

Fighting for people affected by polio's second blow

BEING in an iron lung is like lying in a coffin with your head sticking out. Forty-two years ago, when I was first placed in the iron lung, I was so terrified one of the nurses would open the lung, the pains and aches were secondary. Pain is secondary to your need to take your next breath.

When the iron lung was opened, you could not breathe. A team of nurses would come to change your sheets or pyjamas so that it would be done very efficiently and fast. They would open the iron lung and you would be lying there going blue, fully conscious, but struggling to breathe. The nurses would be watching your colour so they would know when you needed to get back inside the iron lung, fast.

I was diagnosed with polio in 1958 at the age of 15, which is unusual because 90 per cent of polios were affected as younger children.

As a child I was a ruffian. My mother used to say if you were looking for me, you'd find me at the top of the nearest high tree. When I got polio, it caused quite a scene because I was one of 360-odd boys in Clongowes school in Co Kildare, and the diagnosis raised the possibility there was a carrier in the school and others might have been infected. In those days students very seldom got out — once or twice a term if you were lucky.

About two or three weeks before I got polio, I had been at a rugby

The polio epidemics of the 1940s and 1950s affected an estimated 9,000 people in the State, most of them children. Many recovered to live normal lives, but sadly, in their 40s and 50s, about half of polio survivors are developing post-polio syndrome, a debilitating neurological condition. **Jim Costello (56)**, chairman of the Post-Polio Support Group, is trying to help

international between Ireland and Scotland. The doctors reckoned I got the polio from a carrier in the crowd in the main terrace at Lansdowne Road. No one else at Clongowes was affected. My two great interests are rugby and racing and I still go to Lansdowne Road with my lifelong school-friend Phil Mooney, who has spent his life in youth rugby training.

The polio paralysed me from the waist up, attacking my lungs and making it impossible to breathe. I spent nearly nine months in an iron lung without getting out of it in Cherry Orchard hospital. The process of recovery was very gradual. I had three years of treatment in hospital — first at Cherry Orchard, then at the world-renowned Nuffield Orthopaedic Centre in Oxford, England.

I spent most of those three hospital years in a wheelchair and gradually learned to walk during several years as an outpatient at the Central Remedial Clinic in

Dublin. You recover to a certain point, and then stop.

Polio is very indiscriminate in the way that it attacks. Some people are affected in one part of the body, then fully recover. Others are affected in the whole of their body, then only partially recover in the upper half, leaving them in a wheelchair which is the classic image of polio. I'm one of the small percentage of "upside down polios" because I was paralysed in the upper body. I can walk normally, but I must wear a brace to support my back and my arms are paralysed.

I have a very slight amount of movement in my left hand. You have to do the most you can with what you have.

In my 20s I worked in the family business, a clothing shop, O'Reilly's, in Earl Street. When that was sold I was in the restaurant trade for a while, then dabbed in a small way in the property business. I still spend 12-14 hours a day,

about three days a week, at Cherry Orchard in an iron lung, which I have had specially adapted so I can use the telephone, the TV, the lights and the radio — all through controls at my feet, one of which operates a telephone headset, which comes down on an electric arm when I need to use it. The entire staff has been most helpful to me over many, many years, getting me through a number of critical illnesses.

The rest of the week I live in my news in Ballsbridge, which I share with my partner of 15 years, Deila. At home, I use a Nippy portable-respirator for 12-14 hours a day.

My personal assistant, Trish, is like a pair of arms for me. She dresses me, feeds me and does all the normal things for me that one would normally do with one's arms — dressing, feeding, scratching my nose and even going to the toilet. She carries my briefcase around and helps me with my paperwork.

When I'm lying in the iron lung in Cherry Orchard at night, sometimes my thoughts are racing and I cannot sleep. I have a device which enables me to use the telephone so I can stay in touch with the outside world. I cannot write so when I have an idea in the middle of the night at Cherry Orchard, I leave it on the answering machine in the office of the post-polio support group in Carmichael House.

For the past year, with the help of a dedicated committee, I and



Jean Bradley, secretary of the Post-Polio Support Group, have been organising next weekend's conference, Polio in the 21st Century. Since 1994 I have worked on a voluntary basis as chairman of the Post-Polio Support Group. Since I cannot use my hands, I use a voice-activated laptop computer to write, correspond through email and surf the Internet.

According to international research, some 40-60 per cent of polio survivors develop post-polio syndrome 20-40 years after surviving the initial epidemic. They have led useful, independent lives, often with very little contact with the medical profession. Developing the syndrome is a hard blow to someone who is already disabled

in that it causes a second disability through one or all of the following symptoms: extreme fatigue; pain in muscles and joints; decline in ability to carry out customary daily activities such as walking; swallowing and respiratory difficulties, which may present as problems relating to sleep. Diagnosis in people who believed they had recovered may be difficult, because many polio survivors were encouraged to forget they ever had the disease. Polio is not on their current medical records so when they go to their GPs complaining of symptoms, neither they nor their doctors relate the symptoms to the polio they had as children. We commissioned a profes-

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Photograph: Pat
Langan

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sional survey which found many
post-polio people were in urgent
need of things such as bathroom
adaptations, electric wheelchairs
and many other aids and appli-
ances. We have many polio survi-
vors who have worked all their
lives but who have earned rela-
tively low incomes — but just
above the limit for a medical card.
This gives them very little hope
because they cannot afford to pay
for the appliances, aids and phys-
iotherapy they need. We've been
fighting for medical cards for
polio survivors for many years
without much success.

Another problem is that within
the community-care system there
is a lack of occupational therapists
and physiotherapists, so polio sur-

vivors may have to wait a year or
two just to be assessed for things
such as bathroom adaptations.
I'm lucky that I am not affected
by post-polio syndrome at the mo-
ment, and that I have the in-
dependent financial means to
have a part-time carer and the
aids and appliances I depend on. I
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● The medical conference, *Polio
in the 21st Century: The Late Ef-
fects of Polio and Post-Polio Syn-
drome*, will be held on Friday and
Saturday at the Green Isle Hotel,
Dublin. Further information: tel
(01) 873-0338