



The LincPIN

The **Lincolnshire Post-Polio Information Newsletter**
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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. Although it does not provide an endorsement, it is provided as a service to those seeking such information. ALWAYS consult your doctor before trying anything recommended in this or any other publication. **Lincolnshire Post-Polio Network - UK Registered Charity No. 1064177**

Editorial by Hilary Hallam

Our Annual General Meeting will be held on Saturday 29th September 2001 in Lincoln. Full details in next newsletter. The day will run along the lines of the last two years. The meeting will be at Ancaster Day Centre in Lincoln 10.45 for 11.15 start. After this there will be a salad buffet lunch with time to chat. There will be two talks in the afternoon and question time. Rooms have been pencilled in for us at the Ibis Hotel (on the A46 bypass behind the Pride of Lincoln) the room rate is £35 with continental breakfast at £3.95 per person if wanted. (Ibis do not give discounts). Phone number for direct booking mentioning Lincolnshire Post Polio Network is 01522 698333. The hotel now has snacks available each day, but we are still able to bring in our own food, or take-aways. The Pride of Lincoln with full eating facilities is next door. As previous years we will have a leisurely get together both on Friday and Saturday nights in the hotel bar. Lots of sharing of stories and experiences not only of polio but much much more and with lots of laughter. Families and friends are most welcome. We will provide information on Lincoln's attractions on request if those with you would prefer to do the touristy bits.

Other Meetings attended recently. Reports in August. Janice attended the AGM of the Long-Term Medical Conditions Alliance in London. Hilary and Lynn Hobday the Regional Neurological Alliance and Hilary, Lynn and Ted the Lincolnshire Neurological Alliance meetings both in Lincoln. At local meetings representatives of local health and social services listened intently and are now offering places at other local relevant meetings. Although things are moving slowly, they are moving in a positive way. Dr. Elizabeth Dowsett, a Life Member, spoke at the MESH meeting on 2nd June about ME/CFS/PPS and rehabilitation. She asked Hilary to speak to her slides that she now uses as part of her presentation. Dr. Dowsett has now presented to the English and Scottish Parliaments and the Welsh Assembly to her article published in April's newsletter and will be speaking again at our AGM. Dr. Dowsett will be joining us at the Neurological Alliance event in London on June 20th, details back page. See information on the Motability Road Show June 15, 16 & 17th Crowthorne Berkshire - some members are attending and meeting more info back page.

This is my 29th bi-monthly newsletter and I have just realised that newer members who do not have access to the Internet, where you can search our WebSite for information on any subject, would possibly like to have details of the contents of previous newsletters etc. Some subjects we are being asked to include have already been covered in earlier newsletters. We will be discussing this at our next committee meeting and publishing information on all our services in the next newsletter.

Most of your committee have PPS and are limited in what we can do both energy wise and financially. All the work is done on a voluntary basis most often at our own expense. We need more input from our members, especially the UK members, more examples to back up what we are saying; good results with health professionals/equipment companies/etc are as important as bad ones. In fact as I have said in many editorials we need to hear from you; Questions, hints and tips, stories, ideas for future issues, in fact anything that you think other readers would enjoy reading. Please ensure that anything you send quite clearly separates anything that you want publishing from the rest of your letter, including name/town/county/email address/etc.

Polio Survivors questions come by letter and phone and by email from all over the world. Including those who have been given a diagnosis of PPS nearly everyone reports 'they do not understand PPS, they talk to me/ assess me/test me and tell me that I do not appear to have much of a problem, yet my life and functioning ability has reduced 95% over the last few years. They say or look at me as if I am exaggerating my problems, which I am most certainly not. I don't want to be like this, and as I continue to deteriorate I am fearful of what the future holds especially as I do not feel that I am getting any constructive help. Where can I get the multi-disciplinary assessment that articles say is necessary?' Unfortunately at this moment in time we do not think any UK health professional is able to provide multi disciplinary testing - some report lack of funding as the reason. I have therefore written the next article trying to bring together the facts with the reasons why we are still saying that assessments that are taking place are unproductive. For some it will be a repeat of information taken from a variety of previous articles for which I apologise. This article will be sent and handed to various health and government departments in an effort to campaign for a better service not only for Polio Survivors but for all who have chronic neurological conditions with similar problems. The Neurological Alliance estimate that there are three million people in the UK with neurological conditions. We are 'Stronger Together'. Any information that you can add towards this goal would be appreciated.

Address for Secretary and Treasurer, Wendy and Frank Grimmitt is 12 Larch Ave, Allington Gardens, Allington, Grantham, NG32 2DR. This is for anything relating to Membership. Requests for Information Packs, Leaflets, copies of articles, books. <CWGrimmitt@aol.com>

**Most UK Polio Survivors are still reporting unproductive assessments.
The facts and why we believe this is happening
by Hilary Hallam**

Post Polio Clinics of note in the world use holistic multi-disciplinary assessment and some have been doing this for over ten years. In the UK most polio survivors report that they not getting a holistic multi disciplinary assessment but being seen usually in an examination room with little room to do more than walk a few steps. Regardless of the length of assessment most tell us that the end of assessment report most often does not find reasons to explain their new symptoms, most especially loss of functional ability and new weakness. Many feel that what they say is happening or the level to which it is happening is not believed, because it is not seen or assessed. Most tell us that often the report back does little more than rehash the referral letter. So what is wrong and why, and what can be done to improve this.

Manual Muscle Testing (MMT) working through the body asking you to make each muscle work once - grip, pull, push against me - has been used as a standard test for decades that will pick up weakness. From extensively talking with other polio survivors, post polio specialists, personal experience and research of articles the main stumbling block appears to be the fact that MMT does not test pattern of movement. It tests each muscle doing a single repeat of an action.

If we say that:-

- instead of going upstairs normally we are now going up one at a time and pulling ourselves up with our arm
- that our walking has reduced from 25 kilometres down to 25 yards
- that we can lift, but not sustain the lift or drain, top of the stove cooking pans anymore
- that we are coming home from work and crashing out and are unable to do anything at the weekend to get enough energy to go back to work the next week
- that we used to garden and decorate but we can't even mow half the lawn now, etc.,

and this has happened over the last few years then we are reporting new weakness in the way we move, in our patterns of movement and over a period of time.

It has been said many times to those who have visibly lived with their polio 'we do not know how you manage to do that when you have so little muscle available'. The reason is that Polio Survivors used substitution and assistance of other muscles to recover. Many have continued to do this. Most of us who are finding new weakness are using it again, often without

realising it. If one muscle does not work, or is weak, then we ask other muscles or the next muscles to help or take over; we develop different ways of doing actions asking muscles to do movements that they were not designed for. These factors appear not to be known/understood/or taken into account by many health professionals.

Our muscles do have energy but it is limited and to varying degrees. We might be able to repeat some actions a few times, some ten times, some more but then we have to stop and rest. When the test 'grip my hand as hard as you can' is only done once and we do that to level 5 then we are graded at that. However, what we are reporting is a drastic change from being able to use our muscles repeatedly for hours and now we are talking minute/s or less than that, but rarely are we talking about only one repeat or short period of sustaining that muscle action as in a single action MMT.

Recovery took place because undamaged nerves grew extra roots, axonally sprouted nerves, and these took over some of the orphaned muscle fibres. Working muscles were gradually built up to a level and remained that way for a length of time - called our Stable Period of Functioning. One of the criteria for PPS is this stable period of functioning of 10 to 50 years. The next stage is that we start reporting a variety of new symptoms. [1] There are differing theories as to why this is, but one is that the axonally sprouted nerves have worn themselves out by being overworked and are not being replaced. This is happening earlier than that which occurs with age.[2,3]

Many of us report that we started to notice deterioration following something occurring in our lives. From a fall, an accident, an operation, an anaesthetic, are asked to work in a different way compared to our previous work practice, being told to exercise more and you will get better, a period of increased stress, another virus or illness. We report that the same thing months or years earlier did not have this effect. This time we cannot get back to our previous level of function and we want to know why and what is happening to us?

We know from medical research that only 5% of people who take in one of the three polio viruses get ill from mild flu to death, and that 1% get paralysed. That 90% of the body is affected by the virus.[4] We know

- that 60% plus nerve damage produced paralysis,
- 45% to 59% damage and the doctors saw weakness,
- less than 45% damage and weakness was **not** seen. [5,6]

If the doctors found evidence of one of the three polio viruses in tests and we had some paralysis then our diagnosis was paralytic polio; only weakness and it was

non paralytic polio; for those where no weakness was seen, abortive polio. Not different conditions but different levels of the same condition and occurring in different areas of our body.[7] Statements like "I only had polio in my legs" needs to be rephrased to "I had polio and had paralysis and/or weakness in my legs".

We read that in 1961[8] and repeated in 1995[9] that people who had polio have muscles that are functioning at a much lower level. A grade of 5 - normal - is not functioning at 100% but between 53 and 59%. A muscle graded as 4 - good - is functioning not at 80% but at 40% and so on down.

In very basic terms, normally when we ask muscles to work part of the muscle works and the rest is resting ready to take over, say a third and two thirds. We thought our good muscles were 100% we now find they were about 60%, say half working and half resting, and that is what we have lived with allowing many of us to achieve highly even in competitive sports.

As polio survivors experience new weakness, as our muscles are losing their ability, we do not have as much resting muscle to take over. This 53 to 59% functional ability in muscles graded 5 normal is starting to decrease. Take a grade 4 muscle with only 40% functional ability and there is only about 10% resting. [10]

The more we push these weakening muscles, the more we continue to repeat or sustain actions, the more fatigued we get.[11] If we pace and rest and use aids and assistive devices so that we do not waste energy and we use what we have wisely by planning ahead with work and rest periods then we manage better. We can and do slow down our deterioration.[12,13] We are conserving and preserving what we have left so that we can do as much as possible for as long as possible within the new limitations being placed on us. We are getting older and many of us are now having similar problems to those 30 years older than us. Are we worried about what the future holds? Of course we are, and we need help to cope with this and the earlier the better. Leaving the provision of aids till we can't manage without them is shortening the time we will be able to do that function.

