



LINCOLNSHIRE
Post-Polio Network
 U.K. Registered Charity No. 1064177

Information on Polio and its Late Effects.
How the virus affected us. How we recovered.
What is happening to us now.

Assess your daily activities so that you can
Plan your week ahead to better manage your future and
Provide a fuller picture for your medical professionals.

Includes some suggested charts towards your making a
Personal Profile and Time Line of your Polio Life

A Post-Polio Information Service for Polio Survivors and Medical Professionals

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WEB SITE - <http://www.ott.zynet.co.uk/polio/lincolnshire/>

Including the Lincolnshire Post-Polio Library
containing over 100 Full text medical articles

Free Email updating service of new additions to the WebSite
email - LPPNUpdate@loncps.demon.co.uk - type subscribe

The Lincolnshire Post-Polio Network

Is a Post Polio Information Service for Polio Survivors and Medical Professionals.

We are Polio Survivors (not Doctors) who, after years of stable functioning following recovery from Polio, are experiencing new deterioration. In most cases these problems have been gradual and medically noted (not explained) over the last ten to fifteen years, although there are recorded cases of problems starting following a fall, operation, anaesthetic, or other trauma.

We found out that there are late effects to having had polio in one's earlier life and started collecting and collating Polio and Post-Polio conditions related material from all over the World. This includes but is not limited to Post-Polio Sequelae, Post-Polio Syndrome, the Late Effects of Polio, Unstable Polio. There are many terms being used to describe our new symptoms, Post-Polio Syndrome being the commonest.

We provide the widest possible view by making all the information we collect available regardless of our views as to its content as a service to those seeking such information. All research is important. Always consult your doctor before trying anything recommended in this or any other publication.

We are also campaigning for all Polio Survivors to have their new deterioration's and complex medical problems assessed by a holistic multi-disciplinary team of specialists in Polio and Post Polio conditions.

We can be contacted by letter, phone, fax and email. Members receive a 24 page bi-monthly newsletter the LincPIN full of PPS information a month ahead of the Internet version and can subscribe to our Members Internet Discussion List. Two of the leaflets sent to you - on medications and anaesthetics - are reproduced as part of this pack. A current title index of articles in the Lincolnshire Post-Polio Library is included in this information pack. Information on articles added since the issue date of this publication will be found in each newsletter. If you do not have internet access then we can provide copies of the articles at 5p a side. Members copies are post and packing free.

UK Life Membership is £100 - payable in one cheque or by Standing Order 20 x £5.
Yearly Membership is £10 per Year dated the 1st of Apr/Jun/Aug/Oct/Dec or Feb.

Donations towards our work however small will always be gratefully received

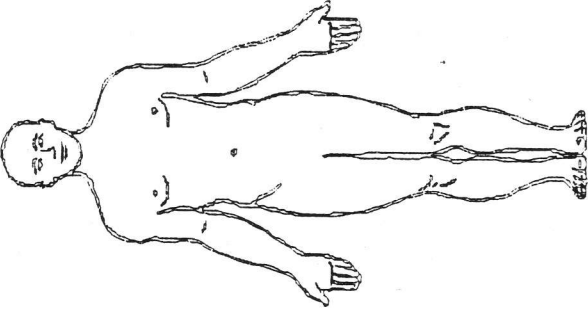
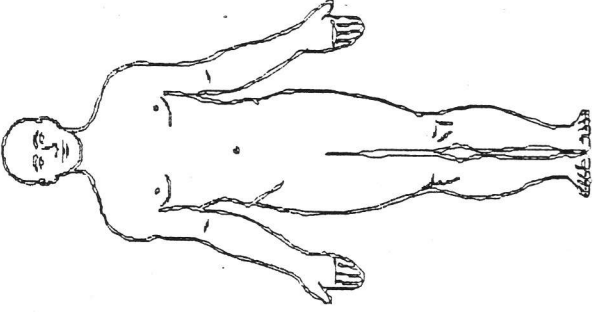
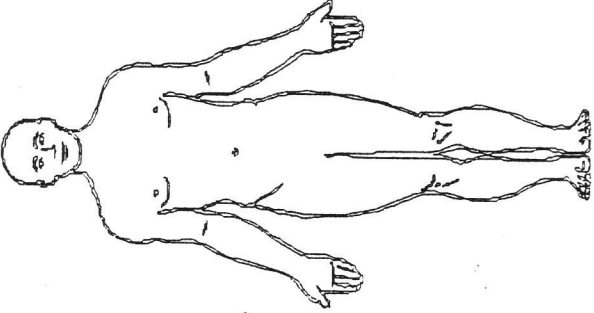
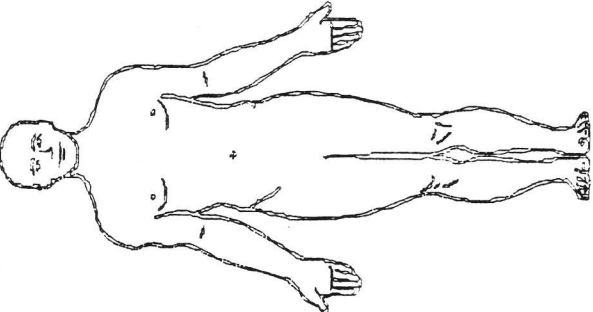
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PERSONAL PROFILE

| | |
|----------------------------------|--|
| NAME | |
| ADDRESS | |
| | |
| | |
| | |
| PHONE NUMBER | |
| EMAIL | |
| DATE OF BIRTH (AGE) | |
| DATE OF POLIO | |
| PLACE OF POLIO | |
| HEIGHT | |
| WEIGHT | |
| LIMB LENGTHS (EQUAL OR ?) | |
| SHOE SIZES | |
| PARALYSED LIMBS | |
| WEAK LIMBS | |
| GP NAME | |
| NEUROLOGIST | |
| REHABILITATION | |
| PHYSIOTHERAPIST | |
| OCCUPATIONAL THERAPIST | |
| SOCIAL WORKER | |
| RESPIRATORY THERAPIST | |
| SPEECH THERAPIST | |
| ORTHOTIST | |
| OTHER | |

| | PRE POLIO | POLIO | BEST RECOVERY | |
|------------|-----------|-------|---------------|--|
| | | | | |
| KEY | | | | |
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DIARY OF EACH DAY'S ACTIVITIES - DATE.....

Notes - Sample showing how pacing and resting and using aids can make a difference.

| ACTIVITY WITH CHANGE ON ROW BELOW | TIME of DAY | TIME DOING | TIME RESTING | PAIN LEVEL | FATIGUE LEVEL | DRUGS TAKEN | FOOD EATEN |
|---|----------------|---|--|------------|------------------|----------------|---------------|
| Getting up, showering and dressing | 8.00 | 30 mins | 1 ½ hour | 3 | 5 | | |
| Changed to Showering Putting on underclothes and callipers Putting on Top Clothes Total time used and resting. | 8.00 | 15 mins 10 mins 5 mins 30 mins | 10 mins 10 mins 10 mins 30 mins | 2 | 3 | | |
| Walking round one shop pushing trolley | 11.00 | 15 mins | 3 hours | 4 | 7 | | |
| Going round more shops using electric scooter and walking when you want to | 11.00 | 2 hours | 2 hours | 2 | 4 | | |
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Overview of the Information Pack

If you are reading this then you are either a Polio Survivor, Carer, Family Member, Friend or Medical Professional. We hope that you find the following information of help in your quest for knowledge of this condition, first noted in 1875. Feedback on the content of this is welcome from all. It is only by sharing information across the world with many specialists and learning from polio survivors experiences that medical help for Polio Survivors new problems is and will continue to improve.

This Information Pack has been formulated for Polio Survivors by Polio Survivors. Our Committee are not medical professionals but together with our members we have a wealth of professional knowledge covering many fields including medical and considerable experience of polio, its late effects and the minefield of trying to get appropriate medical help. Whilst the fact that there is a late stage to polio has probably come as a shock, as you like us believed that it was part of our past and did not expect it to become part of our future, you are not alone any more. Learn about your condition, request a holistic multi-disciplinary assessment, try the advice/treatment/aids that you are given, share what you learn with your family and friends and we hope you, like us, will be able to more effectively manage your life. There is also great support to be found in sharing your story with other polio survivors by letter/phone/email and in real life. Unfortunately to date there are no tests that can say if you have or do not have post polio syndrome, it is a clinical diagnosis of exclusion of other conditions. Remember that just because you had polio not everything is post polio syndrome. You can have any and every other condition instead of or as well as PPS.

You have just learned that there is a late stage to having had polio in one's earlier life and you need to know what should you do next. Firstly you need to be aware that the Polio virus affected many people in many different ways. Some did not even know they were infected but gained immunity to it, some just had 'mild flu', others had a diagnosis of non paralytic polio and some weakness, others were diagnosed with paralytic polio from just one limb to all limbs, some were in iron lungs and some died. Recovery from polio, including paralysis and being in an iron lung was far greater than expected and it does not matter which stage you reached on the Polio line you are now one of a large worldwide 'family' and your symptoms and story are just as important as the next persons.

Secondly, your G.P. - your primary care physician - is probably the most important medical person in your life now. Remember that a GP is not a specialist, but has to have some knowledge about many piles of medical articles for a ten minute appointment to any medical professional does not work. Following many disastrous appointments that our members have had we have formulated this pack with our ideas of ways that you can provide the information necessary in a way that can be assimilated very quickly.

Reading on you will find basic information on polio and what the virus did to our bodies, how we recovered and the symptoms that many Polio Survivors are experiencing some 10 to 50 years following recovery from polio. Then we explain self assessment and how to make a Visual Time Line of your Polio Life and suggest that you build up a personal file about your polio life in two formats - A long and detailed version for your own reference and one page double spaced synopses to hand over to those examining you.

You will then be in a position to think about your own life. Start making notes about your own personal experience; collect information from the past, e.g. photographs and stories from your family. A.C.V. is good to include because what you have achieved in education, your working life, your sports qualifications and hobbies is important. Start making a detailed diary from today, writing down not only what you do but how you do it. Think about what has changed over the last few years. For example, you are 47 and five years ago you were playing tennis and going on long walks but now you find that you are having to go upstairs one at a time, have had to stop playing tennis, and are using a cane when on walks that are getting shorter and shorter. Make photostats of any charts pages 4 - 7 you think you can use, or make up your own, and start filling them in. Contact Medical Records at the hospitals, and your GP for copies of your records. Reading all this will probably bring out many emotions and memories from the past so take your time and ring for a chat if you want to.

WEEKLY PLANNING SHEET - Enter what you have to do, then work round that. 10 TOKENS A DAY - 70 A WEEK
Remember to include tokens for dressing, making food, eating, getting ready for bed, etc.

| TIME | MONDAY | TUESDAY | WEDNESDAY | THURSDAY | FRIDAY | SATURDAY | SUNDAY |
|------|--------|---------|-----------|----------|--------|----------|--------|
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Coping with this new Information.

This may not be easy. There is a lot to read, some quite technical, and it is a good idea to let family or a good friend read it before you do, or at the same time, and definitely afterwards. As you start reading, entering information on forms or writing your story you will start to remember the past, either as fact or just an emotional feeling. It is not easy coping with the knowledge that having recovered from Polio that possibly some of the problems you are now experiencing could be related to the polio you had in your earlier life. For many of us this could be the first time we have thought about or mentioned polio for decades. We all thought it was part of our past and boxed it away in the back of our minds. Now that box is being opened again and coming to terms with what is happening and your new symptoms, regardless of diagnosis at the end, should be treated from the outset.

