



THE POST POLIO SUPPORT GROUP - Polio Survivors helping each other -

This book has been written to inform Polio Survivors who wish to learn more about the Post Polio Support Group;

- **how it supports Polio Survivors**
- **how it structures the various services it can provide**
- **how a Polio Survivor or a medical professional or a member of the public can get in touch for information and support**

The aim is to make the Post Polio Support Group more meaningful to each reader

Setting the Scene

The Post Polio Support Group was set up in 1993 by Polio Survivors to assist people who might be experiencing Post Polio Syndrome. They knew the lack of information available to Polio Survivors, doctors and others about polio and its late effects was a big problem

The Group works tirelessly to

- **Create awareness about Post Polio Syndrome**
- **Provide information regarding the late effects of polio**
- **Ensure that the needs of Polio Survivors relating to their condition are met to enable them to live with dignity**

The work of the Group is guided by the following Principles

- The Post Polio Support Group is member led and Polio Survivors are central to its work
- Services and supports will be provided, based on needs identified through consultation with members, fairly and within the financial capacity of the Group
- The Group will act according to best practice and in line with its Code of Conduct
- Sensitivity, empathy and understanding are central to communication with Polio Survivors
- Polio Survivors will be encouraged and enabled to live their lives with dignity
- The Group will advocate for Social Policy change to

encompass the needs of Polio Survivors

- The Post Polio Support Group will co-operate and collaborate with other stakeholders, as appropriate

The central office for the **Post Polio Support Group**
is at

Unit 319, Capel Building, Mary's Abbey, Dublin 7

Telephone calls, especially from Polio Survivors,
to **(01) 8898920** are welcome

Charity Number CHY 11356

Emails to the Chair are welcome at **chairman@ppsg.ie**

The mission of the
Post Polio Support Group is
to create awareness and to provide
information regarding the late effects of
polio among Polio Survivors, statutory
agencies and the wider medical profession,
and to ensure that the needs of Polio
Survivors relating to their condition are met
to enable them to live with dignity

POLIO

Post Polio Syndrome and Postpolio Myelitic Syndrome

For many Irish people there is little or no knowledge of polio or its effects. Even vaccination against polio is combined with other shots so many don't know that the 6 in 1 for babies includes polio as one of the six vaccinations. Many doctors and other medical professionals qualifying today have not studied polio or its effects, short or long term.

It is to be welcomed that this year (2010) the World Health Organisation has for the first time recognised **Post Polio Syndrome**. It now has an official medical title **Postpolio Myelitic Syndrome**. We hope this recognition will increase awareness, particularly in medical circles.

The Group has done its best to inform all concerned about Post Polio Syndrome. With the help of friends in the medical professions and the Health Service Executive (HSE) it produced Post Polio Syndrome-Management and Treatment in Primary Care. We all call it "The Blue Book" for convenience.

Any member of the Group can request a copy of the Blue Book from the central office by phoning or writing. If you want your doctor or physio or anyone treating you to have it you only have to ask. We also supply it to any caring staff who contact us. They can choose to have the book or the same information on a CD.

If you have had polio, even many years ago and, in recent

years, you are experiencing one or more of the following symptoms you may be living with **Post Polio Syndrome**;

- Muscle and joint pain
- Lack of strength and increased muscle weakness
- Extreme fatigue
- Breathing problems often related to difficulty in sleeping
- Swallowing problems
- Severe intolerance of cold
- Decline in ability to enjoy everyday activities such as walking

Be strong At the moment there is no cure for what you are going through, though there are a lot of things you can do to maintain your lifestyle. You will need a lot of resolve from yourself and the Post Polio Support Group is here to help where it can. You will have to make changes in how you do things but the results will make it worthwhile.

Family and Friends Support Make sure that you and your family and friends understand the problems associated with the late effects of polio and how you can work co-operatively to manage your changing lifestyle. It is important to find solutions to problems so that you continue to enjoy life and keep the independence you have fought so hard for.

Peer Support Other Polio Survivors can be of great assistance to someone coping with the late effects of Polio. They may share your symptoms and may know of treatments that can help you

Diagnosis Diagnosing Post Polio Syndrome is difficult and

is best done by a consultant neurologist who has experience of the condition

Energy Management Strike the right balance between resting and being active.