Polio Survivors are known to be strong minded, determined, sometimes pig headed because we don't need any help Thankyou. This way of living took us way beyond what was expected of us at the time of our polio and has held us in good stead for our stable years. The majority of us thought that our polio was past tense and our recovery level would remain stable and we would be able to continue at that level well into our retirement. The fact that this is not now the case is a considerable shock. We still have polio, it never went away. We do not want to be like we are, we are certainly not exaggerating what we are reporting, for

most of us the doctors is the last place we want to be.

If we report weakness in walking from 10 miles down to 25 yards, is a few steps across an examination room a realistic test? If we say that we are now struggling to get up a flight of stairs will this show in the three steps of a physio gym? Is just taking our history and listening to our reported symptoms enough to ensure that we do not have other conditions as well as or instead of PPS? There are no tests for PPS, its is a diagnosis by exclusion of other conditions.

What we need is productive comprehensive multi disciplinary assessment as soon as we report problems that visually assesses our difficulties. Many are told that there is no funding to provide this, but it would be more cost effective to do this than send us continually year after year on the rounds of hospital departments that take us nowhere. We also need to see information coming down from the top of Colleges of Medicine and Government departments, informing all that polio survivors can have new problems in later life. At the moment its mostly patient to health professional and whereas we are pleased to help we are exhausted by seeming to be 'Ambassadors from another planet'

We want to be supported and advised health professional to patient as to how we can manage the rest of our lives and cope with this new and unexpected return of Polio back from had to has and is going to carry on having.

A few neurological conditions get this support, most do not. We know from the meetings of the Lincolnshire, Regional and National Neurological and Long-Term Medical Conditions Alliances that this is not unique to Polio, that most other neurological conditions have a huge overlap - 80% - of symptoms and problems. Coping, caring, housing problems, benefits problems, and others are the same no matter what condition you have. Add all chronic neurological conditions together and we are a huge - 3 million - and forgotten proportion of the population. Lets have a full time neurological clinic in most major hospitals and share the facilities, refer patients to specific specialists/clinics but case manage them locally.

There is no point in continuing to throw NHS money down the drain with ineffective unproductive appointments. The internet is helping patients research, become more knowledgeable about their condition and manage it better. Expert Patients are important, but we are only a cog in the wheel of getting appropriate medical help. Lets get round the table, share our experience and knowledge from our respective sides and move forward to a higher standard of service for all chronic neurological conditions.

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Our search for a diagnosis.

“As promised a brief account of our search for a diagnosis. I started the consultant trail approximately 5 years ago because of a pain in the hip when walking or carrying heavy loads (I can now look back and recognise many other symptoms I had just got used to). The first doctor I saw was a consultant in rheumatology, he misdiagnosed me as having Polymyositis, started me on steroids, which gave me diabetes, made my thyroid condition worse and later on Inflammatory Bowel Disease. At this point it was decided we had no need to see each other any more.

I was then referred by my GP to a Consultant Neurologist who after 3 years of Biopsies, MRI, EMG and strength tests etc; referred me to The National Hospital for Neurology and Neurosurgery in Queens Square London. After all the usual tests they decided to

admit me into the 5 day ward for a complete set of new tests. After all the tests and another MRI and EMG they finally gave me a diagnosis on January 4 2001. I was given the diagnosis by the consultant as follows "well Mr X..... you have Post Polio Syndrome, I know nothing about this condition you had best get on the Internet". This I did, thank God for The Lincolnshire Post Polio Network. It really helped to talk to someone who understands. Thanks for the information.”
Name and address supplied.

‘Ambassador from another Planet’

I think the cluelessness of many health care providers may be a problem that is more universal than just the encounters we with post-polio have. It seems a universal complaint among people with disabilities like chronic fatigue, muscle myopathies, etc that the health care professionals try to push them to the limits that *they* (the HCP's) think they should be able to achieve without taking the invisible into account. Most of the pt's [physical therapists] I've encountered have never seen a case of polio. It has only been my luck to have had two doctors who had either grown up around it or actually treated it (in Bolivia). I don't know the answer. One does get very tired of being the "ambassador from another planet" as I call it, continually having to educate people in their field so they don't harm me. But education is the missing piece. I've started handing any new doctor I encounter a carefully selected authoritative collection of articles to get off to the right "foot". Does it help? I don't know but doctors and health care types thrive on the article stuff. It can't hurt.
Mare Otoole, Boston USA
<zazencoyot@YAHOO.COM>

All I Want is to Breathe the Air That I Need.

I have provided this story in the hope that it will assist others who have unusual respiratory problems. My research and need for diagnosis has spanned some 25 years and it is only with the help of my family, some close friends, a good GP and a wonderful Physiotherapist (Specialised in Respiratory Issues) that I have been able to withstand the emotional trauma of this 25-year period. My heartfelt thanks also to Hilary who has been the recipient of many questions over the years and has often referred me (amongst other places and people) to the Lincolnshire website for the information we have so gratefully downloaded.

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My apologies to the author of one of my most favourite songs which is the "The Air That I Breathe" sung by The Hollies and very popular in the 1970's. Of course that does somewhat date me I know.

Apart from being a catchy melody this song with its chorus including the line "All that I need is the air that I breathe and to love you" encapsulates my feelings about my addiction to air. The love I have is for my husband and my three sons who have stood shoulder to shoulder with me during this battle I have fought to find answers about my respiratory problems and to be able to breathe easily.

As the years have passed since the initial Polio diagnosis (1954) and the later recognition of the impact of the late effects of Polio (1983) I have been searching for answers for my frustrating breathlessness. This breathlessness has always been with me but, spicing up my life considerably, have been intermittent episodes of acute breathlessness and respiratory distress.

Ask many of my doctors and they would say "Oh no, Margaret, not respiratory distress but an anxiety/panic attack". How silly of me to think that I have respiratory distress when I can't breathe. It is so infuriating to be told that you are having an anxiety attack when you are fighting for composure as breathlessness escalates. Do the Doctors not understand that if one allows oneself to panic at that stage the breathlessness just keeps on getting worse?

I would not like to bore my readers with a long and detailed description of my search for answers so I have prepared a brief synopsis of the many avenues I have tried to get assistance.

I must add that I fully recognise the difficulties I have experienced have been exacerbated by the fact that we, as a family, have had a number of moves within Australia which has meant that I have had to start all over again with new GP's and Specialist Medical personnel each time we have moved. (This sort of reminds me of another song... "pick myself up, dust myself off and start all over again").

In 1954 I was hospitalized with Poliomyelitis and while in hospital I developed Polio encephalitis. On one night some 5-6 days after being hospitalised I was deemed to be 12 hours off being placed in an Iron Lung and my parents were told that I might not live through that night as I was an extremely sick child. I was just nine years old.

Being the stubborn and determined individual that I am, I did survive, albeit somewhat disabled, having lost the use of both arms, neck muscles, some left leg muscles and respiratory muscles, which were also damaged. The degree of damage was not made available to my family after my discharge as some nurse "lost" my muscle chart when my aunt, a Physiotherapist, rang to find out the extent of the damage. All I know is that I was fed thickened fluids and kept under direct observation from the Nurse's station even in the non-acute ward.

I was taken home for rehabilitation. I spent 6 months on a double Thomas splint day and night, (enforced quadriplegia as I could only move my right hand during the day). I then spent another 12 months on the splint at night and was slowly taught to walk again.

When I returned to school some 21 months later I had to wear an arm splint and have a nap every lunchtime and I spent every Sunday in bed for total rest.

Eventually after some 4 years of intensive physiotherapy I was put back into the community as so many of us were, to function as best I could. I got on with life but noticed that strenuous exercise (dancing, bushwalking, rock-climbing etc) caused me to be very breathless even though I exercised as much and as regularly as my peers. It was often thought I was unfit but I felt there was another explanation. I had already learnt to wake myself up when I became breathless during sleep and not to panic when I was breathless, whatever the cause, as panic just made it all so much worse.

While working as a dialysis technician in the mid 60's I was diagnosed as having a benign familial tremor, which causes me to be very shaky in the hands and voice and legs especially when anxious. This is a genetically inherited condition and my family has a number of members who have this disorder. I am in exalted company here, Katherine Hepburn (I am told) has the same condition.

In the late 70's I developed respiratory problems, which were diagnosed and treated as asthma. At this stage I was told that I was acutely anxious and my GP tried to alleviate my acute respiratory problems associated with the asthma attacks by injecting me with Valium. I hasten to add that nearly rendered me unconscious but did not stop the acute breathlessness.

In the 1980's having moved yet again I met another woman who had Polio and who was using ventilatory support. I talked to her and as a result went to St Louis USA to a Polio Conference to see if I could get any answers to my questions. Following this trip I was provided with a volume cycle positive pressure ventilator and told to use it only as a daytime support mechanism. This helped but not significantly and I eventually drifted away from this treatment. I was still having regular Emergency Department visits with respiratory distress but usually leaving after some treatment with the words "Panic Attack" ringing in my ears.

I was still using a number of "tricks" to be able to sleep including pushing my chin up with one hand to assist in opening my airway, sleeping with the head of the bed up on bricks and waking up and sitting up whenever I became breathless and then breathing deeply and regularly until I felt that I could lie down and sleep again.

In 1993 I became very breathless following an infection and I did not pick up afterwards. I went to a variety of Doctors who eventually determined that I had weak diaphragm and inspiratory muscles and asthma and following a sleep study told me I had hypopneas during sleep. Importantly there was no Carbon Dioxide (CO₂) monitoring during this sleep study.

My Oxygen (O₂) level would drop to about 91% during sleep but this was considered not serious. However I was prescribed CPAP with low pressures between 4 and 7 cms of H₂O. In the first few weeks I found it very hard to use this treatment and I became progressively more tired. After about 12 months treatment I became so tired that I would fall asleep at work at 2 pm each day and I headed off to yet another Doctor.

This doctor prescribed BiPAP S as a "cure-all". I mentioned my volume cycle ventilator and was told that it was a dinosaur and that no one used volume ventilation any more. Pressure was the treatment of choice.