You may remember all that happened, you may remember nothing, but you are likely to still have emotional memories and feelings of incidents that have occurred throughout your life that will come to the fore as you start to consider what is happening. Tears are a release of emotion and it does not matter how strong willed and capable you have been all your life it is not a weakness to cry but a process of moving forward. We have to move at our own pace and we suggest that you ask others to allow you to do this. It is a step by step process.

Your parents, if they are still alive, and siblings will also have memories of your earlier polio life and it may not be easy for them to talk either. Parents often blame themselves for our catching polio. However it was not their or anyone's fault. Its just the same for our getting any other virus. Most of us are extremely grateful for all they did for us following what must have been a very traumatic time. We would not be who we are now without it.

Your partners, children, work colleagues and friends also have problems in knowing what to say. Can you relate to being offered help and turning it down and then the next day doing the same thing and struggling and asking why no-one will help you? Lack of awareness of the existence of our condition does not help. Many have told us that their partners have accused them of becoming lazy. You may live alone and have few family and this might be much more difficult for you. Contact with other Polio Survivors can be very helpful because when you talk about your polio life you are talking to people who understand what you mean.

We are aware that not all Medical Professionals are sympathetic and part of this could be that they have little knowledge of Polio and its late effects. You probably already know more than they do about polio, after all you have experienced it first hand. Be open with your GP and tell him how you feel. When you offer information give him one good article to read and the information of where to find more and we suggest that you say something like, 'I don't know how relevant this information is to me, but some of it seems to fit, would it be helpful if I made another appointment so that you can have had time to read it'. An early treatment you might like to ask him to arrange is for some counselling, where appointments are usually 45 minutes, giving you more time to 'talk'.

Filling in forms, for Incapacity Benefit, Disability Living Allowance, Attendance Allowance, Disablement Refurbishment Grants (e.g. alterations to your home for downstairs toilet, shower instead of a bath, stairlift) can be quite difficult. You have probably not considered yourself disabled and you don't really want to fill in these forms. You might have helped someone else in the past thinking it was not that difficult; but putting things down in black and white about yourself and having to divulge your financial situation again and again, does not come easily. Some of the questions have boxes that don't match what you need to write (so add your own), sometimes the question is asked again and in a different way, sometimes its so long worded that by the time you get to the end of the sentence you have forgotten the beginning. We have found that despite your being perfectly capable of filling in these forms it is a good idea to have someone else read the questions out to you and make notes in pencil for you to do it later. Our personal experience of this is that we got stressed out, frustrated and even cried, but when we allowed this to happen by a family member we found that they took on the initial frustration of the wording of the form. In some cases their comments actually made us laugh and its much easier for you to complete the form on the second go. See Advice Sheet page 16 - 17, including addresses and telephone numbers of organisations. If you are not in Lincolnshire then your Community Health Council will be able to advise you.

What is Poliomyelitis?

Poliomyelitis is an acute viral infection with a wide range of manifestations. It is an enterovirus which invades the body through the mouth and then moves on through the intestinal tract, the blood stream and into the Central Nervous System including some parts of the brainstem. The extent of damage depended on how far the virus went in our bodies and how much damage it did. It could be as little as a non specific minor illness or could progress through weakness to paralysis of limbs and even death.

A non specific minor illness would be a slight fever, headache, sore throat and vomiting which develop 3 to 5 days after exposure and recovery occurs within 24 to 72 hours.

The major illness which can take 7 to 14 days to appear will show with a fever, severe headache, stiff neck and back, deep muscle pain. There may be no further progression from this picture of an aseptic meningitis or the disease may go on with loss of selective tendon reflexes and asymmetric weakness or paralysis of muscle groups.

To obtain a diagnosis of 'Poliomyelitis' virus isolation from throat or faeces or a demonstration of a rise in specific antibody was necessary to confirm the diagnosis.

Factors that predisposed serious neurological damage included increasing age, recent tonsillectomy, inoculations (most often Diphtheria, Tetanus and Whooping Cough Vaccine) and physical exertion at the same time as onset of the Central Nervous System phase.

How it affected us and how we recovered.

The nerves that were killed remained dead. If we had more than 60% damage then that part of us became paralysed. If the damage was less than 60% but more than 40% we had weakness. 40% and less damage did not show clinically evident weakness.

Recovery of a muscle depended on how many nerves were left. It was the sprouting of undamaged nerves that allowed us to recover. Nerves sprouted and sprouted sometimes as many as 8 to 10 times and these axonal sprouts took up some of the orphaned muscle fibres. As the muscle obtained axonal sprouted nerves to support it and this increased over 40% then the muscle changed from paralysis to weakness to 'recovered'. Without this marvellous recovery system we would have remained at our worst scenario.

To complicate matters for the medical profession we are all different. We were damaged in different areas, and differing degrees of recovery took place. We then had different doctors with different ideas of treatment, operations, and assistive aids. There were Iron Lungs, Body Plaster Casts and Corsets, Spinal and Other Fusion's, Tendon Transplants, Braces, Callipers, Built up shoes, Crutches, Walking Sticks, Wheelchairs. Hot wet wool blankets wrapped on muscles, physiotherapy, contraptions that we put our feet into and pulled levers to give us electric shocks, the lists is endless.

What appears not to be realised is that our bodies adapted in ways not thought possible. If one muscle did not work very well, then others took over a share of the work. If we could not do something one way, then we found another. We were very inventive.

Following recovery we have done different things with our lives and our bodies adapted in different ways. So there is no one set of facts for our symptoms now, we have to be treated individually and holistically. As we start coping with new changes our bodies continue to be inventive and we may not notice that we are adapting the way we do actions to achieve.

Polio Survivors can tolerate drugs and anaesthetics differently from non polios. We recommend that you read the two articles on pages 18 - 21, (these are produced as leaflets also included with your pack) but reproduced here so that you can retain the information in this folder.

Criteria for a Diagnosis.

A history of remote paralytic polio or findings on history, physical examination results, and laboratory studies compatible with poliovirus damage of the central nervous systems in earlier life[4]

A period where you recovered.

A stable period of functioning.

New symptoms for which no other explanation can be found.

Symptoms.

Fatigue often overwhelming. Both physical and mental.

Loss of muscle strength and/or use, also in muscles thought not to be polio affected

Pain in muscles and joints

Trouble breathing and/or swallowing - Problems sleeping

Intolerance for cold, causing muscle weakness, and sometimes burning pain and/or discoloration in affected limbs.

There may be other symptoms that are related to your old polio.

Diagnosis

It's purely a clinical diagnosis by exclusion of other conditions. - There are no tests to show PPS.

Tests that are being used to assess us.

Obtaining our previous medical history - List of current symptoms - Physical examination.

Manual Muscle Testing - X-rays and MRI scans

Blood Tests - EMG / Electromyography - NCS / Nerve Conduction Studies.

Muscle biopsy - Swallowing tests - Sleep Study

The full picture is not often seen.

Without multi-disciplinary assessment the full picture is not often seen. Health Professionals seeing us now did not see us, before or when we had Polio, or how we recovered, or what we have achieved in the intervening years. Health Professionals seeing us now have rarely seen polio in its first instance. Lectures on polio and its late effects are minimal or not given. Polio is considered to have been eradicated in this country by the vaccine - although there are still vaccine related cases of polio in the UK - and its late effects are little known about. Most health professionals have no idea how we adapted our body - substituted other muscles to do tasks they were not meant to do, bring in other muscles along the chain to help with tasks - and continue to do so. Actions we once found easy, are now becoming more difficult. We know our own bodies well and we can tell when things are changing. You may not realise that you are doing things differently until you start to think about how you are doing each action comparing that with last year, a few years ago, best recovery. Toothache in the bones', a 'numb' feeling inside my leg, it just does not work like it used to, I get home from work exhausted now, are some of the comments made.

Medical Professionals are busy people and appointments are short and you need to be able to show not just your current symptoms but also your whole life story. Its all relevant to what you are experiencing now. Pictorial information can make more of an impact than a long list of problems. See Visual Time Line page 13.

Holistic Assessment

As in most other Post Polio Clinics in other parts of the World this should be a full holistic examination and assessment preferably by a Neurologist/Doctor, Physiotherapist, Occupational Therapist and Social Worker with knowledge of Polio and its late effects. Other specialist Therapists may also be necessary i.e. Respiratory, Speech and Orthotists. The above tests and results will give part of the picture. Each of these specialists only see one part of the whole picture, but the team comes together for a team meeting to manage your case. We need the same here in the U.K.

Notes on tests being done now that may be helpful.

Manual Muscle Testing. This testing is somewhat subjective and dependant on the tester and their strength. Testing a muscle once tests instant strength only, it does not show sustaining or repetitive power. Other activities must be observed. In PPS Manual Muscle Testing Problems Arise from Judgement and Biology by Eddie Bollenbach MA. [Excerpt. If a normal person is standing it is possible that 30% of the muscle fibers in his leg are contracted to maintain his upright position and posture. When those 30% get tired they automatically rest (switch off)— isn't the human body an ingenious creature? — and another different 30% of fibers contract to allow the first group to recoup. This can go on for hours. Someone with PPS may have only 40% of his original muscle fibers. When he or she stands they have only 10% in reserve, so in a short while there are no substitutes to take the load off. The results is fatigue of contracting muscles.... On contraction against a clinician's hand strength may show as normal (5). But this is instant strength, which is what manual muscle testing measures. end] From Polio Biology X - 18.3.2000 - The Lincolnshire Post-Polio Library. <<http://www.ott.zynet.co.uk/polio/lincolnshire/library/bollenbach/biology10.html>> or Newsletter April 2000.

Dr. Perry Ranchos Los Amigos PPS Clinic, California, USA reports that in 1953 Professor WJW Sharrard from Britain found that clinicians failed to identify any weakness unless more than half the anterior horn cells were gone. In 1961, Beasley reported his quantitative studies of muscles with anterior horn cell involvement, demonstrating that such muscles graded 5 were really only about 60 % of 'true normal' and those graded 4 were really only about 40% of 'true normal'. Dr. Perry's measurements of muscle force and EMG analysis confirm that manual grades of good (4) and normal (5) grossly underestimate the amount of weakness that there is in affected muscles - that is these grades are registered by strengths that are only 40 to 60% of 'true normal.'

| GRADE | NAME | % TRUE NORMAL |
|-------|--------|---------------|
| 5 | Normal | 60% |
| 4 | Good | 40% |
| 3 | Fair | 20% |
| 2 | Poor | 10% |
| 1 | Trace | 1% |

EMG - The Polio virus damages nerves and others not damaged sprout to take over orphaned muscle fibres and this varies throughout the body depending on the amount of anterior horn cell damage. The results will depend on where the needles are inserted as to what damage will be seen. A negative EMG for damage from old polio is therefore not conclusive.

Muscle Biopsy - Taking a biopsy from an already compromised muscle could result in further damage and is not undertaken in most recognised PPS Clinics of some standing unless necessary for a specific reason.

Blood Tests - There are a whole battery of blood tests that can be done. If you do not have record evidence or easily visible signs of polio and even if you have been vaccinated against Polio it might be an idea to have a Polio virus titre test done to see if there is a high level result to one strain.