General Health Give your body the best chance it can have by living healthily.

New Aids New lighter callipers and other aids may make your life easier.

Greater Care Always seek professional advice before taking prescription or over the counter medication or remedies.

Specialist Treatment From Physiotherapists, Occupational Therapists, Speech Therapists, Orthotists, Counsellors, Chiropodists, and others.

Specialist Consultations with Neurological, Orthopaedic, Rehabilitation, Pain and Respiratory Consultants, amongst others.

Psychological Support From Psychologists and professional Counsellors.

If you want any advice with any of the issues raised please call Lillian at the Post Polio Support Group, Unit 319, Capel Building, Mary's Abbey, Dublin 7 Telephone (01) 8898920

HOW TO GET THE SUPPORTS THAT YOU NEED

It is clear from the mission statement of the Group that its work is designed *“to ensure that the needs of Polio Survivors relating to their condition are met to enable them to live with dignity”*. It is very important that this work is done carefully and patiently because the correct supports can make a huge difference to someone’s lifestyle.

The Guiding Principles are:

- Services and supports will be provided, based on needs identified through consultation with members, fairly and within the financial capacity of the Group
- The Group will act according to best practice and in line with its Code of Conduct
- Sensitivity, empathy and understanding are central to communication with Polio Survivors
- Polio Survivors will be encouraged and enabled to live their lives with dignity

How to make contact

Any Polio Survivor can contact the Group at any time for support. The central office in Dublin (01) 8898920 is open generally from 8 in the morning to 5 in the afternoon and callers are welcome. Most of the supports are provided by Lillian working with the HSE and drawing on the talents of occupational therapists and perhaps additional medical and other staffs.

Outside office hours Joan Bradley (01) 4549237 can be contacted.

There are answering machines on the office and on Joan's phone. Please leave a message and your call will be returned. Please leave your name and phone number, speaking as slowly and as clearly as you can. We are very frustrated if a message has been left and we can't return a call to the sender.

The Questionnaire

Self assessment of a Polio Survivor's needs is usually done by completing a Questionnaire. Most Polio Survivors complete this and return it in the Business Reply envelope provided. No stamp is needed. Many people in Ireland, as in other countries, do not like form filling - Polio Survivors are no different but remember the Questionnaire is the single most important tool that the Group can use to help a Polio Survivor.

Filling it in can be the most useful thing for any Polio Survivor to do to help him or herself. It is a chance to give a bit of thought to your situation and pass the updated information to the Group. If you would like to fill the Questionnaire over the phone ring the office and it may be possible to do it this way. The Questionnaire has a box for a Polio Survivor to tick that he or she has an urgent need. This can trigger an early call from the office.

Polio Survivors are encouraged to contact the office by phone or letter if they have an urgent need or if circumstances are changed in any way.

Confidentiality

The Questionnaire information and other details on Polio Survivors are held securely at the central office. Generally, after the Questionnaires have been examined, a staff member will contact each person in turn by phone. An assessment is made following this which may be assisted by information from HSE staff and reports from professional staff such as Occupational Therapists (OTs). Any contact with such people will only be made with the permission of the Polio Survivor following discussion. The Post Polio Support Group will work with others, principally HSE, but also perhaps medical professionals, various voluntary and statutory bodies and suppliers to provide the best solution possible.

The final assessment, building on the work done on the phone and the information given in the Questionnaire are the basis for the support of the Polio Survivor.

If you give the best picture that you can of your disability and your situation in your Questionnaire you are giving the Group the best chance to support you properly.

Remember

Polio Survivors can call the office and speak with Lillian who is the Services Co-ordinator. A third party such as a General Practitioner, Polio Survivor's family member or even a supplier can call Lillian but only with the permission of the Polio Survivor.

Some Polio Survivors write to the office from time to time to describe their situations and to seek assistance.

The staff respond to email enquiries about self-assessed need.
Queries to **sic@ppsg.ie**

Personal visits to the office by Polio Survivors are another way to facilitate the assessment of need. These are welcomed but please make an appointment in advance as the person you want to meet may not be in the office that day.