I found that BiPAP was a much better form of ventilation for me than CPAP and for some months after the change I was feeling a lot better but still having episodes of acute respiratory distress requiring hospitalization although the number of hospital visits was decreasing. I might add that no Doctor to date had been willing to provide me with a diagnosis.

After yet another period of respiratory distress and hospitalization, I found yet another Doctor, a sleep specialist, who having done, you guessed it, another sleep study again with no CO₂ monitoring during sleep, decided that I was well enough to fly to the UK mid-1998 with my husband on a business trip. In order to fly I had to use my BiPAP during flight and thanks to the airways not accepting BiPAP machines in flight I had to rent a different machine (VPAP), which had spontaneous/timed mode to regulate breaths per minute.

I moved onto that machine for 48 hrs pre-flight and found to my delight and amazement that I felt better. My husband was also amazed having had no energy for 3 months I suddenly had to be told it was midnight and time for bed. The trip went well although I did get into trouble when the crew depressurized the plane rapidly at 10,000 feet but after a short period we landed and I was able to catch my breath. Much better than other flights without the VPAP when I would turn blue and be acutely breathless for some hours after a flight. Life went on this way but over the last few years I had been feeling progressively older and more tired. I was still working full time and was in very stressful job, which placed 8, 10 and sometimes 12 hour days on me which was extremely stressful and tiring even though the job was quite sedentary.

I had started using an electric scooter for mobility back in 1992 and even with that it became an effort to get out much. My life became a never ending round of work, sleep and housework at the weekends. I sought assistance at work and eventually with no assistance provided, I went on sick leave.

Following this period of stress and worry I developed a pinched nerve in my neck, which led me to consume large quantities of pain medication just to manage a day's work and although I returned to work part-time I was unable to sustain this level of work and I landed in hospital with acute breathlessness. Unfortunately this time I did not recover and was unable to undertake most activities of daily living from that time for a period of some six months.

During this time my husband and I found that while using the VPAP machine my tidal volume (the amount of air one takes in one breath) was not consistent. It would vary from around 180 mls per breath to 480 mls on another breath. There appeared to be no reason for this variation that we could see.

My physiotherapist looked at a few of the many papers I had on Post-polio respiratory issues (mostly obtained from the Lincolnshire website) and then suggested that we look further at the secondary references and after a long search through many University libraries we tracked down those relevant articles.

It was a paper by Plum and Swanson from 1958 that for us, made such interesting reading. This paper discusses the damage to the brain from polio and the effect this damage has on the ability to breath while sleeping. [Ed note, we have a copy of this 27 page article]

Shortly after reading this paper I passed it to my specialist who, for whatever reason, chose to prescribe more VPAP ventilation while advising me that I was suffering "anxiety that required psychiatric treatment".

In desperation I dug out my old volume cycle ventilator and started using that for my afternoon naps and eventually full nights.

"Is there anything sweeter than the first rush of cool air into the lungs after a period of breathlessness?"

Source Unknown

Within a couple of days I was feeling very much improved and then I started looking around for some way of getting to a specialist physician who would be able to assist me with the use of volume ventilation as I was very well aware of the dangers of "do it yourself" home ventilation.

Eventually through the Internet I found the Australian Ventilator User's Network who were kind enough to inform me of a Clinic in Melbourne some 2000 kilometers away. My husband and I drove down to this clinic earlier this year to find that indeed I required volume ventilation and that amazingly we had nearly the correct settings on the "old dinosaur".

The issues for me were that I did build up CO₂ during sleep but as I trained myself to wake up my CO₂ levels did not rise to the same levels as they do for many other people. The breathing pattern I had varied in both rate and depth giving rise to nocturnal hypoventilation and the "panic attacks" were in fact respiratory failure.

We purchased a new ventilator, a PLV 100, and after a couple of sleep studies and some other respiratory tests we were allowed to come back to Brisbane, with the added assistance of phone and email contact with the clinic.

Since that time I have improved so much it has amazed all who see me. I am able to swim a kilometer now having been able to swim just 8 meters in February this year, my pain levels have dropped, my brain fog is much less and I can tolerate cold better than previously.

I have just this week driven the 2000 kms (and return) by myself to the clinic for a follow up sleep study which determined that I am well ventilated but still having disturbed sleep probably from pain so now I am on pain medication at night and I am feeling even better than previously. I have also tracked down an appropriate doctor, newly arrived in Brisbane, who specialises in sleep disorders in people with neuromuscular diseases and he has agreed to provide on the spot care for me with annual check ups from the Melbourne clinic.

I am now looking forward to some years of reasonably stable respiratory capability and in the short term to continuous improvement in my muscles of the shoulder back and chest so that my breathing capacity is the best that I can make it. My heartfelt thanks to all who have assisted me in this period.

Margaret has sent us a copy of the 27 page Plum and Swanson 1958 article.

Next newsletter long article on respiratory problems. Please ring/write/email us with any questions that you would like answering on this subject.

| LEARN A NEW WORD A DAY .. sent in by Richard Dyck <rdyck@ISLAND.NET> | | |
|--|---|---|
| Avoidable \uh-voy' -duh-buhl\ What a bullfighter tries to do | A clumsy ophthalmologist | Rubberneck \rub' -er-nek\ What you do to relax your wife |
| Bernadette \burn' -a-det\ The act of torching a mortgage | Paradox \par' -u-doks\ Two physicians | Seamstress\seem' -stress\ Describes 200 pounds in a size two |
| Counterfeiters \kown-ter-fit-ers\ Workers who put together kitchen cabinets | Parasites \par' -uh-sites\ What you see from the top of the Eiffel Tower | Subdued \sub-dood\ A guy that works on one of those submarines |
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| Eyedropper \i' -drop-ur\ | Relief \ree-leef\ What trees do in the spring | |

NEW BOOK ON PPS
Ordering details follow,
Chapter 2 printed with publishers permission.

POST-POLIO SYNDROME
A Guide for Polio Survivors and Their Families

by Julie K. Silver, M.D.
Foreword by Lauro S. Halstead, M.D.

Chapter 2
Post-Polio Syndrome

With the advent of the polio vaccines, the country's obsession with the disease ended. The vaccines were effective not only in eliminating the polio but also in erasing its prominence on political and health-care agendas. In an amazingly short time, polio was obliterated as completely as if it had never existed. Polio survivors moved on with their lives, the March of Dimes went on to fight birth defects, and politicians promoted other causes. Even medical doctors, if they studied it at all, learned about polio as a historical footnote. Polio was so thoroughly expunged from our national consciousness that it did not seem possible that the nightmares of years gone by could be resurrected.

But in fact, the unimaginable happened. After a long dormant period, during which the vaccines prevented new cases of acute polio, in the late 1970s and early 1980s it became clear that vestiges of the virus had returned to haunt the very people who had survived its initial onslaught. This did not happen in the dramatic, catastrophic way in which polio had appeared in the past, but in a more insidious and persistent fashion. With increasing frequency, polio survivors began reporting new problems that bore a remarkable resemblance to symptoms they had experienced at the onset of the disease decades ago. At first these odd complaints were attributed to a variety of other maladies, including benevolent malingering. As time went on, and more and more polio survivors described a nearly identical set of symptoms, the realization took hold that perhaps these new manifestations were somehow related to the original polio infection. The characteristic symptoms were described in various ways as post-polio sequelae, the late effects of polio, and post-polio muscular atrophy. The term used throughout his book, Post-Polio Syndrome (PPS), is today the common name used to describe these symptoms.

Acute Poliomyelitis and its Relation to Post-Polio Syndrome

Polio is caused by a virus and generally presents with fever, sore throat, diarrhea, and vomiting caused by the virus's invasion of the gastrointestinal tract. In fewer than 5 percent of polio cases, the virus actually invades

the spinal cord and brain, which may result in paralysis and breathing and swallowing problems. The most severely affected individuals died--generally from bulbar polio, which paralyzes the muscles that control breathing and swallowing. Fortunately, the majority of people who had paralytic polio survived the disease and recovered at least partially from the point at which they were sickest.

The initial polio was highly unpredictable in that some who were severely paralyzed appeared to recover almost completely, while others who had less paralysis during the acute phase also experienced less recovery, which resulted in a more significant disability. Lauro Halstead's book, *Managing Post-Polio* describes four stages of polio. The first is the acute febrile illness in which the paralysis is most prominent. Generally in a matter of days, the individual's temperature returns to normal and the second stage begins. This period of convalescence or recovery may last from weeks to years, depending on the individual's age and the extent of the initial paralysis. Children who had extensive paralysis seem to take the longest to recover. Stated another way, children with extensive paralysis have the opportunity to improve for a much longer period than their adult counterparts, who enter the third stage more quickly. Stage three begins rather indeterminately when the individual reaches a level of maximal recovery. It is described as the stage of stable disability or chronicity, in which polio survivors spend most of their lives. Stage four, Post-Polio Syndrome, is experienced by a large number of polio survivors, but not all. It involves new medical problems that are related to having had polio in the past.

Post-Polio Syndrome is characterized by new symptoms that occur in people with a history of paralytic polio after a long period of stability (generally at least fifteen to twenty years) in which whatever strength they had remained unchanged. Frequently, the most prominent and alarming symptom of PPS is new weakness, either in a limb that was known to be involved in the acute illness or in a limb that was not thought to have been affected. This new weakness often heralds a more pronounced level of disability in polio survivors who believed that the worst was over. Some polio survivors are so taken aback by these symptoms that they do not seek treatment until years after the initial manifestations of PPS. In some instances, individuals simply deny that they are having new problems until their condition becomes so pronounced that denial is no longer possible. For other persons, a lack of understanding keeps them from seeking the medical care they need. Still other polio survivors, expert at managing adversity, may genuinely be unaware that anything out of the ordinary is occurring.

Sometimes the symptoms are so subtle that the only way to measure them is by taking a careful history that

spans many years. A typical scenario is that of John Young.

As a young man, John was able to climb stairs uneventfully as long as there was a single railing. Thinking back, he recalls that ten years ago he began to avoid stairs unless they had a double railing. Five years ago, he began to avoid stairs altogether, and at this point he cannot go up stairs at all--even in an emergency situation. John may not have noticed any changes in strength from week to week; yet clearly there has been a dramatic decrease in his strength, which has led to an increased level of disability over the past decade.