Respiratory Tests - The current testing, we believe should also have added to it, lying on either side in case one dome of the diaphragm is affected where lying on the back would not show this. Testing should also take into account the amount of energy spent in the last hour or so. If the Polio Survivor has been resting then energy could be available that would not be if the person, for instance, had just walked along a corridor, or pushed themselves some distance in a wheelchair.

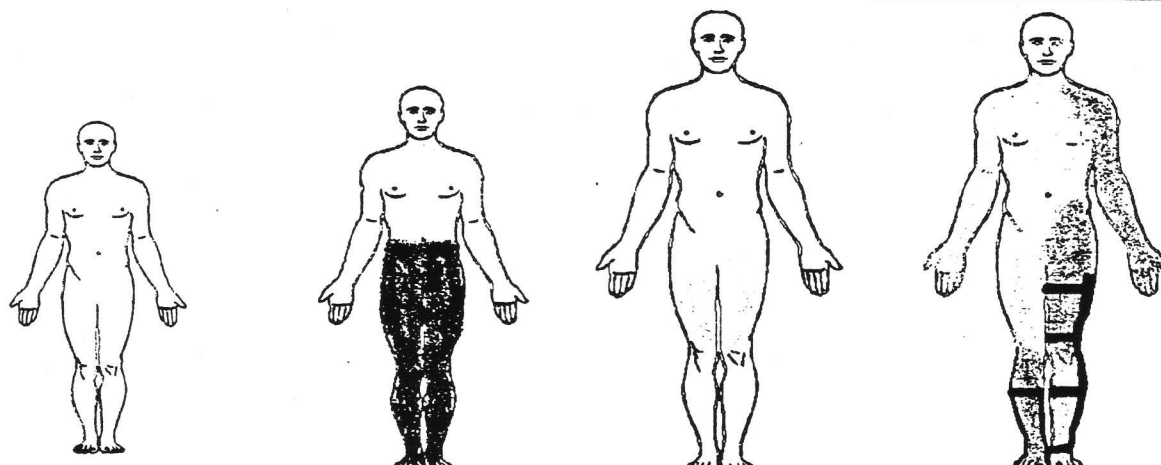
Sleep Study - We believe should be done following a days normal activities and in as near as possible situation that uses the same level and areas of energy you would have used at home.

ASSESSING YOURSELF.

To save time, money and frustration for both Polio Survivors and Health Professionals we need to provide information in a clear, concise and quickly assimilated way. We give below some ideas and examples.

A Visual Time Line of your polio life we believe will quickly show that you are having new problems. Here we show a four body chart as a sample but recommend that you take more bodies than the one we have used for new problems to show the changes that have happened over the last few years. (Blank body charts at the beginning of this pack for you to Photostat).

| SIMPLIFIED VERSION OF VISUAL TIME LINE - HILARY HALLAM | | | |
|--|------------------|--------------------------|---|
| BEFORE POLIO | POLIO | STABLE FUNCTIONING YEARS | NEW PROBLEMS (shaded) SINCE FALL OCT 1988 MAIN AIDS USED |
| 0 - 5 YEARS 2 MONTHS. | 5 YEARS 3 MONTHS | AGE 14 TO 41 | OCT 88 (41) - JUNE 2000 (53) |



| | | | |
|-------------------|--------------------------------|---|---|
| NO KNOWN PROBLEMS | WAIST DOWN PARALYSIS | WEAK THIGHS, BUT ACHIEVED THE FOLLOWING | '99 LEFT LEG UTx SWING '98 RIGHT LEG AFO |
| | RECOVERY SHOWN IN WORDS ONLY | POLICEWOMAN 1969 - 1973 | '97 ELECTRIC SCOOTER |
| | LEARNED TO WALK AGAIN | RLSS LIFEGUARD >1988 | '99 ELECTRIC RISE CHAIR |
| | DROPPED FEET - COULD NOT RUN | ADVANCED SWIMMING TEACHER >1989 | '97 ROLL IN SHOWER |
| | MULT. TENDON TRANSFERS | ORANGE BELT JUDO | '97 ERGONOMIC KEYBOARD |
| | OPERATIONS ON BOTH FEET AGE 13 | CANOE - ICE SKATE DANCE - LONG WALKS | '98 MOBILITY CAR & HOIST |

A chart detailing changes in your life. Start writing down how you do your daily activities. If you were asked to write down how do you roll over in bed, you will probably have to go and lie down and do it to see what actions you do as they have become automatic. Start by picking activities that you know have changed, like walking, climbing stairs, lifting items. Then go through all your daily activities and analyse how you are doing them and if you are doing them in a different way from how you used to do them. Its the differences and when and how they have changed that are important information to pass on to your medical professionals. If you are now using different muscles from normal then that means the muscles that are supposed to do that work, or the muscles that you have been using to do that work have changed. Your health professionals can then look further into the changes and find out why and give you appropriate advice.

The sample on the next page is one way of doing this. Another way is to write these changes under the bodies of your visual time line. So that the changes show with the additional shading.

EXAMPLE OF SIMPLE ASSESSMENT FORM - HILARY HALLAM

| ACTIVITY | AT BEST | SINCE NEW SYMPTOMS FOLLOWING FALL IN OCT.1988 |
|------------|--|--|
| STAIRS | Go up two at a time. | '89 Normal '94 One at a time rt. foot. '97 Pull up with right arm as well '99 Go up once a night only. 2000 Live downstairs - do not use stairs unless no other way to get somewhere. |
| WALK | '69 39 Mile Lyke Wake Walk '73 -'87 2 - 10 mile walks | '91 Started using cane on walks. '95 Started using cane in street '96 Manual chair but could not push it '97 Got Electric Scooter. '98 Got Ankle Foot Orthosis '99 Got Intelligent Knee Orthosis. |
| DRIVE | Advanced Police Driver | '91 Start lifting left leg onto clutch '95 Have to lift leg onto clutch '98 Have to drive automatic motability car. |
| CARRY BAGS | Could carry 56lb Sack of Potatoes | '89 Cannot hold items in left hand have to clutch to chest or hold arms length. '98 Now cannot carry handbag with left arm. |

Diary your daily activities. Start a Diary of your everyday activities. See chart page 6 including sample. We suggest that you start to record items like this and as you go decide what other information would be useful to record. Then you need to start halving the time of any activity that is causing pain and fatigue and see if there is any difference. Different activities take up different amounts of energy so keep halving the time till you find an acceptable time of action and time of rest. Now and then 'scientifically overdo' to check levels.

Give Yourself 10 Energy Tokens a Day - 70 a Week and Plan the Week Ahead.

You are allowed 10 energy tokens a day. You will have to decide the amounts from your available daily energy. When you have worked out activity times that are good for you then give them a token amount. e.g. half a token for 5 minutes ironing. Get ready for and go to hospital for assessment 15 tokens. Only you know what is involved and how much of your daily energy it will use. If you need more than 10 tokens one day then you will need to give up some the day before and also the days afterwards. Simplified sample showing main items only.

| MON | TUES | WED | THURS | FRI | SAT | SUN |
|---|---------------------------------------|--|---|---------------------------------|-------------------------------------|---------------------------------------|
| Shower, Shave Legs, Wash Hair - 6 | Hospital appointment + exam. 15 | Catch up on energy day. 4 in total | Shop at large food store - 7 Rest | Hair Appt & shop - 7 Rest | Rest in day Meal & Cinema - 6 | Dress/Church Mums for Lunch - 6 |

Then look at how you are doing these activities. If you can cut out wasted energy then you can do more of what you want to do. Do you need to iron items or can you get someone else to do them or can you take them from a dryer and hang them up. Do you need to dry yourself after a bath/shower or can you wrap yourself in a towel and drip dry. Do you need to walk all the time or would an electric scooter allow you to get round many more places, getting off and walking where necessary or when you want to. Get an Occupational Therapist to give you advice on items that are available to save you straining your muscles. Jar openers, kettle tippers, a trolley on wheels to push items from one room to another. We know that you like us are saying, 'Yes that will be a good idea in years to come, but I have not got there yet'. Our advice is to try these items out, because you like us might also say, 'I wish I had started using this earlier.' Don't waste energy, use it wisely so that you can do as much as possible for as long as possible within your limitations. Weekly planning sheet at page 7.

Some important facts with reference to medical articles.

- a) At least 90% of all anterior horn cells were in some way affected during the polio infection [1. Bodian 1947].
- b) but required the death of more than 60% to demonstrate any paralysis [2. Bodian 1949].
- c) That 40% damage found on autopsy had not shown clinically evident weakness. [3. Sharrard 1955]. Therefore the diagnosis non paralytic polio comes above 40% and below 60% damage.
- d) The criteria for PPS should now be modified from paralytic polio to... a history of remote paralytic polio or findings on history, physical examination results, and laboratory studies compatible with poliovirus damage of the central nervous systems in earlier life. [4. Halstead & Silver 2000] which quotes Lincolnshire Post-Polio Library article January 1999 Non Paralytic Polio and PPS [5. Falconer & Bollenbach 1999]
- e) That a polio muscle manually muscle testing at '5 - normal' is only functioning at 53 to 59%, 4 at 40%, 3 at 20%, 2 at 10% and 1 at 1%. [6. Beasley 1961 and 7. Perry 1995]
- f) That one off manual muscle testing in a single discipline assessment does not test repetitive or sustaining power - weakness that we are reporting. [8. June LincPIN 1999]
- g) Manual Muscle Testing tests instant strength. Muscle fibres contract, then rest, allowing others to take over. Someone with PPS may have only 40% of his original muscle fibres so in a short while there are no substitutes to take the load off resulting in fatigue of contracting muscles. Explained in Lincolnshire Post-Polio Library article Polio Biology X. [9 Bollenbach 2000]
- h) Decreased muscle strength due to a loss of anterior horn cells is a normal part of the aging process [10 Holman 1986] but there is no significant motor neuron loss before the age of 60 [11 Tomlinson & Irving 1985] yet many postpolio individuals experience serious changes at a much younger age, lessening the credibility of the theory that aging alone can explain the late effects of polio. The youngest patient diagnosed with PPS in Montreal is reported as 14 years of age [12 Cashman 1997]
- i) As we recovered from polio we learned substitution of muscles and we also 'asked' muscles up the chain to help so that we could achieve tasks. Most often we achieved way beyond what was expected initially, totally disguising the actual functioning level of our polio affected muscles. We have not forgotten this but we may not notice that it is happening unless we start to assess how we actually do what we do.

References.