“Services for persons with disabilities seek to enable each individual with a disability to achieve his or her full potential and maximise independence, including living as independently as possible”

HSE National Service Plan 2009

Designing the supports to assist the Polio Survivor

Every Polio Survivor is an individual and always remember that the solution for one person may not necessarily be the same as for another. The following are the areas that are considered in assessing support provision.

Making sure that a Polio Survivor feels as well as she or he can

Trying to assess whether the Polio Survivor is getting proper care and medical attention

General Practitioner (GP) is usually the first point of contact for primary care of the Polio Survivor. It is very important that the GP does not dismiss the Polio Survivor's condition. This can happen with chronic conditions and the Polio Survivor may have to insist that the GP deals properly with the polio patient.

Assessment and Diagnosis is an essential part of the care of a Polio Survivor. There should be good linkages between the neurologist who diagnoses the condition and the medical services that support him or her. These may be hospital based staff that support the neurologist or primary care staff such as the General Practitioner, Public Health Nurse, etc.

The Blue Book, Post Polio Syndrome-Management and Treatment in Primary Care, is the key document to inform medical staff about Post Polio Syndrome. If a Polio Survivor wants to give a copy to someone who treating her or him just ask the office for a copy. If a Polio Survivor would like

someone from the office to speak to his or her General Practitioner or to send a copy of the Blue Book just make a call.

Counselling may help a Polio Survivor if she or he would like to talk about a personal situation which may be causing distress in her or his life.

Speech and Language Therapy is the correct area to approach for help for a Polio Survivor who is experiencing problems with swallowing or with speech.

Making sure that a Polio Survivor walks as well as she or he can

Trying to prevent uneven wear on the body, the skeleton in particular and strain on the muscles. Someone with a good walk is less likely to fall, less likely to suffer a fracture. This assistance may be sourced through the HSE or the Group and the choices of the Polio Survivor are respected in so far as they can.

Orthotics can be used by some to walk better. They can make up for any irregularity in the feet or shortening of a limb. A good orthotic can significantly reduce pain levels.

Customised shoes can help to improve the walk. Often they are worn with orthotics inserted to make sure that the shoes fit exactly.

Callipers or splints can help to support a weak leg. These can be simple support devices or complex ones which assist the functioning of joints. They must be custom made for each person and require patience from the orthotist and the Polio

Survivor to get them working as effectively as possible.

Mobility Scooters can give extraordinary freedom to a Polio Survivor who is experiencing fatigue while walking. They can make so many activities possible that a walking Polio Survivor could not do otherwise. Some can be disassembled quite easily and will fit easily into the boots of cars. A hoist can be fitted to a car to assist with lifting it.

Rollator can be useful for a person that needs more support when walking. Because of its seat it can be used for taking a rest while walking. A rollator can be a great help while working, in the home or at leisure.

Crutches can be useful to steady a person but do not necessarily promote good posture. Under arm, weight bearing crutches are not recommended as they can worsen nerve or skeletal problems by distributing the person's weight badly.

Walking sticks of various designs can be useful for some to maintain balance while walking. A stick should be of a type and size to suit the person.

Trollies can be useful for support and for moving pieces of equipment or household effects. Trollies can be designed for the sitting room, the workplace or the kitchen and some even have brakes on the wheels to give even greater stability.

Making sure that a Polio Survivor manages his or her mobility as best she or he can

Wheelchair A Polio Survivor knows that the option of a wheelchair is available. There may be increasing problems in balancing or decreasing strength in the leg muscles. Some may

have endured fractures of the leg bones but the advice would always be to take to the chair before fractures occur.

Lightweight manual wheelchairs are useful for short transits and can be self propelled. They can be folded to save on space or to fit in the boot of a car.

It can take too much effort for a Polio Survivor to push her or himself in the chair. The advice will always be to conserve strength and to work in stages. Some may have problems with muscles in the upper body.

