now has PPS.

Later that day came my promotion to the Women's Ward. The Sister of this ward was a marvellous old lady, well over seventy, who had come from retirement to help with the nursing shortage. In the first World War her face had been badly scarred by a shell splinter while nursing behind the lines. She was very gentle and sympathetic. After my hand up I found she understood the fright and loneliness one feels at times like that. However much one tries to hide the fear, it is there. With Sister I didn't have to hid it, and this helped enormously.

One of her pet things was a weekly dose of cascara, whether it was needed or not. The vases of flowers must have wondered what had hit them on 'cascara' days. Occasionally Sister stood over us while the dose was administered. No getting away with it then. The consequences were usual and horrible!

The women's ward had had an extension built on to the old ward where my bed was placed. An arched way connected the old and the new parts, and there were windows where there might have been sliding doors. The extension held ten beds, and had radiators so that in winter it was a little warmer.

One evening a blanket that had been left of a radiator began to smoulder and smoke curled up. A few patients started to panic and tried to get out of their beds, but before any damage was done the fire was out.

The private patients' ward were in our block, and a door led to our ward from their corridor. We couldn't wait to tell new patients about the two night sisters who were killed by a bomb as they were coming along that corridor, and of the ghosts who walked at midnight rounds. Oddly enough some years later when I was back in the hospital for treatment, one night unable to sleep and lying in bed

awake I had a weird experience. The door opened and closed, and the boards creaked as if someone had passed down the ward. I couldn't see anyone, and yet had the feeling that some person had gone through. A little later a nurse came down and I asked her who had gone out. She said, 'No-one. Why?' I said I thought it might have been Sister, but the nurse said, 'No, I haven't been off the ward, and she isn't here yet'. I could not to this day say that I saw a ghost. I know I had a very unpleasant feeling. I also know I was awake. So what was it?

We had a lot of flirting between the male patients and the girls, mostly from a distance. There was usually a romance going on, with letters delivered by kindly porters and nurses. Often when the patients were supposed to be asleep they were meeting their opposite numbers. If the Staff Nurse had known, the fur would have flown. All this broke the monotony of the day to day life of the hospital.

One day Mother asked if it would be possible to have me at home. The hospital said that this would be alright if there was a supply of electricity, and if a private Physio would be engaged - there was no National Health Service then. A year after the onset of my illness my parents had bought a small grocery business, with the thought in mind that if I ever came home I would need a lot of looking after, and with the shop I could be cared for and a living made at the same time. But it was an old property with gas lighting. Red tape had to be gone through before eventually we had the electricity installed on the ground floor. With the conditions fulfilled, at long last I was told I could go home.

At 12 o'clock Cinderella's coach arrived with two attendants. The coach admittedly looked like an ambulance, but no Ball could have made me feel so intensely happy. To see again trees lining the roads, traffic passing, people walking along the pavements, life around me once again; and I was going to be part of it!

The ambulance stopped. The doors opened and a pretty little girl ran up and said, 'Hallo'. It was my young sister who was four years old when I had gone into hospital, and was now seven. During all this time we met only twice.

Then I was carried into my new home. The room looked so tiny after the large wards. The settee had been filled with cushions, and as I still couldn't bend I was lifted onto it from the stretcher, and made a big fuss of. My sister was there to see me - the sister she hadn't known. She could vaguely remember a person who could run, jump, dance ballet, and do acrobatics to amuse her. Here was a stranger who lay flat and could only move one arm, and needed the sort of care she associated with a baby. It must have been all very strange to her.

Mother had cooked my favourite dinner, and all was well with the wonderful world. That night I slept in a soft bed with feather pillows. I was at the very peak of happiness. At last I was home. Next morning I woke in agony; too much softness was not for me. So back I went to a hard bed, and pillows with just one feather for luck!

My new Physio came to start my treatment and see what my condition was. The joints were still stiff, also the spine. The left arm was quite useful, and I had learnt to write with it. The right arm was stiff and almost useless. The fingers were curled over and had little grip in them. Slowly, a bit of a time, the adhesions were broken down. This was painful, and there were times when I hit top 'C'! But it had to be done - though it was hard for me to appreciate this at the time.

The treatment lasted only a few minutes but customers knew it was no good coming in to be served in the quarter of an hour before 11 a.m., as Mother would be at the bottom of the garden. Being a sensible woman she knew my ordeal was the only way to recover, but she couldn't bear to hear me being hurt. Once the treatment was over for the day, that was it. I was sore but I had no reason to moan.