The polio survivors who are used to being self-reliant may take new symptoms (such as weakness) for granted and simply adjust to a greater level of disability. Unfortunately, even the most motivated polio survivors can become discouraged when they finally do seek out medical treatment. They lament, rightfully, that they often know more than their doctors about PPS. Those who are discouraged may not persevere long enough to find polio experts who can intervene and provide help. Others are mistakenly convinced that if they give their doctors enough literature on PPS, these physicians will suddenly become experts and will be able to heal them.

Understanding Post-Polio Syndrome

Post-Polio Syndrome experiences the general lack of understanding that is characteristic of many syndromes. Its precise cause is poorly understood; probably it is several simultaneous elements. This is termed multifactorial, in that many factors are influencing the disease process. In PPS these elements include normal aging, in combination with accelerated aging of nerves that were injured by the initial polio. Another major factor is likely the overuse of nerves and muscles that are trying to do the same amount of work with fewer resources. I sometimes use the example of a construction crew that has lost several of its workers. This crew, which now consists of fewer workers but still has the same house to build by the same deadline, must work harder in order to accomplish the task. As the house progresses, more workers drop out because of fatigue and injury. Now the remaining crew is really at a disadvantage and simply cannot complete the task at the same rate or with the same level of skill. The nerves of polio survivors are the construction crew. In most cases, more than 95 percent were injured during the initial polio. Many nerves died, and the remaining ones had to do their own work plus the work of those that died, in order to power the muscles of the body. Over the years, some of the surviving nerve cells just were not up to the task; when they dropped out, the remaining nerve cells did the best they could to compensate.

A syndrome is a collection of symptoms that characteristically occur together. By definition, a syndrome has no single test to identify it. Thus, it is attributed to someone only if they meet specific criteria established by the medical community, and only after all other reasonable (and testable) conditions have been eliminated as possibilities. For diagnosis of any syndrome, the following must occur: 1) an individual must present with specific symptoms, 2) all other possible causes for these symptoms must have been ruled out, and 3) the individual must meet the criteria established for diagnosis of the syndrome.

Because syndromes do not have specific tests that can unquestionably identify them, they are subject to interpretation. Often their validity is challenged within the medical community. PPS is no exception. Although most doctors believe that PPS exists, a few do not. Generally it is inexperienced health-care providers, unfamiliar with treating polio survivors, who dismiss the syndrome. Those of us who routinely participate in the care of polio survivors have no doubt that PPS is real.

Not surprisingly, the ability to diagnose PPS requires a physician to have extensive experience in treating polio survivors in order to know which symptoms may potentially be attributed to PPS rather than some other illness. The diagnosing physician must adhere strictly to the rules stated above for diagnosing any syndrome and must also be familiar with the criteria used to diagnose PPS.

Diagnosing Post-Polio Syndrome

STEP 1: EVALUATING THE SYMPTOMS

Post-Polio Syndrome is a neurological illness. For it to be named as the diagnosis, the symptoms an individual presents with must be consistent with those that are described as the syndrome. One does not need to have all of the manifestations listed below; however, if a patient complains of symptoms that are not listed, other diagnoses should be considered. Some of the symptoms are weighted more heavily than others, and new weakness--the sine qua non--is the most important criterion. The symptoms consistent with the diagnoses of PPS include the following:

- New weakness
- Unaccustomed fatigue
- Pain
- New swallowing problems
- New respiratory problems
- Cold intolerance
- New muscle atrophy

STEP 2: ELIMINATION OF ALL OTHER POSSIBLE ILLNESSES

It is imperative to understand that PPS is a diagnosis of exclusion. In other words, the diagnosis of PPS is assigned only after other diagnoses have been excluded. In reality, it is impractical to test for all other illnesses that may cause the symptoms described above. However, a responsible doctor will consider alternative diagnoses that may produce the same manifestations as PPS. The treating physician should perform an appropriate level of investigation for an alternative diagnosis by taking a careful history and conducting a thorough physical examination. Subsequent tests should be done with the intention of ruling out any disease that may be positively identified by a particular test and any disease in which treatment would differ from that of PPS.

STEP 3: MEETING THE CRITERIA FOR THE DIAGNOSIS OF POST-POLIO SYNDROME

If steps 1 and 2 have been completed and an individual has symptoms consistent with those described in PPS (and no other cause for the symptoms is determined), then the final step is to make certain the individual meets the criteria (as determined by the medical community) for PPS. Those criteria are as follows:

1. An individual must have a known history of polio. Documentation by electromyographic study (EMG) is generally recommended.
2. The individual must have had some improvement in strength following the initial paralysis.
3. There must have been a period of stability (at least one or two decades) in which the individual had no new symptoms.
4. The individual must present with new symptoms that are consistent with PPS and not attributable to some other disease.

Although these criteria are the accepted medical standard, recently individuals with a history of what was thought to be non-paralytic polio have been diagnosed with PPS. Additionally, there have been instances of persons not known to have polio but now thought to have had a very mild, undiagnosed case of the disease. These individuals may be susceptible to PPS as well. Individuals who do not fit the criteria listed above need to have extensive evaluation before the diagnosis of PPS can be concluded.

Persons at Risk

According to a survey conducted in 1987 by the National center for Health Statistics, there are most than 1.5 million polio survivors in this country. An estimated 40 percent (approximately six hundred thousand persons) are thought to have had paralytic polio. We now know that even polio survivors who were thought not to have had paralysis may be susceptible to PPS. Unfortunately, these statistics are

more than a decade old and are useful only in a very general way.

It is extremely difficult to determine how many polio survivors are alive today in the United States owing to a variety of factors such as poor initial record keeping and a lack of follow-up tracking once the epidemics disappeared. Moreover, sometimes polio survivors are not sure whether they had paralysis or not, for the simple reason that a small child who is feverish and in pain often appears lethargic and even limp. This lack of movement may have been mistakenly interpreted as paralysis when in fact none existed. On the other hand, a child with paralytic polio may wrongly have been thought to be exhausted simply because of a more benign illness and may not have been diagnosed correctly with acute polio.

The estimated number of polio survivors who eventually develop PPS is also controversial and ranges from 25 percent to more than 60 percent. Early studies underestimated the number of polio survivors with PPS probably because many survivors had not yet experienced or complained of new symptoms. More recent studies suggest a much higher proportion. As polio survivors age, it is expected that the majority will experience symptoms related to PPS.

The prognosis for preventing further disability is improving with the availability of exciting new research and medical treatments. Because developments in the medical field occur daily and often quite unexpectedly, it is crucial that polio survivors maintain a relationship with a medical doctor who specializes in treating polio-related problems including, but not limited to, PPS. There is no substitute for a polio doctor's thoughtful examination in order to assess what might be causing any new ailments and what the best course of treatment might be.

This book is written so that polio survivors and their loved ones can understand more about aging with polio. It is not a replacement for medical treatment. My goal is that it will enable polio survivors to obtain the best medical care available in order to prevent further disability and improve their quality of life as they gracefully age.

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<www.yale.edu/yup>

[Dr. Silver's mother, uncle and grandfather all had polio so she writes not only from a professional view but also a personal understanding. The book is easy to read and it is possible to dip in and out of chapters.]

This book is hardback, 280 pages. Chapter titles are:-

Foreword

Preface

1. Polio - A look back.
2. Post Polio Syndrome.
3. Nonparalytic Polio and Post Polio Syndrome.
4. Finding Expert Medical Care.
5. The EMG Controversy.
6. Prevailing over Pain.
7. Preserving and Protecting Your Arms.
8. Sustaining Strength.
9. Fighting Fatigue.
10. Controlling Cold Intolerance.
11. Respiratory Problems.
12. Swallowing Issues.
13. Exercise Controls.
14. Energy Conservation and Pacing.
15. Nutrition and Weight.
16. Preventing Falls and Further Disability.
17. Keeping Bones Healthy and Strong.
18. Mobility.
19. Bracing, Shoes, and Assistive Devices.
20. Wheelchairs and Scooters.
21. Surgical Considerations.
22. Complementary and Alternative Medicine.
23. Designing a Safe and Comfortable Living Environment.
24. Insurance and Disability Benefits.
25. Sex and Intimacy.
26. Coping with Polio and Post Polio Syndrome.

Notes

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Ordering details.

The retail cost of the book is £19.95. plus £2.00 p&p.

We have obtained a discount and **cost to members is £13.95 plus £2.00 postage and packing.** Please will you send request and remittance to the Secretary, 12 Larch Ave, Allington Gardens, Allington, Grantham, NG32 2DR. Please allow 14 days for delivery.

P.S. A lady member in Sevenoaks Kent area would like to be in touch with some polio survivors local to her with a view to meeting or being in phone contact. She spends part of the time each year with her daughter in Boston, USA. She is a patient of Dr. Silvers and will be seeing her again shortly at her new PPS Clinic. Please write c/o LincsPPN.

Survey.

We had hoped to bring you the results of the survey in this issue. However we are still receiving forms back from overseas members, who did not get their forms until April. Obviously we want to include the views of as many of you as possible. Therefore the results will appear in the August edition.

If you have still not sent your form back, please do so by 16th July. Extra forms are available if you have lost yours and would like to give us your views. Please ring Janice Eary Vice Chair on 01663 743870 or e-mail janiceeary@hotmail.com.

POST-POLIO SYNDROME
FROM A POLIO SURVIVOR'S POINT OF VIEW

HILARY HALLAM
CHAIR, LINCOLNSHIRE POST-POLIO NETWORK

Physiotherapy Department
Marie Thérèse House
St Michael's Hospital, Hayle, Cornwall.

Thursday 19th July 2001 - 2.00 - 4.00 pm

Did you have Polio?