Powered Chairs can give great freedom. Because this kind of chair is battery powered, moving around causes no extra pressure on muscles or joints. There are many different kinds of chair and it is important that a skilled Occupational Therapist listens to and works with the Polio Survivor to deliver a good mobility solution

Making sure that a Polio Survivor is supported in daily living

Public Health Nurse

Health care starts with the Public Health Nurse. Anyone such as a Polio Survivor with long term health support needs should try to build a good working relationship with her or his Public Health Nurse. This is not easy as nurses join and leave the service on a regular basis: but, even though it can be very frustrating, it is in your interest to try. If you have problems in this area contact the office and, with your permission, we can try to help. The Public Health Nurse may be able to help you access certain therapeutic services, such as;

Occupational Therapy

An Occupational Therapist can be a great source of advice on living with a disability. Certain occupational therapy services may be available in the community. This kind of specialist help can make a big difference to comfort and wellbeing. If you wish to discuss your requirements with Lillian you are welcome as the Post Polio Support Group may be able to help you with occupational therapy assessments also.

Physiotherapy can help painful muscles and joints. It can be used to build up muscle tone which may have been lost. *A gentle form of physiotherapy is always recommended by Physiotherapists for Polio Survivors, ask Lillian. Remember, the Blue Book is an important source of advice that you can give the Physiotherapist.* Carrying out the exercises recommended is a challenge but can produce good results. Please ask your Public Health Nurse about the availability of physiotherapy in your area. If you have problems please contact the office.

Respite Care Breaks

Respite Care Breaks are important for those dealing with disability. They can make a great difference, even for a short while, in the lives of Polio Survivors and their carers. Some HSE areas have respite facilities which can be made available. Ask your Public Health Nurse about their availability. The Department of Social Protection gives a Carer's Respite Grant in certain circumstances which can be a big help. If you have particular respite care needs please contact the office for advice.

Chiropody

Care of the feet can be very important for Polio Survivors and chiropody can relieve pain or soreness and increase comfort while walking or taking part in other activities. Please ask your Public Health Nurse about the availability of chiropody in your area. If you have problems please contact the office.

Aids and Appliances

Aids and appliances may be available through the HSE, principally to those with medical cards. Please ask your Public Health Nurse about the situation. If you have difficulties which may require aids and appliances make sure that your Annual Questionnaire is complete and sent to the office. If you have lost the form please ring or write for another form.

Other Therapies that may help Polio Survivors

There may be particular facilities available in your area for historical or other reasons. Always enquire about them;

Hydrotherapy can also help Polio Survivors particularly in reducing pain while in many cases increasing strength without causing the same fatigue on the body that exercise out of the water might cause. This involves working with a Physiotherapist in a hydrotherapy pool carrying out exercises.

Physical Therapy is somewhat different to physiotherapy and involves working deeply into the muscle

Acupuncture can give some relief to certain Polio Survivors

Massage Therapy can offer relief to some

If you require further information on these therapies please contact the office.

Making sure that a Polio Survivor manages his or her needs and benefits as best she or he can

Knowing what is what

The Citizens Information Board (www.citizensinformationboard.ie) has been given the responsibility by Government to make all citizens of the State aware of their rights and entitlements and provide a Money Advice and Budgeting Service (MABS) and some advocacy services. You can visit their excellent website (www.assistireland.ie) which contains much information to assist people with disabilities.

A Citizens Information Service is provided throughout the country and Citizens' Information Centres are invaluable in helping you work through your needs. If you have trouble having your needs addressed properly you can call the Post Polio Support Group office for assistance.

Housing

Housing is the responsibility of your County or City council. If you have housing needs you should let the council know them, in as much detail as you can, as early as possible. It can take a long time to get the suitable accommodation or the

housing transfer that you will require.

Grants can be provided by the council to adapt your home and application forms and further information can be provided by your council. If you need assistance with the process please contact the office.

From time to time the Group has funds for the provision of stairlifts. Please enquire.

Remember

- **Your social support group will help you by sharing your problems and maybe finding a few solutions**
- **Your health service starts with your general practitioner and your public health nurse**
- **The central office of the Post Polio Support Group can help you along the way, call Lillian at (01) 8898920**

Code of Behaviour

There is much concern, and rightly so, that everyone working with the Post Polio Support Group does so to the highest possible standards. We all know of organisations that did not set proper standards and have seriously failed the people that they were charged with caring for.

This is not to suggest that members and staff of the Post Polio Support Group do not have the best of intentions when working for it: our experience is very positive. We see good work being done to the highest standard every day. None the less it is important that a code of behaviour is laid down as a guide to everyone conducting the Group's business.