The first time I washed up a few things after tea it took me ages. Luckily Mother had padded the sink with towels, as I bounced the cups a bit at first. Slowly I learnt to cope with simple jobs again, and the more I did, the more my muscles improved. Fortunately before I got polio I could cook

quite well, so I knew what ought to be done. Now it was a case of finding the best way to do it within my capabilities. It was fun finding out, and the first cake I made was highly praised although there was too much sugar in it. This in rationing time!

To get out and about I had a long wheel-chair, and as there was very little of me, and little springing in the chair, my bones were padded with pillows. In the summer, tucked around with a warm rug, it was quite cosy, but in winter, although well wrapped up, plus a hot water bottle, it was difficult to keep warm.

Since those days I can sympathise with babies, who have just a small rug around them and an apron, for sometimes looking miserable. The proud Mum is striding along keeping warm, saying to everyone, 'lovely day', and when Junior howls the last thing Mum thinks of is that the poor mite may be frozen.

I found it embarrassing to meet the boys and girls now eighteen and nineteen years old, with whom I had played, flirted, and danced such a few years before, although they were very kind. They had stayed at home and grown up, and for my part I was a stranger in the town and I didn't even speak their language. This emphasized the wide difference between us. They were normal. I was not.

Then a letter arrived from a stranger in the local Youth Club saying he would like to come and see me. We became friends, and he never made any bother about my wheel-chair. He said, 'This is the only way you can get out, and I want to take you out - so this is the way'. This boosted my morale and encouraged me to use a stick instead of crutches. It was a bit awkward at first, as it meant learning a new balance, and the stick looked very fragile after two crutches.

One of my interests was letter writing, and I had a number of pen-friends in the forces. Often when on leave they used to spend a few days with us. The family never knew which branch of His Majesty's Forces would turn up next! It was great fun, and the more so because V.E. day had come, and when my friends said 'cherry' there was a good chance of seeing them again. One or two made it clear that marriage was on their minds, but I didn't want to marry, or even get serious about anyone. I was determined that before that day came I would improve very much - far beyond what I was capable of then.

The end of the war brought its relief and joy. Women - the lucky ones - had to get used to their men at home. Others found the loss of dear ones brought home twofold. Everyone in some way had to readjust and pick up their lives again. An uncle of mine was released from a prison camp, and came to live with us for a while. He bought a sports car and I had my first taste of speed. He used to scare the living daylights out of me, and ever since I have had no real love of speed.

Rationing was still with us and I started to help in the business by cutting up the rations, and at Xmas time weighing out the portions of dried fruit allowed on each ration book. This was a job nobody else liked as it was so sticky, but to me it was a joy to get my hands dirty by work.

Gradually my work in the shop increased, and now around the house I no longer used my stick to walk with. My balance was much improved and I could carry small things from a to b without dropping them. Lifting sugar and flour bags helped my muscles. My right shoulder was weak, and I was unable to lift my arm at the shoulder at all. This was to be permanent, so I have learnt to live with it - or rather without it. The left shoulder was only just able to lift the arm up, so I used to wriggle things to the edge of the shelves, wait till they tipped over, then catch them. This certainly helped the reflexes because if I missed the object it hit my head, or feet, and though a bag of flour over one's head or feet may make a funny sketch, I can assure you that in real life it is not funny!

During this time I joined a club, the members of which were strangers to me. They were a jolly lot, and regarded my disabilities as a challenge once they found I didn't need treating like a piece of Dresden china. It was taken for granted that I would join in outings and activities. If I couldn't climb up or get down one of the lads was always willing to carry me. Once, when in the Cotswolds for a day's outing, I said I would stay at the coach while the others went off. Oh no, that wouldn't do, and

we climbed a gentle slope to the top, but coming down the other side was very steep. The boys lined the path, and I had a fireman's lift to the bottom.

I started to go to local dances, and got a lot of enjoyment from watching others. The jitter-bug was all the rage then, and the swirl of skirts and the beat of the music was new and exciting. In contrast I went to watch Old Time dancing, enjoying the grace and elegance of past days.

An illness hit me and laid me low, and it was decided that I should go for convalescence to Exmouth. This entailed a train journey from Sutton Coldfield via Bristol and Exeter. I had never done a train journey, let alone one of such a distance, and I looked forward to it with mixed feelings. The guard was put in charge of me, and on changing trains at Temple Meads and Exeter I was trundled down passages not normally open to passengers. May I say that the men of the railways couldn't have treated a queen better. At Exmouth the first three taxi drivers refused to take me as I had to be lifted into the vehicle. The fourth driver was kindness itself, and we were away.