1. Bodian D. 1947. Poliomyelitis: Neuropathologic observations in relation to motor symptoms. *Journal of the American Medical Association*, 1947, 134:1148-1154).
2. Bodian D. Histopathological basis of clinical findings in poliomyelitis. *American Journal of Medicine*, 1949; 6: 563-578.
3. Sharrard, W.J.W. 1955. The Distribution of the Permanent Paralysis in the Lower Limb in Poliomyelitis. *J. Bone and Joint Surg.* 37B:540-558. [Lincolnshire Library Full Text]
4. Halstead & Silver 2000. Nonparalytic Polio and Postpolio Syndrome. *Am J Phys Med & Rehab* Jan/Feb 2000
5. Falconer M & Bollenbach E. Jan 1999. Non Paralytic Polio and PPS. [Lincolnshire Post-Polio Library Article]
6. Beasley, W. C.: Quantitative muscle testing: principles and applications to research and clinical services. *Arch.Phys. Med. and Rehab.*, 42: 398-425, 1961.
7. Perry J, Fontaine J, Mulroy S. 1995. Findings in Post-Poliomyelitis Syndrome - Weakness of Muscles of the Calf as a Source of Late Pain and Fatigue of Muscles of the Thigh after Poliomyelitis* [Lincolnshire Library Full Text]
Journal of Bone and Joint Surgery Vol. 77-A, No. 8, August 1995, 1148-1153
8. Hallam H, 1999 Polio Survivors need Holistic Multi-Disciplinary Assessment because the standard Physical Assessment is not adequate. *LincPIN Newsletter* June 1999 3-11. [Lincolnshire Post-Polio Network WebSite]
9. Bollenbach E, March 2000. Polio Biology X - In PPS Manual Muscle Testing Problems Arise from Judgement & Biology. [Lincolnshire Post-Polio Library Article.]
10. Holman, K. (1986). Post-polio syndrome: The battle with an old foe resumes. *Postgraduate Medicine*, 79(8), 44-53.
11. Tomlinson, B., & Irving, D. (1985). Changes in spinal cord motor neurons of possible relevance to the late effects of poliomyelitis. In L. Halstead & D. Wiechers (Eds.), *Late effects of poliomyelitis* (pp. 57-70). Miami: Symposia Foundation.
12. Dr. Neil Cashman Answers Polio Quebec Members' Questions Polio Quebec AGM Sept 1997. [Lincolnshire Library Full Text]

Advice Lincs Check List amended slightly to fit PPS.

Application forms for Disability Living Allowance and Attendance Allowance are not easy to complete. The attached list of care and mobility needs and the time needs is intended to help you fill in the relevant form. Use the Information Pack to diary your activities - time doing and resting and pain and fatigue levels.

Remember how you do these actions is very important. Take into account if you have arranged your furniture so that you can use this to assist you as you do these tasks. How much pain and fatigue does doing these tasks give you? Can you do all these tasks every day, and if not then ensure you write that down? If you can do a task its considered you do not need help, but if you only do this if you are alone at that time and there is no-one to help you and it causes you increased pain and fatigue and/or prevents you doing other task through lack of energy left, then say so. Record how long these actions take.

Getting Up

- Do you wake up very stiff and in pain?
- Do you struggle to sit up or does someone help you?
- Do you have to wait before you stand up?
- Do you need help to support you?
- Do you feel dizzy or light-headed?
- Do you have any equipment to help you out of bed?
- Do you use any furniture for support?

Getting in and out of a Chair.

- Do you need help to sit in a chair?
- Do you need help to manoeuvre your wheelchair?
- Do you need help to position in a chair?
- Do you need help getting out of a chair?
- Do you strain your arms to get in and out of a chair?
- Are you unsteady when standing from a chair?
- Do you feel dizzy or light-headed?

Toilet

- Do you need to go to the toilet often? (How often?)
- Do you have difficulty getting there?
- Is it difficult to sit down and/or get up from the toilet?

- Do you need help to clean yourself?
- Do you need help if an accident occurs?
- Do you need help with adjusting or changing your clothing?
- Do you need help to change a urine bag?

Getting Bathed, Showered or Washed.

- Do you need help to get washed, bathed or showered?
- Would you bath or shower more often if you were able to?
- Can you get in and out of bath/shower?
- Do you have a special bath/shower stool/lift?
- Do you have difficulty getting dried?
- Do you need a towel, soap and/or face cloth passing to you?
- Are you in pain, tired or exhausted trying to do these functions?
- Are you unsteady and likely to fall?
- Do you have difficulty shampooing your hair?
- Do you have difficulty combing or brushing your hair/cleaning your teeth?
- Can you wash your back/feet/all your bits?
- Do you have difficulty cutting your toe and finger nails?

Cooking a Meal

- Can you cut up and peel vegetables/mash items/mix items without discomfort?
- Can you hold utensils normally and safely?
- Can you lift saucepans with contents and drain them, carry them to another kitchen area?
- Do you have to hold onto or lean against work surfaces to work in the kitchen?
- Can you use a cooker, i.e. turn taps and handles safely?
- Are you in danger of burning yourself?
- Can you stand or sit very long by the cooker?
- Do you feel dizzy at all near the cooker?
- Does the activity of preparing/cooking a meal cause pain/discomfort?
- Do you forget to turn the cooker off after use?
- Do you ever miss a meal?
- Do you eat convenience foods/sandwiches because you don't have the energy to do more?

At Meal Times

- Can you hold a Knife, Fork and/or Spoon?

- Can you use both hands at the same time?
- Whilst doing this, do you feel any pain/discomfort/ tiredness?
- Can you hold a cup without pain/need to use two hands?
- Do your hands shake?
- Does someone have to cut up your food/ cut meat off bones or put it on your plate?
- Does someone have to check your food for bones (e.g. fish)?
- Do you drop or spill food?
- Can you carry your food to where you eat it?
- Do you, or are you likely to, stumble/legs give way?
- Do you or are you likely to fall, and if so can you get up unaided?
- Do you suffer from fits or panic attacks?
- Are you short of breath?

Please do not hesitate to contact us if you think of more items or changes to wording that would improve this for Polio Survivors.

If you are not happy with a Medical or Government Dept response to your problems

If you are not happy with anything related to going for a medical appointment, the tests, results, what you are told, letters to your GP, results of benefits applications, etc. then you must contact the relevant departments and put your complaints in writing. A good idea if you do write is to send a copy to your M.P. and a copy to Gillian Merron MP for Lincoln.

It is not easy when going through the stress of new symptoms and the minefield of medical help to cope with the added stress of trying to deal with complaining. However, we have realised that whilst nearly every person that has contacted us for information or advice have had many problems, only a few of us have written to try and get the problem resolved. We now realise that unless we write then the hospital and/or government departments do not know the problems are occurring or how often. We all know one reason why we do not complain and that is the fear of being struck off the doctors list and not getting the help that we need when often there is nowhere else to go. If you feel that you just do not have the energy to deal with a situation like this then please get in touch with us and/or your Community Health Council, or

Advice Lincs,
25/26 The Crescent, Spalding, Lincs PE11 1AF
Tel 01775 714077. Freephone 0800 4238423

Lincolnshire Association of People with Disabilities,
Beech House, Witham Park, Waterside South,
Lincoln, LN5 7JH Tel: - 01522 574194
Email:- Steve.Tyrell@lincs-tecgroup.org.uk

Disability Lincs, Ancaster Day Centre,
Boundary Street, Lincoln,
Tel:- 01522 870602

British Polio Fellowship,
Ground Floor, Unit A, Eagle Office Centre
The Runway, South Ruislip, Middlesex. HA4 6SE
Tel:- 020 8842 1898
Email: british.polio@dial.pipex.com

Medication.

- Does someone have to make sure that you take your medicine (because you are forgetful or confused)?
- Can you see labels clearly?
- Can you open bottles/pill packaging?
- Do you need help with injections/putting on ointment?
- Are there times when you need help with medications/medical equipment?

At night.

- Do you need help getting to bed?
- Do you need help turning over in bed?
- Do you need help replacing the covers?
- Do you need help with medication?
- Do you need help going to the toilet?
- Do you need food or drink bringing to you in the night?

Avoiding Danger.

- Do you drop things?
- Do you find it hard to concentrate?
- Do you have blackouts?
- Do you have spasms/muscle twitches?
- Do you have periods of complete exhaustion?

Mobility.

- When walking how frequently do you have to stop and rest and for how long each time?
- Are you in severe pain or discomfort?
- Does the pain worsen as you walk?
- Does your body swell, e.g. legs when walking?
- Do you use any aids when walking, inc. holding onto someone/something?
- Are you unsteady and have problems with balance?

A Guide for Polio Survivors What you should know about your medications?

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AM Whelan, Pharm D. 1966
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Dalhousie University, 5869 University Avenue,
Halifax, Nova Scotia, Canada, B3H 3J5
UK Drug name version
Andrew Francis Forde MRPharm. B.Sc.Hons

Why you should be informed?

Medications (drugs), may be by prescription, (Rx) or Over-The-Counter (OTC). As a polio survivor you should become an informed user of drugs because

- The drug effect may enhance post-polio symptoms while influencing the primary condition. Fatigue, muscle weakness, muscle irritability (cramps), ability to cough and clear secretions, anxiety feelings, may be increased so that your performance decreases.
- With increasing age the potential for interaction between drugs increases and this effect is often more severe.
- With increasing age individuals are more likely to be taking or be prescribed medications for a variety of conditions, such as hypertension, diabetes, arthritis, insomnia, indigestion, constipation....., the list can go on and on.

Who is at greater risk?

- Individuals with respiratory muscle weakness or paralysis
- Individuals with weakness of the muscles of swallowing
- Individuals diagnosed with Post-Polio Sequelae (Post-Polio Syndrome)
- Older individuals (over 65 years)

You may have experienced a 'full recovery', Grade 5, Manual Muscle Test of involved muscles and were unaware of any involvement of your respiratory muscles, however, research has shown that these so-called 'normal' muscles are not necessarily normal and may be supplied by only 60% of the usual number of spinal nerve cells.

What you should do

1. Change your lifestyle before resorting to use of an OTC drug or requesting a prescription.
2. Always inform your doctor(s), dentist, pharmacist about which drugs you are currently taking regularly, prescription and OTC drugs.
3. Ask your doctor about potential side effects, particularly those that may increase or cause
 - fatigue
 - respiratory weakness
 - muscle weakness
 - dizziness and/or drowsiness which may impede your balance and cause falls
 - increase depression thus changing your perception of pain, making it seem worse
 - insomnia, sleeplessness, will increase fatigue
 - vaso-constriction, may increase cold intolerance.

Remember

- Taking fewer medication is better.
- It is no solution to use drugs and continue to abuse your joints, overuse your muscles.
- It is your responsibility to be informed about your medications so that you can monitor the side effects.
- When certain drugs are taken for a long time you can develop a tolerance so that larger and larger doses are needed.
- Physical dependency, addiction can develop from taking certain drugs, especially narcotic analgesics.

Drugs and Their Effects.

Alcohol:- is a drug. It may-

- inhibit swallowing
- decrease balance & cause falls
- decrease muscle strength

Individuals with any respiratory weakness should avoid alcohol, especially before bedtime.

Cough Medicines & Expectorants.

May contain alcohol or a narcotic (e.g. codeine)

These suppress coughing or loosen secretions. They also cause drowsiness, decreased co-ordination, may give a feeling of chilliness.

Laxatives:- Before medications firstly change your diet and drink more fluids. Get more exercise if advised by your PPS doctor.

- bulk forming stool agents, always with fluids (e.g. bran, Fybogel, Isogel)
- stool softeners, avoid long term use (e.g. Dioctyl capsules)
- stimulant laxatives, occasional use only (e.g. Dulcolax & Ex-lax NOT recommended as treatment for constipation)
- Osmotic laxatives, occasional use only (e.g. Milk of Magnesia -Enemas only use under medical supervision.

Antihistamines, Allergy, Motion Sickness Drugs.

E.g. Triludan, Dramamine, Piriton. These cause drowsiness and can increase fatigue.

Analgesics.

These are the most abused class of drugs and long term use can cause addiction. There are two classes:

1. Non narcotic Analgesics.

Although some may be produced over-the-counter they are real drugs, with potential side effects, interaction effects or dependency effects. Examples are: Paracetamol. Control pain only, not inflammation.