Points covered in the Code

- While the Post Polio Support Group is member based it assists all Polio Survivors in Ireland.
- Polio Survivors are respected as independent, significant people who make their own decisions. They bring their own values into consideration and they understand and agree to any action taken. Privacy is respected and confidentiality of information is assured.
- All who are working for the Group undergo training to improve what they do and how they do it. They try not to overdo things and burn themselves out. They try to be trustworthy at all times and seek help for Polio Survivors. Any Polio Survivor can be sure that he or she will be dealt with fairly and openly by all members and staff.

- All make sure that they and other members follow the code and do not use the Group for personal gain

The full text of the Code of Behaviour is attached. At some stage you may be asked to sign the Code of Behaviour to show that you are bound by it.

Garda clearance

Because of criminal actions against children and vulnerable adults within some organisations and institutions over many years it is increasingly common for organisations to ask the Gardaí to check their records to ensure that people with an inappropriate past are not put in a position where they are working with potentially vulnerable adults. The Group has started to be part of this process.

All members of the Post Polio Support Group must be older than eighteen years so child protection does not become an issue. You may be asked to undergo this clearance at some stage in the future. This will be done following full consultation and only with your full agreement. Any matters concerning Garda clearance are treated as highly confidential at all times.

Code of Behaviour towards those affected by the Late Effects of Polio or Post Polio Syndrome

The Post Polio Support Group (PPSG) was established in 1993, and incorporated in 1999, with the aim of providing aid, support and advice to those who had experienced paralytic Poliomyelitis at some point in the past and who were now experiencing Late Effects of Polio or who had been diagnosed with Post Polio Syndrome. PPSG has a member base but will and does provide advice and information to all who have a need. Members or any Polio Survivor may apply for and be granted a range of services such as aids & appliances, respite care and physiotherapy, etc. The PPSG is a registered charity and is non profit making, it relies on grants from both public and private bodies as well as fund raising activities to achieve its stated goal.

The Board of Directors of the Post Polio Support Group, members of its Committees, individual Directors, all members carrying out voluntary work and Group Employees are bound by a code of behaviour in the way that they interact with themselves and the membership of the Group. These are as follows: -

The Board of Directors of the Post Polio Support Group, members of its Committees, individual Directors, all members carrying out voluntary work and Group Employees treat Polio Survivors as persons of intrinsic worth with a right to determine their own priorities, entitled to respect and dignity

and to due regard for their moral and cultural values. At all times they take care not to intrude inappropriately on Polio Survivors' privacy and treat as confidential all information obtained in the course of their interactions. As far as possible, they ensure that each Polio Survivor understands and consents to whatever action they propose to take on her or his behalf.

The Board of Directors of the Post Polio Support Group, members of Committees, individual Directors, all members carrying out voluntary work and Group Employees monitor and develop their skills and ethical awareness on an ongoing basis. They recognize that their expertise and capacity for work are limited, and they take care not to exceed organisational norms or personal limits. In all Group activities they act in a trustworthy and reputable manner towards Polio Survivors and the community. They refer Polio Survivors to colleagues and professionals, as appropriate, to ensure they receive the best available service. They treat others in a fair, open and straightforward manner, honour commitments, and act to clarify any confusion about their role or responsibilities. They give reasons for their decisions and restrict information only when the wider interests of Polio Survivors as a group or individuals clearly demand respect for confidential interactions. They deal appropriately with personal conflicts of interest and take action against harmful or unethical behaviour in colleagues.

The Board of Directors of the Post Polio Support Group, members of Committees, individual Directors, all members carrying out voluntary work and Group employees do not use any interaction or relationship to exploit Polio Survivors in

order to gain financial or other benefits for themselves, their family or their friends. In carrying out business, including making appointments, awarding contracts, or recommending individuals for rewards and benefits, they make choices on merit. They do not place themselves under any financial or other obligation to outside individuals or organisations that might seek to influence them in the conduct of the work of the Group. They declare any private interests relating to their duties and take steps to resolve any conflicts arising in a way that protects the interest of Polio Survivors and that of the Post Polio Support Group.