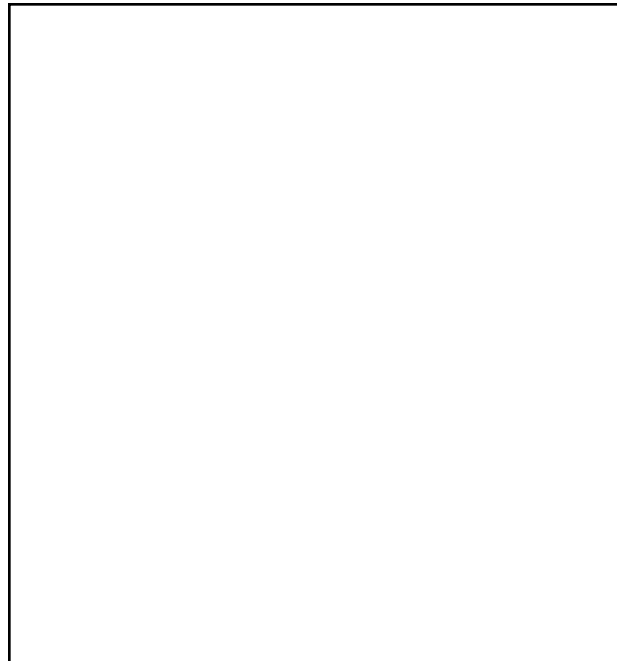
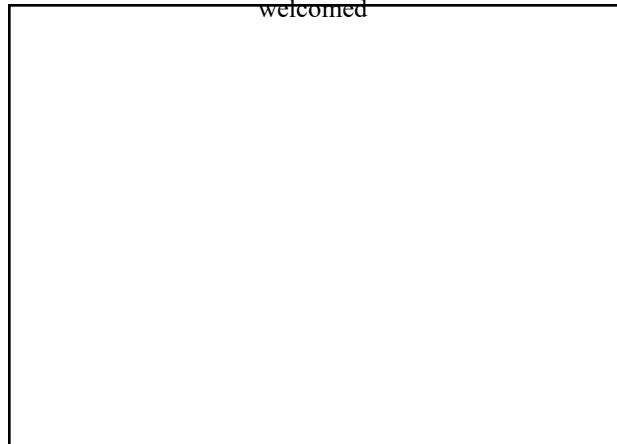
Are you a medical or allied professional who could be treating clients who had Polio?

If the answer to either question is YES,
please telephone to secure a place - (01736) 758875

Free Parking

Refreshments available - nominal fee of 50p
Donations to the Lincolnshire Post-Polio Network

welcomed



**NUTRITIONAL ADVICE TO COMBAT
OSTEOPOROSIS**
by member Vivien Holland

When we read that one in three women and one in twelve men will get osteoporosis it naturally gives us concern. This is especially so, when we read how important exercise is and maybe we're unable to do much at all. We tend to feel we must be at very high risk. Obviously if some exercise is possible, that would be beneficial, although each one must assess this individually as it would be quite counterproductive to aggravate painful muscles or bring on exhaustion. The good news is that there is a lot we can do to combat osteoporosis or even reverse it to some extent through good nutrition, so today I'd like to discuss this.

As we get older we tend to produce less stomach acid, needed for digesting food, and this is needed for absorbing calcium from our food along with other nutrients. If you are troubled with indigestion, you might assume you have too much stomach acid, but this is often not the case. You can test this out by having a teaspoon of cider vinegar in a little water at the start of a meal. If you have low stomach acid, this will help you digest your food, but on the other hand, if your problem is too much acid, your discomfort will increase, and you'll know that isn't appropriate for you. If it does help, you could make a point of having cider vinegar before each meal, or perhaps half a grapefruit or a salad dressing with lemon juice or vinegar with the meal. Calcium supplements vary considerably as to how much is absorbed, especially in people with low stomach acid. For instance, calcium citrate, calcium lactate or calcium gluconate are absorbed much better than calcium carbonate.*

It has been noted that osteoporosis is most prevalent in the western world and many link this to a diet high in animal protein and refined carbohydrates such as foods made with white flour and sugar. Another factor is the high phosphate content of the carbonated drinks that have become so popular. Years ago they used to be just an occasional treat, but now many drink them on a daily basis. These foods disturb the acid/alkali balance in the body. Calcium from the bones is then used to help bring about balance and it is then excreted in the urine. Smoking, coffee and alcohol all contribute to lower bone density, so try to give up smoking and moderate coffee and alcohol if necessary.

Aim for a diet rich in vegetables and fruit (dark green leafy vegetables and berries such as

blackberries, raspberries, bilberries etc. are especially good), wholegrain cereals, lentils and pulses, along with moderate amounts of fish, meat, eggs and dairy products. As people get older the majority seem to find that they are better eating small meals but more frequently - possibly five or six times a day. These will be easier to digest, will help to keep up energy levels and, provided the meals are not too big, will even help to keep weight under control. It's very important, though, to choose foods that are nutritious and to chew thoroughly. If you have a sweet tooth it's especially important to choose sensibly. Dried fruits, such as sultanas and raisins, but also prunes, figs, dates and apricots are packed with minerals and can be very satisfying when you must have something sweet. If you are able to do some baking, recipes can be modified to use wholegrain flour with dried fruit used for flavour and sweetness, and very little need for additional sugar. I like to add extra ingredients like an ounce of wheatgerm or soya flour which will make a cake more nutritious.

Although I've mentioned that high animal protein diets are not recommended, quite often people don't eat enough protein. Proteins are like building blocks needed throughout the body, including the bones where it forms the latticework around which calcium and other minerals are deposited to form bones. Also, insufficient protein is usually responsible for that weak feeling when you feel you must have something sweet. Have a little balanced meal with some protein instead, and make sure you eat before you get really hungry. This will help to keep energy levels up. Such a meal would contain a little protein, some unrefined starchy food along with some fruit, vegetable or salad. It could be something as simple as a chunk of cheese and an apple, or some nuts and raisins. There isn't space to give much detail on meal suggestions here, but this is something I'd like to deal with another time.

Finally, just a very brief word about hormone treatments. This is a very individual matter and something you'd need to discuss with your doctor. Some women do get benefit from conventional HRT and some studies combining this along with nutrition and appropriate supplements have shown good results. Another type of hormone treatment is undergoing trials at the moment and looks very promising. Dr. John R. Lee in America has been using Natural Progesterone Cream with his women patients for a great many years. Initially he used it with women who were unable to take conventional HRT treatment, but then it became his treatment of choice. Not only did he find it helped their menopausal symptoms but their bone

density increased too, sometimes quite dramatically. There are doctors in this country that will advise you on this, but they are in the private sector. For further information, write to the Natural Progesterone Information Service at P.O. Box 24, Buxton, SK17 9FB, enclosing a stamped addressed envelope. Also, the National Osteoporosis Society have useful leaflets that give practical information on all aspects of osteoporosis. Their address is P.O.Box 10, Radstock, Bath BA3 3YB. Tel: 01761 471771.

* If you'd like a leaflet on appropriate supplements to take, you can write to me with an s.a.e. at 32 Green Lane, St. Albans AL3 6EZ.
<vivienholland@hotmail.com>

Sharing how you manage has helped me.

We all need reminders to make more use of WC's/ scooters and not take chances when it comes to falling down. Its got to be one of the most difficult things in all of this that we have to accept. This not walking while we still can. Yes, we do need the exercise and can't just sit all of the time. But, to use it at the times we are more vulnerable to fall seems to be key. The secret is to learn just when that is. The only way I am (very slowly I'll admit) learning it is when folks like yourself share how you are doing it.

Yes, spirituality is very important. I know I'm not good at accepting anything totally on my own, by my own devices. Its something I have to pray for, along with the ability to stay in the now.

I've long ago learned that I can do (not do?) almost anything for a short period like one day, sometimes one half a day. Its when I think about this is now "forever" that I get rebellious and into trouble. At the same time I am learning to really savor and appreciate each thing I either really can or think I can still do.

This week and next it is redoing our front yard. We started last weekend. I found I really can't lift a shovel of dirt (not even a half shovel) so Lon had to do all the spreading of the load of top soil that came on Friday. I helped by raking. I overdid it and knew I was when doing so. But, I choose too as I know that its something I won't ever do myself again. So I savored every moment as we worked. (even my frequent breaks. I think I took about three to Lon's one).

I felt the ocean breeze on my face, whisking away the perspiration. I felt the clumps of dirt beneath my feet and the feel of it against the rake. I didn't

really do that much, but enough to capture the feelings to savor on future days when I will be watching, directing and maybe serving cool drinks to those doing the actual work.

The next day "we" put in a concrete block path with borders. I did help with the measurements. And succeeded at handing Lon three squares before I had to resign that position. When he had four or so in place he would shovel dirt on top and using the rake I'd get it in-between the spaces. He had to tamp it down. Really, I thought I was doing good till he came along and with one good tamp got it down another inch! VBG... (very big grin) I ended up giving him lots of moral support.

Now its time to plant our groundcover. I am proud that today I got FOUR plants in the ground. Did two in the morning and two more this afternoon. I figure at this rate it will take me an entire week to get the plants in the ground. But, on Saturday Lon will be home and I'm betting it will get finished as he will probably get three or four in for each one I do. But, I don't care. It's what I can still do.. and I'm savoring it. I know that any future gardening I do will be raised beds and already tilled dirt. And, you know what that will be just fine.

Even now while the flower bed between the house and pathway isn't raised its only 2 feet deep and I'll be able to easily weed it while sitting on my camp stool. Feeling really good about getting done what I did. So what if the laundry is stacking up and the dishwasher not yet empty. I had to choose.. the plants won! <VBG>

From: Ellen also known as Moon Shadow
<lonellen@HARBORSIDE.COM>

Free Directory Enquiries from BT.

Did you know that as a disabled person you can get free directory enquiries? A fact that BT keep underwraps! Follow these simple steps to get you free calls to directory enquiries.

- 1 Call 195 and ask for registration.
- 2 Give them you name and address and they will send you a simple form to complete.
- 3 Complete the form and ask you district nurse or GP to stamp and sign form, return in prepaid envelope.
- 4 Get PIN from BT and enjoy!!!
- 5 Tell all disabled friends/colleagues.

Yash and Greg Airth <airths@yahoo.co.uk>
PS We will be at Motability Roadshow on June 16th.