Non steroid anti-inflammatory drugs (NSAIDs) such as: (OTC) Aspirin, Advil OTC, (Rx only) medicines Orudis, Motrin, Indocin, Feldene. NSAIDs can control inflammation and pain but may cause dizziness, muscle weakness, drowsiness.

2. Narcotic Analgesics.

These may be used in dental surgery, other surgeries, or as sedatives, pain relieving drugs. Examples: Codeine, morphine.

- Produce central nervous system depression. Can produce physical

dependency

- Increase respiratory depression
- May require increasingly larger doses to gain the same effect.
- May cause postural hypotension (fainting)

Things to consider:

- Can a pudendal, spinal or epidural anaesthetic be used instead of a general anaesthetic?
- Avoid unnecessary elective surgery.
- Appropriate use of analgesics helps to control pain.
- Avoid use of analgesics helps to control pain
- Avoid taking narcotics, try aspirin, NSAIDs.
- Protect your joints! Use a cane or other ambulatory aids. Wear your orthosis.
- Try hot or cold packs, taking a shower, a bath, going to a pool to relieve muscle and joint pains.
- Change your lifestyle, practice a work-rest routine.

Stimulants

Avoid amphetamines. Some anticholinesterase drugs, e.g. pyridostigmine (Mestinon, Rx only) may influence fatigue level. [Since date of publication further research has shown this not to be as successful as hoped for]

Avoid over exertion, use a work-rest lifestyle.

Antidepressants, Anti-anxiety drugs.

One third to one half normal dosage may be adequate. Many of these drugs (benzodiazepines e.g. Rx only, Valium, Librium, Lorozepam are also muscle relaxants, sedatives and may increase fatigue, decrease strength. Barbiturates may be used for sedative, hypnotic or anticonvulsant activities.

- Avoid drinks and foods that may enhance effect, e.g. Alcohol, coffee, especially at night and if you have respiratory muscle weakness.
- Seek counselling for feelings of depression.
- Join a polio survivors support group, become informed, involved.
- Seek out social contacts, go on outings, volunteer, play darts, play anything, get a hobby! Find a distraction.

IN CONCLUSION

This is only a brief review. Drugs taken for cardiopulmonary and other problems may have important interactions with polio related symptoms.

Only you can identify yourself as a polio survivor to your doctor, dentist and pharmacist - ensure they know what drugs you are taking, and become familiar with potential side effects.

Always remember, it is no solution to take medications and continue to abuse your joints and muscles; change your lifestyle and protect your joints and muscles FIRST.

ALWAYS CONSULT YOUR DOCTOR BEFORE TAKING OR CHANGING DRUGS

You are going to have Surgery A Guide for Polio Survivors

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Why preparation for any surgery may be important

As a result of the polio virus infection, nerve cells in the spinal cord and brain stem which control limb and trunk muscles, muscles of breathing and swallowing, were affected.

After rehabilitation you may have had a full recovery or were left with weakened or paralysed muscles, specially if you were on a respirator your breathing muscles were affected and even with apparent full recovery, these muscles may be weak. You may not know that these muscles were affected.

Despite apparent full recovery, polio survivors have fewer nerve cells supplying their muscles than individuals who never had polio. This often means that your muscles have been working at greater capacity than in a non polio person and, as you age, these overused muscles are starting to wear out. Additionally, joints controlled by weak muscles may have instability, poor alignment and have arthritic changes.

Some polio survivors are experiencing new health problems of fatigue, new weakness, new pain, cold intolerance, breathing, coughing or sleep problems.

Even if you are not experiencing new problems, your polio history puts you at greater risk of potential problems during and after surgeries than a person who has not had polio.

Individuals who experienced breathing problems during acute polio, perhaps were on a respirator or in an iron lung, have a spinal curvature (scoliosis) are at greater risk even if there are no apparent problems prior to having surgery.

You should take the responsibility to inform, re-inform and educate surgical staff; including dentists, of your polio history, current level of functioning, fatigue level and known responses to medications

You always should carry a card, an Injury Control Checklist, or wear a Med Alert bracelet stating that you are a polio survivor. You may not always be able to speak for yourself! You could be unconscious.

Medications required for surgical procedures, before, during and after the surgery may further affect your ability to:

- breathe
- cough and clear secretions
- move about - in bed or out of bed

You may be placed at greater risk to develop post operative complications, such as pneumonia, partial collapse of a lung, deep vein thrombosis. An informed medical or dental staff will be alerted to this increased risk and be able to take the necessary precautions.

For what types of surgery is this important?

It is important for ANY type of surgery that requires anaesthesia, pain medication, muscle relaxants, sleep medications.

This includes dental surgery such as tooth extraction, orthodontic surgery, surgery as a day patient, as well as surgery as an inpatient.

If you have weakness of your respiratory muscles, discuss with your family physician and the surgeon whether the surgery can be

performed under a local rather than a general anaesthetic. Could a spinal anaesthetic be used? Your fatigue level should be assessed. A pre-operative referral to a respirologist may be advisable.

What to do when surgery is required

- Discuss with your family physician, the surgeon and anaesthesiologist what type of anaesthesia will be, can be used.
- Ensure the clinic / hospital staff are aware of any functional limitations you may have, such as the use of any aids.
 - raised toilet seat
 - grab bars next to the toilet, washbasin, in the shower, on the bath
 - grab bar over the bed
 - normally use a cane, crutches, a wheelchair? Will this be feasible after surgery?
 - you may need to use certain aids for a short period post-surgery, ones you don't normally use.
- Confirm before admission that any essential aids (e.g. Grab bars) are present in the ward / room that you will be in.
- Alert the surgical team to your level of fatigue. Are you able to have day surgery scheduled, planning to return home and function there following the surgery?
- Is pre-surgery testing planned for the same day as the surgery? Can you manage this?
- If surgery is planned on your legs; will you be required to use crutches following, be non-weight bearing for a period? Will your arm strength permit this? Presence of arthritis, perhaps involving your hands, or a scoliosis should be noted.

Medications

Any adverse responses you are aware of in relation to specific medications should be made known. The assistance of your family physician should be recruited to ensure the surgical team is fully aware of how medication(s) affect your level of function.

What effects can different medications have?

- **analgesics (narcotics)** such as codeine,

morphine, Valium etc., will depress the cough reflex, decrease the ability to breath especially deeply, or to cough properly required to clear the lungs of secretions. Muscle weakness is increased possibly causing greater problems in moving about in bed, to the bathroom etc.

- **muscle relaxants**, these may further impair your ability to breathe, cough, swallow and move your body .. do routine activities.

- **sedatives, hypnotic drugs**, these also decrease the respiratory drive, increase drowsiness (as intended) which may result in shallow breathing, ineffective coughing, and with the lack of movement, increase the risk of a deep vein thrombosis.

If during the acute polio illness you were in an iron lung or on a respirator, told you had bulbar paresis or paralysis although you perhaps are unaware of any respiratory or swallowing problems now, this information should be given to the medical-nursing team.

You should ensure that another individual, spouse, relative, friend, is available to remind, if necessary, the health care team of your polio status and level of function.

What about the post operative period and discharge?

- Again, the team should be made aware of your level of function, any aids needed, in order to set an appropriate management plan.
- Your home situation should be explained. It may be necessary to have temporary Home Help, it may not be feasible for you to initially return to your home.

The health care team can only act in your best interests if they are informed about your polio history, current status and possible existence of adverse reactions to medications.

Originally written for Nova Scotia Polio Survivors Support Group. 1966.



The Lincolnshire Post-Polio Library

A Post Polio Information Service
from the Lincolnshire Post-Polio Network

<http://www.zynet.co.uk/ott/polio/lincolnshire/library/>

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- Airway Secretion Clearance by Mechanical Exsufflation for Post-Poliomyelitis Ventilator-Assisted Individuals - 16 pages** 1993
John R. Bach, MD, William H. Smith, Jennifer Michaels, MD, Lou Saporito, BA, Augusta S. Alba, MD, Rajeev Dayal, BS, Jeffrey Pan, BS
- An Approach To The Patient With Suspected Post Polio Syndrome - 11 pages** 1995
MEDICAL ADVISORY BOARD of the POLIO OUTREACH ADVISORY COUNCIL
- Anticholinesterase-responsive neuromuscular junction transmission defects in post-poliomyelitis fatigue - 14 pages** 1993
Daria A. Trojan, Daniel Gendron and Neil R. Cashman
- Anticholinesterases in Post-Poliomyelitis Syndrome - 11 pages** 1995
Daria A. Trojan and Neil R. Cashman

B

- Be True To Your PPS And Your Teeth Won't Be False To You: Preventing Complications In Polio Survivors Undergoing Dental Procedures - 7 pages** 1996
Richard L. Bruno, Ph.D.
- Bouncing Back Without Guilt - 7 pages** 1993
Wendy Clyne PsyD.
- Bromocriptine In The Treatment Of Post-Polio Fatigue: A pilot study with implications for the pathophysiology of fatigue. - 10 pages** 1997
Richard L. Bruno, Ph.D., Jerald R. Zimmerman, M.D., Susan Creange, M.A., Todd Lewis, Ph.D., Terry Molzen, M.A., and Nancy M. Frick, M.Div, Lh.D.

C

- The Cause And Treatment Of Post-Polio Fatigue - 10 pages** 1995
Richard L. Bruno, Ph.D., Nancy M. Frick, Lh.D., Susan J. Creange, M.A., Todd Lewis, Ph.D., and Terry Molzen, M.S.
- Changes in Post-Polio Survivors Over Five Years: Symptoms and Reactions to Treatments.** 1995
Mary T. Westbrook, PhD
- The Contribution Of Childhood Physical And Emotional Trauma To The Development Of The Post-Polio Personality - 11 pages** 1995
Nancy M. Frick, M.Div, Lh.D.
- Correlation of Electrophysiology with Pathology, Pathogenesis, and Anticholinesterase Therapy in Post-Polio Syndrome - 14 pages** 1995
Neil R. Cashman and Daria A. Trojan

D

Did you have acute poliomyelitis? An Explanation for Polio Survivors about Post Polio Sequelae - 4 pages and LEAFLET
 J. M. Walker, PhD, PT, C. Grant, BSc(Physio) 1996

The Distribution of the Permanent Paralysis in the Lower Limb in Poliomyelitis - A Clinical and Pathological Study - 21 pages
 W. J. W. Sharrard, London, England 1955 UK

Do PPS Cometh After A Fall? - 5 pages
 Richard L. Bruno, PhD 1997

Dr. Henry Holland writes about as a retired physician-psychiatrist with PPS - 4 pages 1997

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- Urogenital problems and PPS - 1 1997
- Virtue of Self Denial - 3 1998
- You Were There - 4 1999

Dr. Neil Cashman Answers Polio Quebec Members' Questions - 4 pages
 Dr. Neil Cashman 1998

E

Early Memories Of Having Polio: Survivors' Memories Versus The Official Myths - 16 pages 1996
 Mary T. Westbrook, PhD

Electrodiagnostic Findings in 108 Consecutive Patients Referred to a Post-Polio Clinic - The Value of Routine Electrodiagnostic Studies - 4 pages
 Anne C. Gawne, Bao T. Pham, and Lauro S. Halstead. 1995.

