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## HOW SELF ASSESSMENT CAN HELP YOU OBTAIN BETTER CARE FROM HEALTH PROFESSIONALS

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The most reported problem to our Network, not only from the U.K., but from around the world, is that the assessment that has taken place did not find evidence of the symptoms / level of symptoms being reported.

Polio Survivors often spend months, sometimes years, putting off going to a doctor to find out why they are experiencing pain, fatigue and functional decline. To then be told that there is nothing or little wrong with them causes considerable stress. Each negative appointment causes frustration, anger, and more stress that makes our medical condition worse.

Again and again, through lack of knowledge about polio, they tell us that they had what must have been a mild case of polio because they recovered so well and managed so much in their lives. Regardless of level of recovery they are so proud of their achievements. Then comes the but ... But, after a fall, an operation, an accident, a period of huge stress, something changed because from then on the harder they pushed the worse they got. Their lives are changing so much why are they having such a hard time getting medical help?

So why is this happening? We have highlighted eight possible reasons that we believe should be taken into consideration.

1. Not enough facts about Polio and its late effects are being taught in Medical Schools.
2. Interpretation of facts in medical articles.
3. Diagnoses were made using test results, physical examination and clinical observation of the weakest part of the body.
4. The extent of recovery from Polio is often not realized.
5. There are no tests for PPS. It is a diagnosis of exclusion.
6. The way we present our symptoms.
7. The way questions are asked, and the way we answer.
8. Manual Muscle Testing – validity and reliability.

We will then show how self assessment can provide us with more information so that we can answer questions more accurately and ensure that the picture in the health professionals mind matches ours.

We do ourselves no favors when asked, "Can you get up a flight of stairs?" In just saying "Yes", without adding, "but I go up one step at a time pulling myself up each stair with my arms, and for the last year or so have had to stop halfway and rest, but five years ago I was able to walk up and down normally and carry items."

Polio survivors are notorious for being strong willed, determined and not requiring help to do even quite heavy tasks. Unfortunately we are also highly skilled in not 'seeing' or wanting to 'see' that we now need some help, human and/or aids and assistive devices. We

expected that we might have to change the way we lived our lives when we got old – about 90 – but not in our 40's, 50's and 60's.

Polio survivors have a variety of muscle weaknesses in a variety of areas. There is no set pattern – a nightmare for health professionals. We will demonstrate a few of the changes that we have noticed in how we go about our lives. If the way you do an action of daily living has changed in the last few years then there has to be a reason or a number of reasons for this.

We know that making notes is a good idea so we don't forget anything, but arriving with pages of them and articles off the internet is more likely to set up a barrier than be helpful.

Appointment times are limited – there will probably not be time to discuss more than a couple of issues. To help you remember dates and medical facts it is an excellent idea to make up a large file on yourself containing anything you consider relevant, including newspaper items, certificates, a couple of photographs, covering:

1. Medical History
2. Work History
3. Physical Ability before current problems (include sports, exercise, hobbies, crafts, housework, etc).
4. Problems with diagnosis, assessment, treatment, employer's understanding of your new problem, welfare applications, etc.
5. Current problems.

We can be better prepared if we write notes on what we want to discuss at the appointment. We can look at the file and take out the relevant information. Now look at your notes again as if you were the health professional at this appointment. If you were doing the report at the end of this appointment, what facts would you write down.

Health professionals have a variety of ways of running their appointments and we cannot dictate how the appointment will go. We can, however, set the scene with a "Good morning, Dr. X, thank you for seeing me about my ....." "I have made a few notes so that I don't forget anything and thought you might like a copy for your records."

Remember the health professional is seeing you as you are now, they do not know what you were capable of five, ten, twenty or more years ago. They may think Polio, and go back to the short lecture they were given at College and assume you have been as you are now since your polio.

What is important is the change in how you do actions of daily living. Why have you changed the way you do this action?

As an aide to writing your own report we provide a three columned sheet of actions of daily living. (See page further in newsletter.) We appreciate there is little room in each block to write down more than a few words. You can either write up the information on a separate sheet of paper, making short notes that will fit, or use this as a basis for your own chart. IF you can show a series of changes for some actions, then do a chart just for them with added columns. Then grade them, starting with the action that shows the highest level of change. The two or three actions that show the biggest change are the ones to demonstrate.

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