Ironing from a man's point of view

I immediately take all my clothes that would need ironing from the washer just as soon as the wash cycle

is ended. I shake them out and put them in the dryer with a fabric softener sheet for about ten minutes and then, one garment at a time (restarting dryer each time until through) I remove and hang up the clothes, smoothing out any wrinkles as I go. I then let the clothes air dry. My trousers especially have a better crease when I do it this way. If the clothes dry real quickly, I start hanging them up even before ten minutes are up. The purpose for putting them in the dryer is to activate the fabric softener sheet.

If I forget and let the clothes dry all the way, I just seem to have more wrinkles. If I let the clothes set in the washer without getting to them as fast, I seem to have more wrinkles. But, you know, since I seem to have more wrinkles myself these days, wrinkles aren't something that worry me too much. I guess wrinkles are God's way of telling us not to worry too much about the little stuff.

Kenneth L Rhea <klrhea@ebicom.net

Ironing in the Shower without effort!

A lot of items can be "ironed" in the shower! As in , when one takes a suit out of the luggage at a motel the night before a wedding, etc. Slacks, skirts, some shirts and so forth. Hang up on a hanger in the shower (away from the nozzle where they don't actually get wet.) Then the steam, or hot moist mist from the bath 'relaxes' the fabric. Next a.m. presto, a de-wrinkled pair of pants, blouse or whatever hanging from the towel rail, waiting for you.

Philip Thetford <phillipt@BELLATLANTIC.NET>
Packing that leaves less creases.

My life has changed considerably in the last couple of months since I found PPS and new friends on the Internet. I have just joined and thought you might find this tip helpful. When travelling with a friend she packed each item, blouse, skirts, etc., in an individual gallon zip lock bag. She left just a tad of the air in it. I about died laughing when she opened up her suitcase, but she had a great sense of humor. I'm not cruel, my reason for laughing is that I used zip lock bags for everything and washed them out for reuse. My kids thought I was a tad loose minded. ☺

"Susan E. Karnes" <SEKARNES722@AOL.COM>

IN MY DREAMS

In my dreams
I walk without crutches or braces.
In my dreams
I run and dance to the music of my mind,
Whirl to the stars on wings uplifting,
Visit mountains and lakes,
Mysterious India,
and frozen tundra.
My legs inert go nowhere.

My soul flies free and roams anywhere
In my dreams.

©Arleen Curtis <aecinfla@yahoo.com>

I had polio in 1953, age 23. I had two children before and two children thereafter. Couldn't run, but could walk all day, could climb up a curb or down one curb, push furniture around, climb on a chair by way of two super-strong arms - thus able to paint a room, or even wallpaper.

PPS began 1984, when I acquired braces for the first time, and it's been downhill ever since. I walk in the house using walls and furniture, crutches outdoors or electric cart. Upper body strength is poor now although I didn't have any noticeable polio weakness in arms at the time.

I moved to Florida in 1993 (go outdoors any time) and during the winter "season", am in a mixed chorus with weekly rehearsals, play shuffleboard leaning on a crutch (and win), play bocchia and win, and play pinochle year-round. Grandchildren are growing up but range from age 2 1/2 to 22. Maybe see them once a year.

I travelled to Germany alone in 1982, used crutches for speed. Went to Japan in 1985, and Europe (London, Paris, Florence, Venice, Rome) in 1986. Both those last trips made the PPS worse, but I wouldn't trade the experience. I've seen Notre Dame, the Coliseum and those are precious memories. If I had the strength, I'd go on a Kenya safari trip, or Egypt to see the Pyramids, but I can't do that anymore. I'm 72 and he's 7 years older and doesn't like walking. He says I walked him all over Europe, can you believe it??? In Rome, we took the bus, I asked dove', meaning where, and the passengers understood and told us where to get off the bus. But then we walked 3-4 blocks, to a square, sat down and had a beer, and I'd ask dove' and off we went another few blocks, another square, this time an ice cream so I could sit and rest. That's how I walked him all over Europe!(Grin). I like reading, movies, science fiction, Harry Potter, the Ring Trilogy. I was President of the Lincoln Nebraska Polio Support group for a few years.

If anyone in the UK without email would like to correspond then please send letters via Hilary.
Arleen Curtis <aecinfla@yahoo.com>

Could this be a prescription for PPS?

You need only two tools.
WD-40 and duct tape.
If it doesn't move and it should, use WD-40.
If it moves and shouldn't, use the tape.

THINGS THAT WORK:

- 1 Flies or bees bothering you? Spray them with hairspray and they will take a quick dive.
- 2 Sealed envelope - Put in the freezer for a few hours, then slide a knife under the flap. The envelope can then be resealed. (hmmmmmm...)
- 3 Use Empty toilet paper roll to store appliance cords. It keeps them neat and you can write on the roll what appliance it belongs to.
- 4 Whenever I purchase a box of S.O.S Pads (Steel wool), I immediately take a pair of scissors and cut each pad into halves. The scissors get sharpened this way too.
- 5 Use vertical strokes when washing windows outside and horizontal for inside windows. This way you can tell which side has the streaks. Straight vinegar will get outside windows really clean.
- 6 Candles will last a lot longer if placed in the freezer for at least 3 hours prior to burning.
- 7 To clean artificial flowers, pour some salt into a paper bag and add the flowers. Shake vigorously as the salt will absorb all the dust and dirt and leave your artificial flowers looking like new!
- 8 Spray your Tupperware with non-stick cooking spray before pouring in tomato based sauces and there won't be any stains.
- 9 Wrap celery in aluminum foil when putting in the refrigerator and it will keep for weeks.
- 10 Cure for headaches: Take a lime, cut it in half and rub it on your forehead. The throbbing will go away.
- 11 To get rid of itch from mosquito bites, try applying soap on the area and you will experience instant relief.
- 12 Ants, ants, ants everywhere ... Well, they are said to never cross a chalk line. So get your chalk out and draw a line on the floor or wherever ants tend to march. See for yourself.
- 13 When you get a splinter, reach for the scotch tape before resorting to tweezers or a needle. Simply put the scotch tape over the splinter, then pull it off. Scotch tape removes most splinters painlessly and easily.
- 14 Now look what you can do with Alka Seltzer.
 - * Clean a toilet. Drop in two Alka Seltzer tablets, wait twenty minutes, brush and flush. The citric acid and effervescent action clean vitreous China.
 - * Clean a vase. To remove a stain from the bottom of a glass vase or cruet, fill with water and drop in two Alka Seltzer tablets.
 - * Polish jewellery. Drop two Alka Seltzer tablets into a glass of water and immerse the jewellery for two minutes.
 - * Clean a thermos bottle. Fill the bottle with water, drop in four Alka Seltzer tablets, and soak for an hour (or longer, if necessary).
 - * Unclog a drain. Clear the sink drain by dropping three Alka Seltzer tablets down the

drain followed by a cup of Heinz White Vinegar. Wait a few minutes, then run the hot water.

Prayer for the stressed

Grant me the serenity to accept the things I cannot change, the courage to change the things I cannot accept, and the wisdom to hide the bodies of those I had to kill today because they got on my nerves. Also help me to be careful of the toes I step on today as they may be connected to the feet I may have to kiss tomorrow.

And help me to remember - when I am having a bad day and it seems that people are trying to wind me up, that it takes 42 muscles to frown, 28 to smile and only 4 to extend my arm and smack someone in the mouth.

**Reprinted with permission from the
Rancho Los Amigos Post Polio Support Group
Newsletter - February 2001.**

Dr. Jaquelin Perry sent us a letter from one of her Post polio patients who has successfully lost weight without exercise. Dr. Perry wrote "This patient attends my post-polio clinic, and thus, I have witnessed her progression in this weight loss effort. I asked my patient to write up the story of her weight loss without exercise, so that I could share her success story and practical steps with other post polio patients who are struggling in this same area". This person wishes to remain anonymous, but here is her story.

**Weight Loss With NO Exercise -
Testimonial from a Post Polio Patient.**

I became overweight at about nine years of age. At the age of seven years I had an experimental (then) surgery to stop the growth of my right leg (polio leg) so it would not be shorter (estimated 10") than the left at maturity. It was estimated I would be about 5'6" at the end of my growth, however, I am 4 feet 7 inches tall (I think I have shrunken now). I have been fighting my weight since then. About four years ago I was at my top weight (324 pounds and 4'7"). I did have some excuse. For the first two years I was on steroids for out of control asthma. My weight went from about 160 pounds to 324 pounds. My health was bad, my asthma was bad, and I couldn't move well, however, I was still walking at this point. I also did not have a good balanced diet, although I am not a snacker.

The scare I had that shocked me into losing weight was the news I had Type II Diabetes. I had seen the results of diabetes in others (blindness, limb loss and death) and I wanted no part of this. As part of my medical care I found the secret to my eating. A dietician showed me I was eating entirely too much for my activities, especially at dinner. I also loved the wrong foods like breads, pastas and potatoes (the starches). Sometimes my meals consisted of two or three starches at a meal, usually at night. The portions I served myself were also too large for my activities.

Now my two largest meals of the day are breakfast and lunch.

Breakfast: Eggs (or egg substitute), meat, potatoes (no toast) or toast (no potatoes) and orange juice.

Lunch: The largest meal at 1 - 2 p.m. meat, starch, vegetables. I have a problem here because I do not like salads! Those are for rabbits its!

Dinner: The evening meal is usually my smallest meal consisting of soup, a sandwich, and fruit (mostly canned).

Over time I have lost my taste for sweets. When I went off my cholesterol medications my blood pressure returned to normal. I do eat some sweets once in a while. I take 2 Senior multivitamins every day, 1 Calcium, 2 vitamin C (mid morning and PM). Sometimes I have a yoghurt, cottage cheese, or fruit with a hard cheese for a snack. My eating depends on the energy level I have to fix a meal and pain stamina I have for that day. If I don't eat well mid-day or evening. I drink Slim Fast at bedtime or if hungry during the night.

I do not count calories! That gives me brain freeze! I look at portion size and salt free seasonings (I have a fluid retention problem). I use onions, and garlic to enhance food taste. I do not fry foods or use much cooking oil or butter. Microwave food is great!

The portion size taught to me by the Dietitian.

