

GOOD HEALTH / CASE BOOK

THE polio epidemics of the Forties and Fifties are distant memories since the introduction of mass vaccination against the disease. Many who did get it fought to regain their mobility and, eventually, came to believe they had rid themselves of the virus. There are at least 50,000 British polio survivors — including Lord Snowdon and singer Ian Dury — but many are now finding that polio has come back to haunt them. Peter Jay, who is married with three children and runs his own picture-framing business near Kings Lynn, Norfolk, lives with post-polio syndrome every day. Having thrown away his callipers when he was 14, at 52 he faces a future in a wheelchair. Here, he talks to JACKIE SPRECKLEY.

ABOUT ten years ago I realised that something was seriously wrong. I was at work when suddenly my leg gave way and I fell into a stack of glass.

I'd already been feeling increasingly exhausted and had pain in my legs, lower back and shoulders, but this fall frightened the life out of me.

My doctor referred me to a rehabilitation specialist, who said quite bluntly that my muscles, joints and ligaments were over-used and that I'd have to take it easier, even go back to wearing callipers. Otherwise, she warned, I'd soon be in a wheelchair.

I was devastated. Like most of us who got polio, I was always told: 'Get up and go! Use it or lose it!' That made me a fighter. So to be told, all those years later, that the physical gains I had won were now slipping away was hard to face. I'd had no idea at all about post-polio syndrome.

I was three when I caught polio in 1949. I ended up paralysed from the neck down, lying flat on my back in a cast for nearly 18 months. There were 11 children in the ward, and of the four who didn't make a complete recovery, I got off the lightest. Even so, my left leg and the lower half of my right were seriously weakened.

Gradually I began to recover until I was able to stand in a walk-frame. But even after being discharged, I still faced a night-time year of painful physiotherapy and hydrotherapy three times a week.

I wore callipers and heavy surgical boots, and had to sleep in splints. My legs would get twisted in bed because my body moved but my legs didn't. I'd have to call out for Dad to unravel them.

When I finally got to primary school, after missing the first year, I had one of those big old-fashioned wheelchairs. The older boys used to push me to lunch, which was in the village hall.

But after so long in hospital, I loved being back home. I was nursed so well by Mum, and my younger sister was my legs. I'd sit in front of the fire and she'd run around getting my toys, anticipating my every want.

She actually taught me how to ride a bike, when I was about ten.

DIAGNOSIS

DR JOHN SHINEERSON, Director of Respiratory Support at Papworth Hospital, Cambridge, says:

WITH post-polio syndrome, the nerve fibres which regrew after the acute illness are dying back prematurely. The reason for this appears to be because they grew in an unusual way as the patient

covered all those years ago, and had to supply a much larger number of muscle fibres than normal as they did the work of those destroyed by the polio virus. So every time a nerve

I thought I'd beaten polio ... but now I face the rest of my life in a wheelchair

It took all the summer holidays. I still had callipers but managed to ride with one pedal and a fixed wheel. After that I never looked back. I could roam the fields and woods around our village — the freedom was wonderful. Until then I'd either been pushed in the wheelchair or carried on Dad's shoulders.

Even so, I wasn't allowed out on wet days because you only got one pair of surgical boots which had to last a year. Mum would have tears in her eyes as she stopped me from playing outside, but we couldn't risk ruining my shoes.

Eventually she bought me some old-fashioned galoshes. They were far too big and would trip me up, but at least I could go out and feel like a normal boy.

THEN the operations started. By the time I was 12, we worked out that I'd been in hospital for just over one-third of my life.

I found secondary school absolutely exhausting — all that walking between classes. I was late to every lesson, no matter how I hurried. It was all terribly stressful.

So my parents looked for a smaller school. Unfortunately the limit in those days for school transport was three miles and we

impulse travels down the nerve fibres, they have to do five or ten times as much work and supply a bigger group of fibres. After 35 or 40 years they just wear out and die. This causes new weakness and pain, and if the breathing muscles are affected, patients can't breathe properly when they are asleep.

About 60pc of polio survivors run in to these problems, but there is a lot patients can do to help themselves, in particular building in rest periods during the day to cope with the fatigue and weakness.

lived just under three miles away from this new school. So I missed a further term while my parents batted to get transport for me.

Eventually Dad wrote to Rab Butler, our local MP, and within days a taxi was laid on — a beautiful Lagonda owned by the man who ran the local bus company. I can remember going to school down the old A11. That was the first time I'd ever travelled at 100 mph!

My legs slowly got stronger until I was 14 and could throw away my callipers and boots. That was great, because now I could wear baseball boots and jeans just like other teen-agers. My strong arms, right leg and back compensated for my left leg. From then on, apart from being unable to run, polio wasn't an issue.

I left school at 15, trained as a hairdresser and opened my first shop in Stansted, Kent, when I was 17. I had no worries about being on my feet all day but Mum bought me a barber's chair with a swivel seat on the back for when we were busy and I was tired.

I married Serena when she was 18 and I was 23, and bought our first house, a beautiful cottage with a 100ft lawn. The only problem was finding a motor mower that would go slow enough for me.

Then the three-day week was introduced. We sold the barber's shop and I got a gamekeeper's job on a magnificent estate in Herefordshire. I worked 18 hours a day rearing pheasants, partridges and mallard. I was in my 30s, as fit and strong as I've ever been.

Part of it, I'm sure, was that I wanted to prove I could do everything, despite having had polio. In the early days, polio patients were set near impossible standards of performance during their treatment, and I think most of us have maintained that attitude ever since. We didn't consider ourselves disabled. If you survived you got better — it was as simple as that.

Having got gamekeeping out of my system, Serena and I decided to settle down and start a family. For the next 22 years we worked hard to build up a picture-framing business in Sutton Bridge, near



Polio victim Peter Jay: He now faces a daily battle to stay mobile

Kings Lynn, Norfolk, and raised our three girls, Clare, 23, Annie, 19, and Abigail, 17. The business went well, we paid off our mortgage and built our own bungalow.

It was a few years later that I started to get problems — severe pain, overwhelming fatigue and weakness. I feared the worst, because my dad and grandad had both died young of cancer. The last thing I expected to be told was that my problems were connected with polio.

SUCH a diagnosis made me very depressed. I was in my early 40s and the doctors were telling me that I had to take early retirement. It took me a long time to come to terms with that.

Then two years ago I started choking at night because I could not breathe. It seems my throat muscles and some chest wall muscles have got weaker. Now I attain only the lightest level of sleep, which leaves me exhausted.

I also have to eat differently. I chew slowly and swallow with my

chin tucked in. I can't eat floating solids, such as cornflakes in milk, because they make me choke. This could be life-threatening, so I really have to take care.

I have two full-length callipers and can't walk far. When I was first diagnosed with post-polio syndrome, I could still walk five or six miles. Now I can't walk 100 yards.

I've got a manual wheelchair but find it difficult to use because I get a lot of pain in my shoulders. I've bought a second-hand power one and it probably won't be long before I have to use it all the time. But I look at it this way: a wheelchair will give me mobility and allow me to get out and about — just like my bike did when I was ten.

I thought I'd beaten polio once and for all when I was a child, and now I'm having to fight all over again. Whatever I do, I have to give it my all. That's what being a polio survivor is all about.

MORE information, including a video called Living With The Late Effects Of Polio (£7.50 inc p&p), is available from The British Polio Fellowship, Eagle Office Centre, The Runway, South Ruislip, Middlesex HA4 6SE, tel. 0181-842 1898.