When I arrived at the Home, I was tired, dispirited and lonely. To greet me was, 'We do not take cripples. You will have to go back to-night'. At this I lost my temper and asked why they had accepted my booking if they didn't take cripples. They had had a full report from the Almoner of the hospital in Birmingham, and anyway they were being paid. I refused point blank to leave the house and demanded a bed for the night - the one they had prepared for me on the ground floor. The following morning I was told rather condescendingly that it had been decided that I could stay - on the condition that I didn't call the staff too much. (Since those days the place has been re-organized, and is now a properly run Home).

As I couldn't sit down I ate standing up, and my meals were laid in the lounge so that I didn't upset the guests.

The house was in a perfect position just across the promenade from the sea. From the garden I could lie and watch the world go by. My walking distance was limited, but I could manage to walk to the sand without too much difficulty as long as I was given a hand. To try walking on sand was a mistake, as I found at my first try. A local boatman noticed my difficulty, and came to my rescue and carried me to solid ground. He told me not to try that again, and thereafter gave me lifts to my deckchair and back to 'dry land' again. When he wasn't on duty someone else took his place. They treated me like a queen, and were very kind.

I never got a boat ride. For three days there were gales, and we stood in the windows to watch the sea. Lightening forked, and the waves thundered against the rocks, and sent spray high in the air to fill the sight with a million colours, like twinkling lights. Watching one marvelled at the awe-inspiring spectacle, but said a silent prayer for those at sea riding out the storm.

One Sunday a couple of fellows stopped to talk over the garden wall. The quiet one had a red rose in his button-hole. He asked me why I was staying there. I said because I had hurt my hip. To me that covered the obvious; the stick and my limp. My gammy hand was tucked into my trouser pocket. I never expected to see him again. He was a baker, and started to bring freshly cooked tarts for our afternoon teas. We met on most days during the last week of my stay. When I was leaving he asked if he could write, and we swapped addresses. His name was Don. He was the same age as myself, twenty, and he lived with his sister in Withycombe.

The letters started to arrive full of news and interest, and soon I was watching for them. The next year he came to stay with us for his holiday, and we got to know each other better. Suddenly it dawned on me that I had dropped all my boy friends and that my feelings were concentrated on Don. This feeling had crept up on me so quietly that it came as almost as a shock; I was in love, and I didn't want to be in love.

We got engaged at Easter, and he came to live close by. He knew my limitations, but encouraged me to try new things. So my first local train and bus rides into town were taken with him. I found buses awkward to get on to, with the step up from the platform just after getting on the footplate. For by

that time the bell would have rung and the great beast would hiccup just as my foot was on the step. Many is the time I would have fallen backwards but for Don's grip. He was strong. We were young, engaged, and in love and so with our future in front of us life was good. Looking back it seemed a time of laughter.

Once while looking over the caves at Cheddar Gorge we did not realize there was a table of rock across the cave which was a hands and knees job until the people in front began crawling. We were about to turn back; but one man pushed my ankles and another my shoulders and through I went.

My improvement progressed. I could now cook quite well, and household chores became more extended. In the shop my counter work was better.

In 1950 we had been engaged for two and a half years, and we booked Whit Monday as our wedding day. The reaction among our friends when this was announced were mixed. Most gave congratulations and the credit for being sensible enough to have gone into the problems that could arise, and to have asked the advice of the doctor. There was a small section who thought it wicked for a cripple - a word I hate - to marry a normal man. Some even accused Mother of getting rid of her responsibility by palming me off on that 'nice young man'. Little did they know what Don said about some of them.

I have met this type of person many times since. These people think they have a right to ask the most personal questions on the briefest of acquaintance. Their faces seem to quiver while they ask, leaning very close, 'I hope you don't mind me asking dear, but how do you manage in your married life?' My stock answer is, 'I have always loved housework, so I enjoy running my own home'. I know, and they know, that this is not what they mean at all! When they get exasperated, because all the leading questions are turned aside, they go off in a huff, thinking what a dumb cluck I am. Or, if I tell them straight out to mind their own business, I am the one who is rude. You just can't win. What puzzles me is that these people can speak like this to me, but wouldn't dream of asking the same questions of their own friends, or even members of their own families.

A week before my wedding day it was bitterly cold; so cold that an aunt suggested I wear my Dad's long johns under my dress. This I did not agree with. On Whit Sunday it brightened up, and Whit Monday was beautiful.

My white wedding dress hid my limp, and my weak right hand was able to hold my bouquet. My Father was a short man and rather bothered about lifting me in and out of the wedding car. A six foot tall friend lifted me in, and dashed to the church to lift me out. My dressmaker was waiting to straighten my dress and see all was well.