Meats: 'Fist Size' for any meats. The meat (any) is the size of one large chicken thigh, medium breast, or two small thighs. It changes with the size of a person's fist. 1/4 cup starch (1/4 cup equals one large ice cream scoop). Cooking instructions for regular mashed potatoes work with Molly McButter or Cremora. 1/2 cup each of two types of vegetables.

Snack foods: small yoghurts and cheese bricks are good snacks. I even eat peanut butter snack crackers.

My activity level came to a halt about one year into losing weight. When I started modifying my eating. I was still walking (three years ago). As of three years ago, I became a couch and wheelchair potato. The only exercise I get now is transferring from couch to scooter (in the house) and changing positions on the couch.

I did not know it was possible to lose weight and not exercise. But by just cutting down on the volume of food and changing the way that I eat, I have gone from 324 pounds to about 175 lbs. or less. I am trying for 125 - 130 lbs. (the weight I was when I got married). I am now much healthier, my blood sugar is normal, and my asthma is minimal. I have lost three dress sizes. Now I have to figure out how to lose more from where I sit! I am a living breathing, real live post polio patient who found out she COULD lose weight with NO EXERCISE!

Rotator Cuff Surgery - and PPS.

This has been compiled with the help of polio survivors at different stages of having this surgery over the last six months. My thanks to Janet, Barbara, Peggy, Richard and Anita. The rotator cuff is your shoulder joint. The surgery can be done in two ways, open or arthroscopically.

More and more polio survivors with painful shoulder/s are eventually having/requesting an MRI and finding that the damage to their rotator cuff is **more** than their doctor expects. ("orthopedic doctor she referred me to, jumped to the conclusion that it was only a small tear, and that I wasn't a candidate for surgery...all without doing any x-rays, MRI"). Normally one of the rotator cuff muscles is torn by a fall or injury. ("walked around the bed to get to the bathroom in the dark. I tripped over a laundry basket and fell"). Polio survivors can have all three muscles torn, and sometimes the biceps tendon is also frayed. Rotator cuff tears can happen after a fall or injury to the shoulder but in polio survivors this can also come on over time due to the many years of using ones arms as extra to the legs to rise and lower from chairs/floor/transferring.

For a polio survivor - especially one who is already experiencing some late effects of their polio - any surgery has to be considered carefully. Surgery on your shoulder/s means that at least one arm is going to be out of action for some considerable time post surgery. Full recovery with 90 to 100% return of function from rotator cuff surgery for a polio survivor can be nine months to a year. There are stages to go through and it is imperative to assure yourself that you can transfer yourself or with help for all actions of necessary daily living till you are able to use this arm normally again. Until you strap this arm to your body you may not realise how much you do with it. (Further info later in article). The following are the general instructions for post surgery.

- Six weeks with no use of the arm at all. The arm is held in a sling and swath. There are below elbow and hand exercises that you need to do to keep the swelling down. Therapy is necessary to ensure that your arm does not stiffen up and that range of movement is kept. The therapist will move your arm for you ensuring that you do not use the repaired muscles. ("It's painful, bearable but essential")
- Six weeks to six months you can now move your own arm with restrictions and you must put it daily through its range of movement and work to a treatment plan. ("You cannot use your cane with this arm, you cannot use it to transfer, you cannot lift more than the weight of a mug of coffee")
- From six months on you can start lifting more

weight, using that cane again, and start using it to transfer. (You will be given extra exercises)

Pain after the operation is high. ("I was asked how bad my pain was between 1 to 10, I said 20. I told her it was easier to have a baby, and I meant it.") Richard had a local anaesthetic pump directly into his shoulder for three days, plus he had a morphine pump for 36 hours whilst he remained in hospital. After this he was prescribed strong painkillers and over the counter analgesics in addition. He had to take all these on a regular basis plus use heat and freezer packs. (Said by many "My arm muscles would go like 'hard rocks' which was very painful"). The pain gradually lessens but this continues for some months. Janet now eight months post surgery "The pain is still so bad from the shoulder down to the hands. But, I've stopped taking regular Tylenol as my fingers started to swell." Richard now three and a half months post surgery "at last I am having some pain and drug free hours but I still need some over the counter analgesics most days"

The biggest problem is frustration in not being able to use the arm as you want to. Depending on how much use you have of your other three limbs this can cause a variety of problems. What you need to do is to practice pre operation and plan ahead. Using aids and assistive devices that you might only need for a while post surgery to help and make sure you do not fall and damage the surgery is essential.

Finding comfortable positions comes a close second especially as sleeping on the operated side is not possible for some months. Janet says "I made a nest with the bed pillows and got in the middle". Having a variety of sizes of pillows available is helpful.

Before you agree to this operation ensure the health professionals involved are fully aware of polio and its late effects. It is imperative that your muscles, in all limbs, are graded correctly. In the States medical professionals specialise far more than in the UK and one surgeon does arms and another legs and sometimes even just parts of them. Therefore it is imperative that they realise what you do with this arm, and that having it out of action for this length of time could make a drastic difference to your life.

It is advisable to ensure that your surgeon and anaesthetist are aware that polio survivors can experience problems with anaesthesia and positioning on the table and in recovery. Provide them with copies of the articles on anaesthesia and PPS in case they have not read them. If you are still concerned then ask to speak to them again explaining that you are not questioning their knowledge or expertise but for your own peace of mind you need to be sure that they do not think you are 'an awkward patient' but an informed one about your own condition and previous experience.

Richard says “shortly after I came round I was having difficulty breathing and they raised the back of the bed to help but made it worse. I needed to be laid flat with a small roll of material under my neck and it took him some minutes before they understood. As soon as they did this then I could breathe so much more easily.” As for the most part we are totally unaware of what happens in the operating and recovery room it is essential that you ask for an honest report so that if you have another operation you can pass this information on.

It is important that your stay in hospital, which is likely to be longer than for a non polio, goes well. Whereas for many non polios this can be done in a day surgical unit, it is likely and preferable that you stay at least one, possibly two nights. If you have special needs with transferring, toileting, dietary, then it is advisable to have someone with you who understands all this and can do the talking for you for those first few hours/day or two. It seems surprising that facts like ‘no dairy’ can produce food with “oh its only got 2% milk in it, I am sure that won’t harm you”.

Most hospitals procedure is to ask you NOT to bring your own drugs in with you. If you need to take these drugs at a certain time of day - even though you have pre informed them of this fact - then it is advisable that the person with you has these drugs with them in the event that they have not been prescribed. Richard “I take regular drugs that I could not take for 16 hours. As soon as I was aware enough I asked for these drugs to find that they had not been prescribed and we had to use those brought with us”. In Britain we are usually given drugs for a few days to take home with us giving us time to get someone to take our discharge letter to our doctor and the next day pick up the prescription that has been advised in the letter. In the States you are given a prescription on the day you leave starting with the next dose after leaving hospital. With drugs only four hours apart this does not allow a lot of time, but with the knowledge in advance you can prepare for this.

As mentioned before it is really helpful if you can meet the post operative therapists before the operation so that they can see how you manage your daily activities. The best thing you can do is to put that arm in a sling for a few hours over two or three days and go through your actions of daily living and pick out where there are problems. You can then show this to your post operative therapists and between you work out ways to cope, and what aids you might need to use for a few weeks/months to make life easier. It might mean that to begin with you need someone with you 24 hours a day to assist with toileting, dressing especially if you wear orthotics or need both hands to put on shoes, and making meals for you.

The other reason for meeting the post operative therapist pre the operation is that apart from seeing how

you do what you do (which is likely to be different from the norm). They can also go through the post operative exercises with you so that you know what to expect and they know how far and how often you can do them now. Its useful to do these exercise with both arms if you can to ensure that you do not stiffen up. Remember that unless they are and have been working with polio survivors who have late effects of polio they may not understand that you cannot repeat the exercises the number of times they would expect from a non polio, and that you may not be able to do more than a few minutes at a time. (“They thought I was being a wimp till they read some info on PPS”) By meeting with them pre operation you can explain and show them how you use your muscles and work out a possible schedule. Pain will be a factor post operation, and their moving your arm passively for those first six weeks will hurt but it’s absolutely necessary to keep your range of movement and prevent adhesions.

If you use a chair or scooter and are told that you cannot have it in hospital then ensure that the manual chairs that you might have to use are wide enough to accommodate you and your arm in a sling, do have removable sides and foot rests if you will need them moved to transfer.

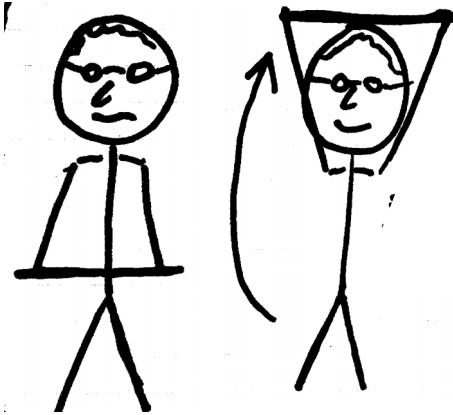
Richards therapist - Cordell Carmalt - provided us with a set of exercises for the six weeks to six months period. Richard worked out a system that brings these exercises into his daily routine, so that he does them bit by bit during the day, pacing them with his level of daily activity. For instance when watching TV he will do a couple of arm movements each time there is a change in program or advert break. This way of pacing these exercises has worked well for him. I also do some of these exercises and my range of movement is improving slowly. Remember you must check with your GP or therapist before starting any non prescribed treatment.

peggym@home.com

Anita Bjorling <anitabjorling@HOTMAIL.COM>

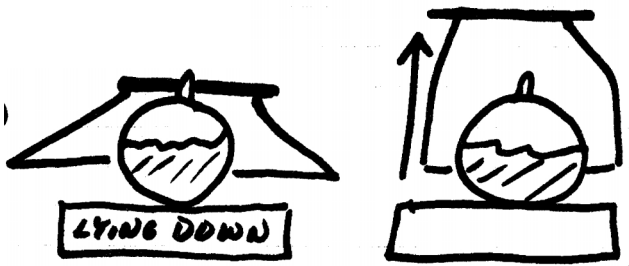
SIX WEEKS POST ROTATOR CUFF SURGERY EXERCISE PLAN FOR POLIO SURVIVORS.