Electrophysiology and Electrodiagnosis of the Post-Polio Motor Unit - 14 pages 1991
 Daria A. Trojan, MD, Daniel Gendron, MD, Neil R. Cashman, MD

Endurance Training Effect on Individuals With Postpoliomyelitis - 15 pages
 Brian Ernstoff, MD, Hakon Wetterqvist, MD, PhD, Henry Kvist, MD, PhD, Gunnar Grimby, MD, PhD 1996

| | |
|--|-----------------|
| Energy Conservation, Occupational Therapy, and the Treatment of Post-PolioSequelae 12 pages Grace R. Young, MA, OTR | 1991 |
| Exercise - What Is Right For You - 3 pages Mavis J. Matheson, MD. | 1995 |
| Experiences Adapting To BiPAP+Mask Technology - 7 pages David Ronfeldt | 1997 |
| F | |
| Fainting And Fatigue: Causation or Coincidence - 6 pages Richard L. Bruno, Ph.D. | 1996 |
| Fibromyalgia Is Common in a Postpoliomyelitis Clinic - 10 pages Daria A. Trojan, MD, MSc, Neil R. Cashman, MD | 1995 |
| Findings in Post-Poliomyelitis Syndrome - 12 pages Jacquelin Perry, M.D., James D. Fontaine, M.D. and Sara Mulroy, PH.D., P.T. | 1995 |
| G | |
| Gait Analysis Techniques - 17 pages JoAnne K. Gronley and Jacquelin Perry | 1984 |
| Gastrointestinal Involvement In The Post-Polio Syndrome (PPS) - 9 pages Sinn Anuras, M.D. | c. early 1990's |
| A Guide For Post-Polios - Do's And Don'ts - General Therapies And Things To Avoid - 3 Post Polio League | Unknown |
| H | |
| The Hassles Of Living With Post-Polio: Some Survival Strategies - 11 pages Mary T. Westbrook, PhD | 1995 |
| Health and Demographic Characteristics of Polio Survivors - 11 pages Sandra S. French and G. Sam Sloss | 1999 |
| L | |
| The Late effects of Polio - Information for Health Care Providers - (Booklet avail from BPF) Charlotte Leboeuf | 1992 |
| Late functional deterioration following paralytic poliomyelitis - 12 pages D. Kidd, R.S. Howard, A.J. Williams, F.W. Heatley, C.P. Panayiotopoulos and G.T. Spencer | 1997 UK |
| Let's Sleep With Our Nightmares and Follow Our Dreams - 7 pages Sunny Roller, M.A. | 1997 |
| A Letter to a Polio Survivor - 4 pages Professor Richard L. Bruno PhD | 1997 |
| A Look At Feet (for people with the late effects of polio) - 6 pages Beth Rose, B.A., B.Sc. (O.T.) | Unknown |
| M | |
| Managing the Late Effects of Polio from a Life-Course Perspective - 7 pages Frederick M. Maynard | 1995 |
| Management of post-polio syndrome - 16 pages Daria A. Trojan, Lois Finch | 1997 |

| | |
|--|--------------|
| The Mayo, The Lancet, and The Revolting Polios - 7 pages Compiled by Helena Edwards | 1995 UK |
| Muscle Function, Muscle Structure, and Electrophysiology in a Dynamic Perspective in Late Polio - 8 pages Gunnar Grimby, MD, PhD, Erik Stålberg, MD. | 1995 |
| Muscle Recovery in Poliomyelitis - 23 pages W. J. W. Sharrard, London, England | 1955 UK |
| N | |
| National Rehabilitation Hospital Limb Classification for Exercise, Research, and Clinical Trials in Post-Polio Patients - 13 pages Lauro S. Halstead, Anne Carrington Gawne, and Bao T. Pham | 1995 |
| The Neuroanatomy Of Post-Polio Fatigue - 10 pages Richard L. Bruno, Ph.D., Jesse M. Cohen, M.D., Thomas Galski, Ph.D. and Nancy M. Frick, M.Div. | Unknown. |
| The Neuropsychology Of Post-Polio Fatigue - 8 pages Richard L. Bruno, Ph.D., Thomas Galski, Ph.D., John DeLuca, Ph.D. | 1993 |
| Non-Paralytic Polio and PPS - 11 pages Marcia Falconer, Ph.D. cell biology and Eddie Bollenbach, M.A. biology | 1999 |
| Nutrition and Post Polio Syndrome - 3 pages Janice Hartman | Unknown |
| O | |
| Occupational Therapy and the Postpolio Syndrome - 11 pages Grace R. Young | 1989 |
| An Open Trial of Pyridostigmine in Post-poliomyelitis Syndrome - 11 pages Daria A. Trojan and Neil R. Cashman | 1995 |
| P | |
| Pain And Post-Polio Syndrome - An Overview - 3 pages Paul E. Peach, MD. | 1999 rec'vd. |
| Pain Relief - Some tips from the collected wisdom of the Internet Polio Mail List - 3 pages Assembled by Tom Walter | Unknown |
| Pathophysiology and diagnosis of post-polio syndrome - 13 pages Daria A. Trojan, Neil R. Cashman | 1997 |
| The Pathophysiology Of Post-Polio Fatigue: A Role for the Basal Ganglia in the Generation of Fatigue - 19 pages Richard L. Bruno, Ph.D., Robert Sapolsky, Ph.D., Jerald R. Zimmerman, M.D., and Nancy M. Frick, Lh.D. | 1995 |
| Physiotherapy Management of The Late Effects Of Polio - 15 pages Christine Uriadka, Physiotherapist | 1997 |
| Polio Biology I - An Introduction to the Virus - All by Eddie Bollenbach M.A. - 3 | 1998 |
| Polio Biology II - Post-Polio Syndrome's Elusive Etiology - 4 | 1999 |
| Polio Biology III - What About If We Need The Virus Later? - 3 | 1999 |
| Polio Biology IV - Polio And Limiting Variables - 3 | 1999 |
| Polio Biology V - How To Avoid Limiting Variables While Exercising - 3 | 1999 |
| Polio Biology VI - The Polio War and Vaccine Strategy - 4 | 1999 |
| Polio Biology VII - Holistic Polio - 3 | 1999 |
| Polio Biology VIII - Post-Polio Pathogenesis - 3 | 1999 |
| Polio Biology IX - Peering at Post-Polio Syndrome under the Microscope - 4 | 2000 |
| Polio Biology X - In PPS Manual Muscle Testing Problems Arise from Judgement & Biology | 2000 |

| | |
|---|---------|
| Polio and CFS/ME - 3 pages Dr. Richard L. Bruno | 1998 |
| Polioencephalitis and the Brain Fatigue Generator Model of Post-Viral Fatigue Syndromes. 17 pages Richard L. Bruno, Ph.D., Nancy M. Frick, Lh.D., Susan Creange, M.A., Jerald R. Zimmerman, M.D., and Todd Lewis, Ph.D. | 1996 |
| Polioencephalitis, Stress And The Etiology Of Post-Polio Sequelae - 15 pages Richard L. Bruno, Ph.D., Nancy M. Frick, M.Div., and Jesse Cohen, M.D. | 1991 |
| Polio Feet - There's a reason you have cold feet - but you can keep warm and stay cool - 3 Richard Bruno, Ph.D. | 1996 |
| Poliomyelitis - 12 pages D Kidd, AJ Williams, RS Howard | 1996 UK |
| Poliomyelitis: New Problems From An Old Infection - 8 pages John Shneerson MA DM FRCP FCCP | 1998 UK |
| Polio returns to haunt G.P.'s - 3 Pages Thomas Moore | 1992 UK |
| Polio Survivors Abroad: Canadian Roulette, Rue Britannia - 6 pages Dr. Richard Louis Bruno | Unknown |
| Polio Survivors as Patients - Guide for Emergency Care & Surgical Health Workers 4 pages and LEAFLET J. M. Walker, PhD, PT, C. McGowan & G. Vardy | 1996 |
| Post-Poliomyelitis Fatigue Where Is The Lesion? The Controversy - Three Points Of View 4 pages Dr. Neil Cashman | 1997 |
| Postpoliomyelitis Syndrome: Assessment of Behavioral Features - 11 pages Donald L. Freidenberg, David Freeman, Steven J. Huber, Jacquelin Perry, Armin Fischer, Wilfred G. Van Gorp and Jeffrey L. Cummings | 1989 |
| Post-Polio and Post-M.E. - New book furthers polio hypothesis - 5 pages Jane Colby | 1996 UK |
| Post-Polio And Physical Therapy - 3 pages Susan L Fish MAPT | Unknown |
| Post-Polio Sequelae - Assessment and Differential Diagnosis for Post-Polio Syndrome 15 pages Lauro S. Halstead, MD | 1991 |
| Post Polio Sequelae - Effect of Treatment and Noncompliance on Post-Polio Sequelae 10 pages. Paul E. Peach, MD., Stephen Olejnik, PhD | 1991 |
| Post Polio Sequelae: An Explanation for Health Professionals - 4 pages and LEAFLET J. M. Walker, PhD, PT, K. Sweet, BSc(Physio) | 1996 |
| Post-Polio Sequelae And The Paradigms Of The 50's: Newtie, Ozzie and Harriet versus Paradigms of Caring and a Future for Rehabilitation in America. - 8 pages Richard L. Bruno, Ph.D. | 1995 |
| Post-Polio Sequelae: Physiological and Psychological Overview - 8 pages Nancy M. Frick, M. Div. and Richard L. Bruno, Ph.D. | 1986 |
| Post Polio Sequelae True Answers for Friends and Family - 3 pages Kessler Institute for Rehabilitation | Unknown |

| | |
|---|---------|
| Post-Polio Syndrome - 10 pages Lauro S. Halstead | 1998 |
| PPS and Intimacy - 4 pages Linda Van Aken and Henry Holland MD | 1998 |
| The Postpolio Syndrome - An Overuse Phenomenon - 21 pages Jacquelin Perry, M.D., Gregory Barnes, B.S., R.P.T. and JoAnne K. Gronley, M.A., R.P.T. | 1989 |
| PPS Questions and Answers, March, 1995 - 6 pages Richard Bruno and Nancy Frick | 1995 |
| Post-Polio Syndrome: Where Do We Go From Here? - 5 pages Mary T. Westbrook, PhD | 1996 |
| A Practical approach to the late effects of polio - (booklet avail. from BPF) Charlotte Leboeuf | 1991 |
| Predicting Hyperactive Behavior as a Cause of Non-Compliance with Rehabilitation: The Reinforcement Motivation Survey. - 12 pages Dr. Richard L. Bruno | Unknown |
| Predictive Factors for Post-Poliomyelitis Syndrome - 16 pages Daria A. Trojan, MD, MSc, Neil R. Cashman, MD, Stanley Shapiro, PhD, Catherine M. Tansey, MSc, John M. Esdaile, MD | 1994 |
| Preventing Complications In Polio Survivors Undergoing Surgery - 9 pages Richard L. Bruno, Ph.D | 1996 |
| The Psychology Of Polio As Prelude To Post-Polio Sequelae: Behavior modification and psychotherapy. - 16 pages Richard L. Bruno, Ph.D. and Nancy M. Frick, M.Div. | 1991 |
| Pulmonary dysfunction and its management in post-polio patients - 18 pages John R. Bach and Margaret Tilton | 1997 |
| Pulmonary Dysfunction and Sleep Disordered Breathing as Post-Polio Sequelae: Evaluation and Management - 13 pages John R. Bach, MD and Augusta S. Alba, MD | 1991 |
| R | |
| Recognizing Typical Coping Styles Of Polio Survivors Can Improve Re-Rehabilitation - 5 pages Frederick M. Maynard, MD and Sunny Roller, MA | 1991 |
| A Report Into The Consequences Of Living With Polio For 63,500 Years - 16 pages Peter Field | 1995 UK |
| S | |
| Silicon, Sex and Polio Survivors - 4 pages Dr. Richard L. Bruno | 1995 |
| Spinal tap for PPS? NO !!! - 3 pages Tom Walter | 1997 |
| Stimulation frequency-dependent neuromuscular junction transmission defects in patients with prior poliomyelitis - 15 pages Daria A. Trojan, Daniel Gendron and Neil R. Cashman | 1993 |
| Strategies for Exercise Prescription in Post Polio Patients - 19 pages Anne Carrington Gawne, MD | 1995 |
| Stress and "Type A" Behavior as Precipitants of Post-Polio Sequelae: The Felician/Columbia Survey - 7 pages Richard L. Bruno, PhD, and Nancy M. Frick, MDiv, LhD | 1987 |