While getting ready I saw Don crossing the road. I looked at him and knew beyond doubt that he was the man for me. I gave a silent prayer of thankfulness to God for all the help He had given me, and asked for guidance and help in our future.

Our honeymoon was spent in London, in a heat wave. When the papers say eggs can be fried on the pavements I can now believe them. We found travelling by tube was much the easiest way. Though when we first used them I had the fear that I should be left behind - but I wasn't. On a later holiday I was shut in the doors, but I did get away with my skin. I enjoyed the escalators, as I had when a child. Secretly I loved to go on them, and searched out the longest ones. We came down to earth, back to a bedsitting room. We were lucky, ground floor rooms and flats being then, as now, like gold to find. We had the use of the kitchen. The bathroom was upstairs, but with an outside toilet I could manage. I was still working in the shop, and Mother gave us our main meals so that apart from snacks all I had to prepare was Sunday dinner. Our home was small, and I could manage.

Don hit a bad patch in health (which I hoped was not the result of my methods of looking after him!). He had boils, whitlows and trouble with his stomach. These proved to be caused by his job, and he was advised to change to outdoor work. In a snowy February he went from the heat of a bakery to the real cold outside. It did the trick and his health improved.

That summer I began walking from our digs to the shop, a matter of a couple of hundred yards, and felt very clever. A funny thing happened one afternoon as I was walking from the shop. Coming towards me on the other side was a woman, limping with the same leg and using a stick in the same hand as I do. When she drew abreast she began to upbraid me for mocking her, and said that I should be ashamed of myself etc. I was so flabbergasted that all I could manage to get out was, 'But I always walk like this'. It was quite a few minutes before I could convince her that this was the case.

Autumn came, and while on the way to work one morning I tripped, fell, and knocked myself out. The landlady found me spark out and rather wet in the drive. My head had met a sharp stone on the way down, and this caused four stitches and a week in bed. After that I had to promise to be less independent and to wait until I could get someone to walk with me.

The new Elizabethan era commenced. The Queen was crowned. In the same month we heard that through the help of our doctor we had been allocated a bungalow. Within ten days we had moved. Our furnishings were only the bare essentials, but it was heaven to have a place of our own. For the first few days I wandered round the place unable to believe it was ours, and fearing I would surely awake to find it gone.

As I could not bend to the floor, ways and means had to be found to cope with the house. A small shovel attached to a long handle, and a strong cobweb brush were indispensable for picking things up. One of the most useful tools was a swivel mop without the mop head, ideal for picking up things which have a small lip or a handle. Polishing was easy. After putting the polish on, a duster was dropped and then I used my foot. It is much easier to get into corners with one's foot.

Another old faithful is my walking stick, without which I would be lost. I couldn't get dressed, as everything has to start at floor level and come upwards. The one thing I have to leave to Don is my stockings as they are too delicate. At this job he is good, and rarely ladders them.

My fingers slowly got used to handling hot dishes from the oven, because if they did happen to be too hot I still had to hold them until I reached the nearest side table. All this took time to learn, and during this apprenticeship, Mother and Don were most helpful.

One lunch time on the radio they asked for requests for a new T.V. show which was to be called 'Songs for the Asking'. They were needing songs which had a memory connected with them. Just for fun I wrote of my iron-lung tune. A long time after this a telegram arrived to tell me that a producer was coming to see me.

To say that I was surprised would be an understatement. The producer explained that they thought my story was just what they needed, but the song was not the type of music which the programme used. As the orchestra was the Welsh Orchestra, would I mind if they played a tune called 'If my Heart had Wings'. The program was to be on Tuesday, 25th October 1955 at 7.30.

We, my Mother, Don and I, travelled to Cardiff on the Monday, and a limousine was there to meet us at the station. It took us to the Park Hotel where the B.B.C. had booked our rooms. It looked a rather large place and I had visions of getting lost in the corridors. I didn't do that, but while Don was out for a short time I went to the bathroom and arrived back at our room to find that the door had swung shut. The key was on the dressing table. Feeling very much a fool, I wandered around until I found a manageress's office and meekly asked for a pass key. I made sure after that that the key was on the right side of the door.

We spent the evening in the hotel, and after dinner went for a drink. As the bar was only down the hallway Don went ahead while I was powdering my nose. The room he went into was a long one and he had gone to the far end. I started after him, and had gone a few yards when a gentleman touched my arm and explained that this was a gentleman's only bar. I crept out.

At eleven o'clock next morning we met the other 'requesters' and Franklin Engelmann, the compere of the show. We ran through our stories. This done, we had lunch together.