IMPORTANT - This exercise plan was prepared for a **specific person** to start six weeks post rotator cuff surgery. If you have this surgery your therapist will give you a plan for you. However, you can use these exercises to help you keep supple. Check with your GP or therapist first that it is OK for you to do each exercise. Start slowly repeating them to your level, rest in between if necessary. You need not do them all at once, try fitting them into your daily pattern of living. Cordell Carmalt OTR/L, Bradenton, Florida.

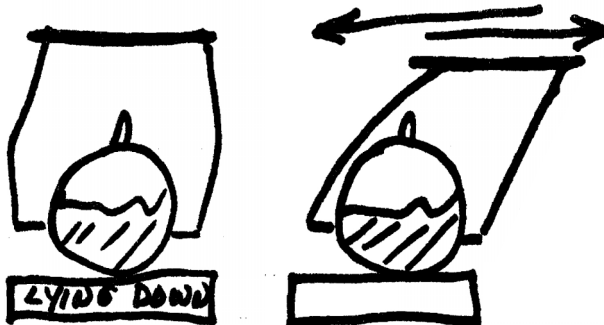


Dowel Exercises 1" PVC pipe 20" to 24" long

1. Start Lying Down.
Keep elbows straight and pull dowel back as far as possible. Stretch that shoulder!
Return to Start and Repeat.

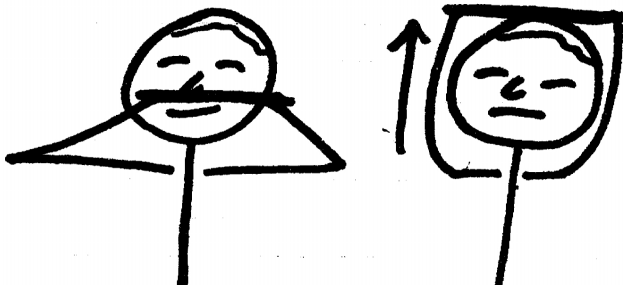


2. Start Lying Down.
Start with dowel below chin level if possible.
Push straight up. Try to touch the ceiling by lifting your shoulders off the bed.
Return to start and repeat.



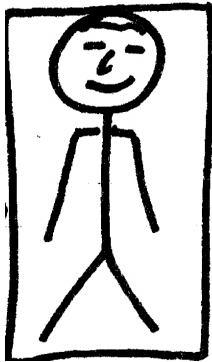
3. Start Lying Down with dowel above head.
With elbows straight, move dowel as far to the right as possible. Then to the Left.
Stretch those shoulder blades.
Do five each way if possible.

After 2 weeks, do these first three exercises sitting up and add the following one.

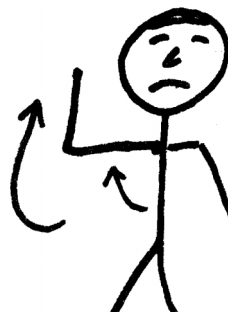


4. Sitting Up.
Start with the dowel under your nose.
Push straight up high as you can.
Return to Start and repeat.

RANGE OF MOVEMENT / STRETCHING

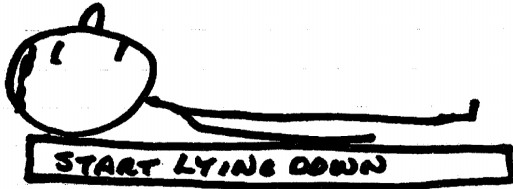


5. Start lying down.
Shoulder Abduction.
Slide arm on bed
Then turn hand so that palm faces you above shoulder height.
Try to bring arm up to the side of your head.
Go as far as possible,
Then let your carer/therapist stretch you as far as you can go.
Return to Start.
Repeat.



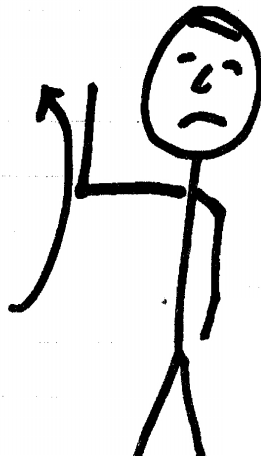
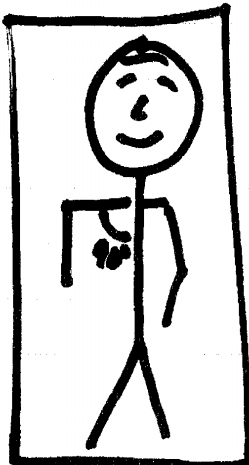
6. Rotator Cuff.

- Start lying down and with arm at side.
Pull Arm into 'I Swear' position.
Return to Start without stretching.
Repeat

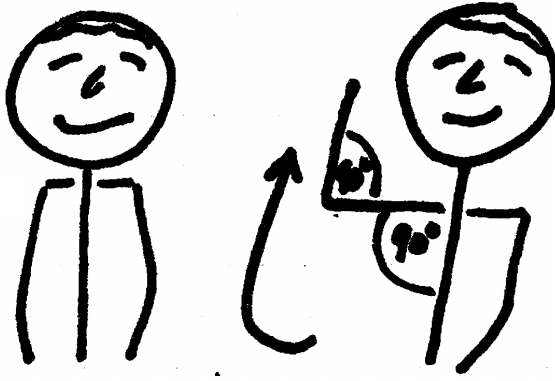


7. Shoulder Flexion.

- Start lying down with arm at your side.
Keep elbow straight.
Pull arm behind head as far as possible.
Use all your strength coming back, then have carer/therapist stretch you as far as you can stand it, but keep trying to pull the arm back with your own muscle power (hurts less after rotator cuff surgery if you do this)
Return to start. Repeat.
Stretch should be done every day until you have achieved normal range of motion.

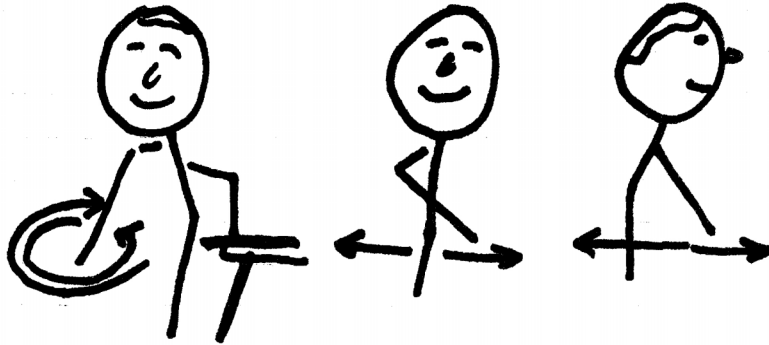


8. Start lying down
Place arm in internal rotation as shown.
Rotate your arm back and try to touch the bed with the back of your hand.
Then rotate the hand downward and try to touch the bed with the palm of your hand.
Have carer/therapist stretch you in both directions.
Try to pace yourself.
Remember if your shoulder is comfortable at your end of range of motion when you are exercising you are not gaining!
Go into the Uncomfortable Zone.



9.

Start sitting with arms down.
Pull up to the 'I Swear' position.
Pull hand back as far as possible.
Return to Start and Repeat.



10.

Standing. Place one hand on a table or the back of a chair and lean over slightly. Have your arm go in ever larger circles, then side to side, then front to back. This loosens the shoulders. Make movements as big as you can.

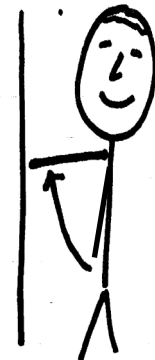


11.

Face wall with hand at side. Keeping elbow straight, but barely touching the wall with 'walking fingers' bring arm up as high as possible. Mark progress with pencil or tape a yardstick to the wall to mark progress. Push for higher and higher.

Face to the right/left and abduct your arm up the wall as far as you can. Barely touch the wall use 'walking fingers'. Mark your progress. Once you can get it higher than your shoulder turn your hand palm up to go higher.

12.



Other exercises that you can do to help you keep your arms supple and prevent oedema post surgery. In the short run oedema (swelling) delays healing and increases pain and stiffness. In the long run this causes fibrous deposits in tissues, making them seem woody, causes scars to form between layers of tissue and reduces the nutrition and elasticity of nerves, vessels, joints and muscles. These exercises can be done at any time to help keep you supple. Remember to do them to your own pace and repeat as often as you are comfortable with. Try fitting them into your daily routine.

- 1 Lying on your back with your arms by your side raise your arm from elbow to hand up and down.
- 2 Sitting with arms by your side turn your wrists over and back again, up and down.
- 3 Make a fist, being sure each joint is bending as much as possible. Relax and then straighten fingers as much as possible. Relax and repeat.
- 4 Holding hand palm upright and in line with arm bend top two sets of knuckles down and back.
- 5 In same starting position bend all fingers down to 90 degrees and back again.
- 6 In same starting position touch thumb with each finger.
- 7 In same starting position touch base of little finger with thumb.

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**Meet other members attending
16th June 2001 - 2.00 p.m.
Refreshment Area**

Phone contact on day - Hilary - 07748 185065

**In Search of a Service -
the Experiences of People**

with Neurological Conditions.

This new report by The Neurological Alliance is being launched at the end of a days events in London on June 20th 2001 at the Paragon Hotel, Earls Court. The date has been picked to tie in with the week long World Congress of Neurology taking place at Earls Court. Guests from this congress are being invited to the launch.

‘The Neurological Alliance consists of 48 organisations representing people with several hundred neurological conditions. During the afternoon we will be demonstrating how by working together patient groups and professionals can pursue the highest standards of service and care for the estimated three million people affected by a neurological condition.’

We are having a stand and attending the afternoon and early evening events. Report next newsletter. If anyone in the surrounding area is interested in meeting up please contact us on 01522 888601. If voice mail connects leave name, phone number and mention June 20th.

**Lincolnshire Post-Polio Network - UK Registered Charity 1064177
Donations large and small towards our work are always welcome.**

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**Hon. Sec. Wendy Grimmitt <CWGrimmitt@aol.com>
12 Larch Ave, Allington Gardens, Allington, Grantham, NG32 2DR**

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