| | |
|---|---------|
| Subspecialty Clinics: Physical Medicine and Rehabilitation - Management of Postpolio Syndrome - 23 pages Gudni Thorsteinsson M.D. | 1997 |
| Survey of the Late Effects of Polio in Lothian - 34 pages or Booklet from Dr. Pentland. B. Pentland, D. J. Hellowell, J. Benjamin, R. Prasad. | 1999 UK |
| T | |
| Tips for Physiotherapists. South Alberta PPSG | Unknown |
| Tom Walter - | |
| Coming Back From Hell or Something Worse than PPS? - 3 pages | 1998 |
| Pain Relief - Some tips from the collected wisdom of the Internet Polio Mail List - 3 pages | Unknown |
| Spinal Tap for PPS? NO !!! - 3 pages | 1997 |
| Take a Look at Estrogen - Hormone Therapy May Be Right For Women With PPS 4 pages | 1998 |
| Terminology - 4 pages | 1997 |
| U | |
| Ultimate Burnout: Post-Polio Sequelae Basics - 6 pages Dr. Richard Louis Bruno | 1996 |
| Unusual Cases: Postpolio syndrome - 10 pages Paul Ballinger MRCP, MRCGP, DCH, DRCOG | 1998 UK |
| W | |
| What you should know about your Medications - A guide for Polio Survivors (NZ Version) 4 pages and LEAFLET J.M.Walker Ph.D., PT, AM Whelan, Phar. D | 1996 |
| What you should know about your Medications - A guide for Polio Survivors (UK Version) 4 pages and LEAFLET J.M.Walker Ph.D., PT, AM Whelan, Phar. D., Andrew Francis Forde MRPharm. B.Sc.Hons | 1996 |
| Y | |
| You are going to have surgery - A Guide for Polio Survivors - 4 pages and LEAFLET J. M. Walker, PhD, PT | 1996 |

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People who had polio and are experiencing new symptoms need to be assessed by medical professionals who are experienced in Post-Polio to determine what is wrong and to give correct advice. We can only make these documents available to you. YOU must then take what you believe to be relevant to the medical professional you are seeing. We are collecting and collating everything we can to enable medical professionals to make informed decisions. Other medical conditions must be looked for first, Post-Polio Syndrome is by diagnosis of exclusion.

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LATE EFFECTS OF POLIOMYELITIS



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A large number of Canadians who developed polio as children or young adults are now reaching their fifth and sixth decade. With this aging, these individuals are facing unique problems as a result of having polio many years ago, problems that have come to be known as The Late Effects of Poliomyelitis. The last epidemic of poliomyelitis in Canada was in 1955. As a result of the Salk and Sabin vaccines, the number of cases decreased dramatically after this year.

A ribonucleic acid virus of which there are three strains, causes poliomyelitis. The virus attacks and destroys the anterior horn cells (alpha motor neurons) of the spinal cord and brain stem. The alpha motor neuron and the many muscle fibres innervated by it is called a 'motor unit'. Loss of these motor units results in the paralysis associated with poliomyelitis. Surviving motor units, recognizing that muscle fibres are left without innervation, send out terminal axon branches, referred to as 'collateral sprouting', thereby, re-innervating the muscle to some degree. As a result of this process, an alpha motor neuron may innervate up to seven times the normal number of muscle fibres. These large units are termed 'giant motor units,' and account for the recovery of muscle function following the paralysis caused by the poliomyelitis virus.

Polio survivors were taught to push themselves, and regardless of the degree of neurological recovery, they have led active and productive lives. Now, due to the late effects of poliomyelitis, they must relive their experience with poliomyelitis. What was in the past can no longer remain there. The childhood memories of isolation, separation, iron lungs, bracing and pain surface as these poliomyelitis survivors age. As a result, they must deal

with new problems of pain, fatigue and diminished function.

The late effects of poliomyelitis can be categorized into three distinct symptom complexes. The first, **Progressive Muscular Atrophy**, is the progressive wasting and weakening of muscle group[s] leading to progressive loss of neuromuscular function. This is relatively rare. On the other hand, the other two complexes, **Biomechanical Sequelae** of poliomyelitis and **Post-Polio Syndrome**, are common and account for a significant degree of impairment and disability in this aging population.

BIOMECHANICAL SEQUELAE

The most common biomechanical sequelae is premature osteoarthritis of both upper and lower extremity joints. Lack of normal muscle strength around lower extremity joints results in abnormal 'wear and tear' on these joints. As a result, premature degeneration develops, particularly in the knee joints. This is characterized by joint pain with weight bearing activities, joint stiffness following periods of immobility, joint effusion and joint instability. This instability develops as a result of loss of integrity of the joint capsule and ligaments in addition to muscle weakness. As a consequence, falls become increasingly frequent, leading to further injury.

Premature degeneration of the hip and ankle joints is also a common complication due to residual weakness in the lower extremities as a result of poliomyelitis. Often, these joint problems develop in the so-called 'good leg', the extremity not affected by polio. This is a result of over-work of the strong leg in order to compensate for the weaker extremity. Early degenerative osteoarthritis often develops in the upper extremities, particularly in the shoulder joints, due to prolonged use of walking-aids such as crutches or a cane. Joint pain and the concomitant loss of function has a significant impact on the quality of life.

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POST-POLIO SYNDROME

Perhaps the most disabling and least understood late effect of poliomyelitis is Post-Polio Syndrome. This is a term, coined in 1984 following the first international Post-Polio Conference in Warm Springs, Georgia, to describe a cluster of symptoms and signs experienced by poliomyelitis survivors 25 to 40 years after their original illness. The *criteria* for the diagnosis of Post-Polio Syndrome includes **a history of paralytic poliomyelitis, a stable period of neurological status after recovery, residual neurological deficits due to the initial poliomyelitis, new subjective muscular weakness, generalized fatigue and diffuse muscle/limb pain.**

Our understanding about Post-Polio Syndrome is limited at the present time. We know that Post-Polio Syndrome is not a reactivation of the poliomyelitis virus. Preliminary research has demonstrated some immunological data, but currently, there is insufficient evidence to attribute this condition to an autoimmune phenomenon. There is inconclusive evidence to conclude that Post-Polio Syndrome is a result of some other infectious process. In other words the etiology of Post-Polio Syndrome is unknown.

The prevalence of Post-Polio Syndrome was originally estimated to occur in one-third of polio survivors. However, it has recently been estimated to be as high as two-thirds of all polio survivors (Personal communication, International Conference on Polio, St. Louis, Missouri, May, 1997). Perhaps, the most debilitating aspect of Post-Polio Syndrome is the fatigue associated with this condition. The fatigue varies in severity; however, many patients report hitting the proverbial 'Post-Polio Wall', referring to an inability to carry on with an activity due to fatigue. This often occurs in the early to mid-afternoon and necessitates a rest or nap. Fatigue frequently precludes socialization and other enjoyments, thereby detracting from the quality of life with advancing age. Individuals with Post-Polio Syndrome frequently report increasing muscle weakness. This new weakness is not necessarily confined to muscles or areas of the body originally affected by the poliomyelitis virus. It can occur in the so called 'normal' limbs. This weakness can also affect the trunk musculature resulting in truncal instability, impaired balance and respiratory complications.

Ten percent of motor units are lost due to degeneration with each decade after the age of 60 years due to the aging process. Poliomyelitis survivors may have fewer motor units as a result of the original poliomyelitis infection and the remaining motor units may be giant units. Therefore, a relatively small loss of motor units can have

a disproportionate impact on function.

This weakness may or may not be demonstrable in a clinical assessment. This may be due to the insensitivity of manual muscle-testing or by the fact that the weakness is due more to easy fatiguability of muscle as opposed to pathophysiological weakness per se. Irrespective of the etiology of the reported weakness, it has a profound impact on the individual's level of function. Frequency of falls increase, and concerns regarding safety arise. Ambulation may become increasingly difficult, necessitating the use of braces and ambulatory aids.

Very little is understood about the pain in Post-Polio Syndrome, recently termed '*Post-Polio Pain*' (Personal communication, International Conference on Polio, St. Louis, Missouri, May, 1997). This pain does not resemble that of other more familiar conditions. It is described neither as an ache or a burning. It tends to be migratory and not necessarily localized to muscles or joints. It tends to worsen towards the evening and responds poorly to traditional analgesics.

While weakness, pain and fatigue tend to be the hallmarks of Post-Polio Syndrome, this condition can be associated with a number of other problems including decreased balance, frequent falls for no apparent reason, variable paresthesiae, daytime somnolence, non-restorative sleep, sleep apnoea, restless leg syndrome and swallowing difficulties. Furthermore, individuals may report mild cognitive problems such as impaired short-term memory and decreased concentration.

The diagnosis of Post-Polio Syndrome is one of exclusion. Other causes for a patient's symptoms should be vigorously investigated. The list of differential diagnoses is long; however, the more common conditions that Post-Polio Syndrome may mimic include fibromyalgia, hypothyroidism, early polymyositis and depression. A thorough history and physical examination along with laboratory investigations will usually lead to the underlying etiology of the patient's symptoms.

All patients should be screened for psychological factors, particularly depression. This, however, can be difficult. One must determine if the depression is a primary cause of the individual's somatic complaints or is the depression secondary to the effect that Post-Polio Syndrome has had on that individual's quality of life.

There is no 'test' for Post-Polio Syndrome. Electromyography (EMG) can demonstrate features of the original poliomyelitis infection, i.e. giant motor units with no ongoing denervation. EMG cannot, however, diagnose Post-Polio Syndrome, and the EMG may, in fact, be normal in spite of the history of poliomyelitis.

Therefore, the diagnosis of Post-Polio Syndrome should only be made when the criteria outlined above have been met and all other potential etiologies have been excluded.

TREATMENT

Unfortunately, there is no 'cure' for Post-Polio Syndrome. As noted above, traditional analgesics tend to work poorly in this patient population. Non-traditional therapies such as tricyclic agents may, in some cases, be effective. Traditional physiotherapy tends to be of limited value, whereas, acupuncture and Shiatsu massage tend to be more effective for pain relief.