The cars called for us about one thirty, and took us to the Sophia Gardens. The trees looked lovely in their autumn dress. The afternoon was a confusion of rehearsals, music, cups or tea, and tempers getting very frayed. There were also funny incidents. The baritone's tights split as he bent down. A tree that was nailed to a wall slowly fell sideways until it found a resting place on the head and shoulders of the harpist on the next set - he was playing in the Enchanted Garden. There was the tenor trying on four different wigs in succession to see which came out best on the cameras. I was surprised that the choir wore blue shirts because they came out the whitest.

7.30, transmission time. 'All quiet please'. We were on! Don had to hold me on the chair, I was shaking so much. Gosh, me next! My mind went blank. Franklin Engelmann came up the aisle, smiled, and we were away. I forget the name of my song - it was in French. He covered up for me very professionally. He was a very charming man.

Then it was all over. I wondered what Mother thought of me. All she said was, 'You never smiled once'. We had a drink with the cast and all concerned, and said our goodbyes. On Wednesday we returned home, and had the B.B.C. to thank for an unforgettable experience.

The following spring the Ministry of Pensions said I might have an invalid carriage, and in this I found my freedom. I had to pass a sort of test to find out if I could handle her. What a thrill down a hill in Birmingham with the Man from the Ministry running beside me - how he could have stopped me goodness knows. Going to work now was fun. Rain never bothered us, and only fog and snow kept us in. Don used to ride his bike, and on nice summer days we used to ride through the country lanes and wind up at a country pub for a beer.

My parents and Don used to get bothered when I was out alone. They said I wasn't safe, and looking back I don't suppose I was. One of my favourite tricks was to find a good steep hill and 'let her rip'. She used to go like the clappers. When the Ministry called in these chairs, oh! how I missed her, and although they sent me another she was too heavy for me to manage.

In the late 1950's I hit a bad patch in health, and for a year one illness after another came along, and I was more in bed than out of it. Don during this period was so loving, and looked after me with the greatest care. My resilience and the will to fight back were stretched to the limit, and I became the victim of a nervous breakdown. I lost interest in most things, and just wanted to stay in bed all day. For the first three months of this illness we lived at my Mother's and then the treatment began to work. We came home, and slowly I picked up the reins, and in a year I was fine again. A new club for handicapped people was opened, and was asked to become a member. Before long I was on the committee, and soon found that it could be interesting. I made some very good friends there. Before long Don was helping and was co-opted onto the committee, although he prefers to be in the background helping where he is needed. Personally I would rather be in the swim, and help organize events - not that all ideas work out as they should. One lesson life has taught me is, 'you can't please all the people all the time'.

My breakdown taught me far more about myself - with the aid of a psychiatrist. I have got a temper, but because I hate rows have always tried to control it. I have many times swallowed the temptation to answer back, only occasionally losing the battle. A drug - part of the treatment - made me brutally truthful and I fear shock a few people. My diplomatic side disappeared, and I said exactly what I thought. Nowadays, if I really get mad, I let rip and if things go wrong I admit it, but I talk my worries over with Don instead of bottling them up.

1965/66 was a rough spell. For ten years I had had an ulcer on the left ankle and various treatments had been applied, including an operation to tie the vein, and rests in hospital for three weeks at a time - but to no avail. It was decided that two operations were necessary, the first to cut out the ulcer, the second to graft skin over the scar. Both were successful, and although the inside of the ankle is scooped out a little, at least the skin is now healthy.

In 1966 another great surprise; after fifteen years of marriage I found I was pregnant. Years before we were advised against having children. We had, thought, complied, but here it was. Why, I don't

know, but for two months I never told anyone about it. Then I saw a doctor, who immediately sent me to a specialist. It wasn't to be, and I had to lose my baby. To save my health a hysterectomy was advised. Over many years I had heard many old wife's tales, so, as I was in a place which specialised in gynaecology, I asked all the questions, to which I got the correct answers. They wiped away a lot of fears. The staff were wonderful to me all the way through, and my recovery went according to plan.

For once, I followed orders. For example, to have help during the first three months with housework, so as not to lift anything heavy, or damage the muscles while they were healing and knitting together. I was walking about, and even went on holiday, after a week. Soon I was enjoying life to the full.

Looking back over the years I must admit my life has not been dull. The road has been up hill and down dale, sometimes getting lost for a time in deep forests where the sun does not seem to penetrate. I have learnt many lessons from life, and am still learning about people and this wonderful world that we live in. My life so far, seems to have been split into three parts; complete mobility, immobility, and half of each. There is an old saying, 'Life begins at forty'. What will the future hold?

My good fortune has been my parents, my dear husband, and all their comfort and help. My Maker made everything possible.



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