HEALTH: FIGHTING AND SURVIVING ALL OVER AGAIN: PATRICIA ROCK'S CHILDHOOD POLIO RETURNED IN AN UNEXPECTED WAY, WRITES THOMAS MOORE

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Had Patricia Rock been properly diagnosed when she tried to stand on her crutches again after a spell in hospital, she might still be walking. Instead she has spent more than 10 years in a wheelchair, battling against immense fatigue, muscle weakness and pain in her back.

Ms Rock is a polio survivor. The virus left her with paralysed legs at the age of two. With the help of callipers and crutches, she enjoyed 30 years of upright activity, but 12 years ago her polio returned in an unexpected way. Ms Rock is one of a number of polio survivors to develop a newly recognised syndrome called 'late effects of polio', which can appear 30 or 40 years after the original attack. Doctors now believe that in about a third of polio survivors, muscles eventually become too weak to support limbs; in some more serious cases, breathing and swallowing can become an effort. Other survivors may experience fatigue only.

Ms Rock had packed her life with activity. She worked full-time as a welfare officer for a disability organisation, went on archaeological digs and excelled at wheelchair basketball. She won a number of Commonwealth paraplegic swimming medals in backstroke.

'I was a go-getter. Polio became less and less of an issue as I grew older and realised I could do most of the things able-bodied people could. I didn't have a progressive disability and, unlike some polio survivors, I didn't have any respiratory difficulties,' she says.

Her life changed when she was forced to come off her crutches when she developed tennis elbow. Because of her reliance on her arms, she was admitted to hospital for intensive physiotherapy and expected to leave after a week with her elbow healed and her crutches back under her arms.

It was not to be. 'Once they had got my arm working, I stood up on my crutches, as usual - and passed out. I had incredible back pain, which I had never had before.' Even now her doctors are unclear as to why the first hospital spell precipitated the weakness of her back muscles. They suspect that the inactivity caused by the unrelated tennis elbow accelerated a process that she would otherwise have experienced gradually.

Two mistakes were made. First, Ms Rock was given a potent analgesic for the back pain, but everyone forgot that she should have received a reduced dose because of her polio, which had left her with poor circulation. As a result she could not clear the drug from her body in the normal way. The overdose sent her chest and back muscles into spasms, she had difficulty breathing and her vision deteriorated.

Ms Rock spent the next three months in hospital. Her back was so weak and painful she could not even sit up. Doctors could find nothing wrong with her, and physiotherapists thought she was malingering.

The second mistake was to make every effort to get Ms Rock back on her feet. Ten years on, the emphasis is on resting the overused and exhausted muscles. 'It is very frightening not being taken seriously by the medical profession. My spine was packing up 40 years early and nobody would listen to me,' she says.

Ms Rock was finally seen by a consultant who specialised in curvature of the spine. He saw from her X-rays that she had a double 'S' bend in her spine. Immediately she was given a corset to support her back that allowed her to sit up - and she was told to stay with her wheelchair. Had she tried to stand much longer, she would have broken her back, the consultant said.

All this pain and difficulty had made Ms Rock suspect that her orthopaedic problems and muscle fatigue might be linked to her childhood polio, but her theories attracted no support from her doctors. Then Ms Rock heard about a conference in St Louis, Missouri, devoted to 'the late effects of polio'. She booked a flight, and it was a decision that changed her life.

During three days she sought advice from dozens of specialists and fellow polio survivors. They confirmed that her back muscles, damaged by the polio virus, had begun to wear out, and without muscular support her back had collapsed, causing the double curves. She was told to slow down, take plenty of rest and gradually build up her muscles. If she ignored the advice, she risked permanent damage to her back. 'At last I knew what was happening to me and that there were other people experiencing exactly what I was. I couldn't sleep because I was on such a high,' she remembers.

Ms Rock returned to the UK and began to put her life back on the rails. At about this time a handful of British specialists were starting to think that there might be problems, and a rehabilitation unit was set up at the Royal National Orthopaedic Hospital at Stanmore, London. The Stanmore unit has developed a reputation for looking after every aspect of post-polio management. Counsellors and social workers are on hand to help patients to come to terms with their post-polio diagnosis.

Dr Joseph Cowan, director of the unit, estimates that around a third of the 'tens of thousands' of people affected by polio in the post-war epidemics will experience late effects to some degree. Many have yet to approach their GPs.

Doctors have generally been slow to recognise the link between the musculoskeletal symptoms and polio. Many polio survivors who approach their GPs are told their symptoms are simply due to ageing. Dr Cowan says this is rarely the case. If there are no signs of thyroid problems or anaemia, doctors should refer for a full orthopaedic and respiratory assessment. 'GPs need to be aware of this problem. They are patients' first port of call. Post-polio must be included in the diagnosis of patients who present with fatigue.'

Dr John Shneerson, consultant chest physician at Papworth Hospital, Cambridgeshire, agrees. He warns that new musculoskeletal symptoms should never be ignored in polio survivors. 'Not all polio survivors will experience late effects, and in others it will be mild. But if anyone notices any changes, they should seek advice,' he says.

In most cases it seems that the muscles originally affected by polio are those which later begin to weaken. People who were kept alive in iron lungs during the original infection because the virus had weakened their respiratory muscles may have difficulty breathing in later life. They suffer interrupted sleep because of their laboured breathing and are consequently exhausted during the day.

Dr Shneerson says a ventilator can cure the problem. But he adds that people with breathing difficulties must be carefully assessed to find the most suitable device. Mechanical support can also help. The centres with the most experience of assessments are Papworth, and St Thomas's and the Royal Brompton hospitals in London.

Dr Geoffrey Spencer, consultant in charge of the respiratory unit at St Thomas's, has seen around 600 polio survivors at his clinic. He says doctors are beginning to understand what causes the muscular degeneration. During acute polio, the virus attacks and destroys many of the nerves controlling muscle fibres. Without nerves, the fibres cannot work; and without work, they die. Polio survivors have to use their full muscle strength to do the simplest of daily tasks, and the overused muscle fibres begin to wear out.

Dr Spencer says it is crucial to pick up the loss in muscle strength early and then identify the activity that is causing the overuse. Simple lifestyle changes take the pressure off the muscle and after a while light activities become possible once again. Procrastination can lead to chronic strain and cause irreversible loss in muscle function. 'There's no point just saying take it easy, but we can usually find the source of the trouble,' Dr Spencer says.

Ms Rock adopted a lifestyle that was gentler on her muscles, and until she damaged her shoulder in a recent accident, she was nearly back to full strength. She was able to discard the back support corset a year ago and can sit unaided in her chair. She works part- time, is researching a PhD and sits on various disability committees. She has come to terms with the fact that her back muscles will never be strong enough for her to stand. 'I will never walk again, but I don't have the muscle weakness any more. I get episodes of back pain every few years, but that is treatable.

'Fortunately, I had the money to go to another country to find out what was wrong with me. But if we had had post-polio clinics in this country at the time, I might have been diagnosed at an earlier stage and my back might not have collapsed. I only hope other people take note.'