Various pharmacological agents have been used to treat the fatigue of Post-Polio Syndrome with little success. Methylphenidate (Ritalin) has been used, with anecdotal reporting of improvement in fatigue. No controlled studies are available to evaluate the efficacy of this drug. Pyridostigmine (Mestinon) has also been tried. This drug has recently been evaluated in a clinical study by Doctors Neil Cashman and Daria Trojan of the Montreal Neurological Institute. Unfortunately, there was no evidence of improvement in reported severity of fatigue in individuals using this drug.¹ The authors do not recommend the use of pyridostigmine for the fatigue of Post-Polio Syndrome. Therefore, the primary management of fatigue in this condition is through energy conservation techniques and pacing strategies.

Appropriate exercise is extremely important in poliomyelitis survivors. In the early days, individuals recovering from poliomyelitis were instructed to exercise. They were led to believe that the harder they worked at exercise, the better their recovery would be. Now, however, it is believed that overwork of giant motor units may cause premature degeneration of these units due to 'burn out', leading to muscle weakness and loss of function. On the other hand, an individual should avoid muscle weakness that results from lack of use. Therefore, these individuals should perform regular exercise that is of low resistance and non-fatiguing in nature. Given the many orthopaedic problems associated with the late effects of poliomyelitis, water exercise is usually the most effective and safe method of maximizing and maintaining muscle strength.


The goal of treatment is to enhance the quality of life in those individuals with the late effects of poliomyelitis. This is achieved through life-style management, consisting of energy conservation and appropriate exercise. Various assistive devices are available to enhance the individual's level of function.

When indicated, pulmonary function tests and a swallowing evaluation will help to direct appropriate treatment of these problems.

Psychological counseling may be required, particularly when a reactive depression exists. Psychological intervention can help these individuals deal with their physical limitations and functional losses. Some require assistance to accept the assistive devices that are now necessary for day to day activities. Others need help to deal with repressed childhood memories that can no longer remain buried.

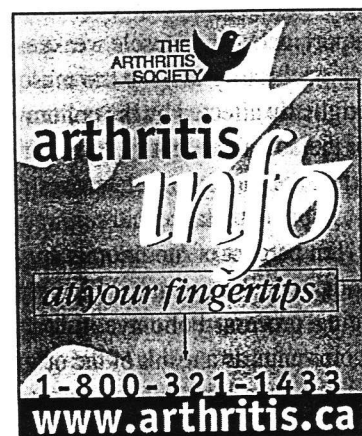
Although there is no cure for Post-Polio Syndrome, the prognosis can still be positive. With the appropriate interventions and a willingness on the part of the poliomyelitis survivor to adopt the life-style changes required, these individuals can maintain a high level of quality of living as they age.

The Post-Polio Clinic, West Park Hospital, Toronto, is the only one in Ontario and one of only a few such clinics in North America. The clinic provides a comprehensive multidisciplinary evaluation of poliomyelitis survivors. The core team consists of a clinic coordinator, physiatrist, occupational therapist, physical therapist and social worker. Support services include psychological, orthotics, dietary, respiratory, sleep and swallowing programs. Following their assessment in the Post-Polio Clinic, problems related to the late-effects of poliomyelitis are identified and management recommendations are offered to the client and their referring physician. The objective of the Post-Polio program is to address the needs of this very unique aging population of poliomyelitis survivors. The Post-Polio Clinic can be accessed by any physician wishing to refer one of their patients for assessment.

More information regarding the services offered through the Post-Polio Clinic, West Park Hospital, can be obtained by telephone, (416) 243-3600, ext. 2260, or by fax, (416) 243-8947. 

REFERENCE

1. Polio Network News, International Polio Network, Saint Louis, Missouri, Winter 1998, Vol. 14, No. 1.



For the Lincolnshire Post-Polio Network
Article on Manual Muscle Testing by Professor Murray Maitland, March 1993

The loss of muscle function following polio has been documented in several studies. It was found that symptomatic subjects had evidence of more severe original polio involvement by history (documented electromyographically), were weaker and capable of performing less work than asymptomatic subjects, and recovered strength less readily than controls.¹

Dalakas and coworkers have performed several studies examining the histology and electromyography of people with chronic polio.^{3-5 7} Dalakas et al., examined muscle weakness that developed a mean of 28.8 years after recovery from acute polio. The researchers concluded that new weakness was a dysfunction of the surviving motor neurons that causes a slow disintegration of the terminals of individual nerve axons. Dalakas also studied thirty-five muscle biopsies performed on 27 patients with postpoliomyelitis progressive muscular atrophy (PPMA) (8 patients had two biopsies) and 5 asymptomatic postpolio patients in an attempt to define diagnostic criteria for the newly weakening muscles and to provide insights into the mechanism of the disease. The newly weakened muscles show signs of recent denervation.³

Rekand et al. studied 148 people with post-polio syndrome and they found that while Although symptoms defined in the PPS are unspecific and may occur in the general population, the risk for developing such symptoms are higher among the polio victims. The difference in risk among nonparalytic and paralytic patients may depend on the extent of motor neuron damage in the acute stage.⁸ Rekand et al. also studied 39 patients who had polio. Three patients (6.7%) had neurologic and neurophysiologic findings and development of symptoms consistent with motoneuron damage. The authors concluded that some nonparalytic patients may have subclinical acute motoneuron damage with subsequent development and manifestation of motor weakness and neuromuscular symptoms many years later. These symptoms should be considered a differential diagnosis in patients who have a history of nonparalytic poliomyelitis.⁹

The evaluation of muscle function (strength) using manual muscle tests is subjective from grades 3 through 5. Strong muscle contraction is rated as 4 or 5 but the definition of "normal" is not adequate in this subjective test to differentiate between weaker and stronger muscles. Bohannon and Corrigan found that manual muscle tests of grade 5 had enormous variation in force, up to 86% of all quantitatively measured forces. These findings help to explain the insensitivity of manual muscle testing at higher force levels and why it has such a profound ceiling effect.²

There can be many technical reasons for this effect including the fact that examiner strength limits detection of moderate quadriceps weakness with manual resistance.⁶

Sharrard studied polio patients by autopsy.¹⁰ He found that muscle grades of 3 were given to individuals with 85% denervation of the muscles. In other words, profound muscle weakness must be evident before abnormal grades are given.

Quantifiable muscle strength tests are commonly carried out using an isokinetic dynamometer (Biodex, Cybex, Kincom). Using this technique we assess muscle function in a controlled manner. Endurance, fatigue, maximal torque, pain free torque, power and work are some of the variables that I have measured, and are well documented in the literature. We use 5 definitions of normal depending on the condition we are examining:

1. Less than 10 percent difference between sides
2. Strength to body weight ratio
3. Minimal or no symptoms
4. Compared to normal, age-matched values
5. Sport or activity specific

At this time, I am attempting to develop more efficient, alternative lower extremity muscle tests but they have not been validated at this time.

Reference List

1. Agre JC, Rodriquez AA. Neuromuscular function: comparison of symptomatic and asymptomatic polio subjects to control subjects. *Arch Phys Med Rehabil* 1990; 71:545-51
2. Bohannon RW, Corrigan D. A broad range of forces is encompassed by the maximum manual muscle test grade of five. *Percept Mot Skills* 2000; 90:747-50
3. Dalakas MC. Morphologic changes in the muscles of patients with postpoliomyelitis neuromuscular symptoms. *Neurology* 1988; 38:99-104
4. Dalakas MC, Elder G, Hallett M, Ravits J, Baker M, Papadopoulos N, Albrecht P, Sever J. A long-term follow-up study of patients with post-poliomyelitis neuromuscular symptoms. *N Engl J Med* 1986; 314:959-63
5. Dalakas MC, Sever JL, Madden DL, Papadopoulos NM, Shekarchi IC, Albrecht P, Krezlewicz A. Late postpoliomyelitis muscular atrophy: clinical, virologic, and immunologic studies. *Rev Infect Dis* 1984; 6 Suppl:S562-S567
6. Mulroy SJ, Lassen KD, Chambers SH, Perry J. The ability of male and female clinicians to effectively test knee extension strength using manual muscle testing. *J Orthop Sports Phys Ther* 1997; 26:192-7
7. Ravits J, Hallett M, Baker M, Nilsson J, Dalakas M. Clinical and electromyographic studies of postpoliomyelitis muscular atrophy. *Muscle Nerve* 1990; 13:667-74
8. Rekan T, Albrektsen G, Langeland N, Aarli JA. Risk of symptoms related to late effects of poliomyelitis. *Acta Neurol Scand* 2000; 101:153-8

9. Rekand T, Karlsen B, Langeland N, Aarli JA. Long-term follow-up of patients with nonparalytic poliomyelitis. *Arch Phys Med Rehabil* 2002; 83:533-7
10. Sharrard WJW. Muscle recovery in poliomyelitis. *J Bone Joint Surg [Br]* 1955; 37:63-9

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From: Murray Maitland <mmaitlan@hsc.usf.edu>
To: Hilary Hallam <hilary.hallam@lincolnshirepostpolio.org.uk>
Date: Tuesday, March 25, 2003 10:12:21 PM
Subject: MMT
Folder: Inbox/Lincolnshire Post-Polio Network

Hilary:

Just a note to say that I know the book you refer to. It is a book we use for students, and contains good technical detail. What is missing from your perspective, is the issue of validity and reliability.

Murray

Hilary Hallam wrote:

> Hello Murray,
>
> Monday, March 24, 2003, 10:09:17 PM, you wrote:
>
> MM> Dear Hillary:
> MM> I am finally getting back to fun, academic things after a term of
> intensive
> MM> teaching. I have finished a literature search on strength issues in
> post-polio
> MM> sufferers and also manual muscle testing. Now, I need to organize it into
> MM> something useful. In addition, I have sent an email to a physical
> therapist/researcher/professor
> MM> that specializes in post-polio dysfunction. This note is just to let you
> know I haven't forgotten, and that I should
> MM> have it organized tomorrow.
>
> MM> Murray
>
> Thankyou so much for letting me know. I look forward to hearing more
> from you.
>
> I purchased a book via the Internet....
> Handbook of Manual Muscle Testing by Nancy C Cutter and C. George
> Kevorkian. Very comprehensive.
>
> What I would like to do is to see some research into testing muscles
> as per this manual and then relating that to actual functional ability
> of the polio survivor.
>
> I anticipate being back in Florida mid July now - as Richard L Bruno
> is speaking in the UK on the 12th July. I anticipate being in FL for
> about four to six weeks. I am speaking at the San Francisco PPS
> Conference on September 19th and am not sure yet if we will fly or
> drive. As my partner and I both have electric wheels we need transport
> when we get to CA, so if we can find something suitable we might
> drive. We will then be back in the UK from October to very early
> January 2004. Then in FL again till mid May or June if there is a GINI
> International Polio Conference.
>

> My GP is impressed with the improvement in range of movement that AIS
> has given me. I can now move with greater ease, e.g. am able to turn
> over in bed at night at a lower level of wakefulness. I still suffer
> from muscle and central fatigue, to almost the same level as before. Its use
> all the aids and assistive devices and pace and rest to get the most
> out of my energy tokens.
>
> My thanks for your time and interest.
>
> --
> Best regards,
> Hilary Hallam, polio of 1952
> Founder and Chair,
> Lincolnshire Post Polio Network, UK
> www.lincolnshirepostpolio.org.uk
<mailto:hilary.hallam@lincolnshirepostpolio.org.uk>

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