

The RESPONAUT

A QUARTERLY BY, FOR AND ABOUT PEOPLE WITH
RESIDUAL RESPIRATORY PARALYSIS

Vol. 1: No. 2

March, 1964

Keeping in Touch

A HAPPY EASTER TO YOU ALL

The truth of our position was nailed to the Cross nearly 2000 years ago. Alleluia!

Your many letters have been most encouraging. We all know we are going to have an even harder struggle once we undertake writing to M.Ps and other influential people. The fact that we are all doing this together, and have this news-letter in which to report progress, will give us a feeling of unity and strength which will help us in the struggle.

Spring is the time for striving, when new things push to find their place in the sun.

Copies of our news-letter are sent to the Minister of Health and many M.Ps, polio organisations, editors of interested papers, and friends of our cause - as well as to Responauts. If you know of any other person or organisation needing copies, just let us know. We do not have many spare copies of the first issue left.

Copies have crossed the sea to Australia and America. I have suggested to our friends in the editorial offices of the Toomey J. Gazette that we form an Association of International Responauts - A.I.R. for short. Perhaps we can combine in the A.I.R. year-book which we hope to produce in December.

There is so much news of post-polio activity and enterprise that I am inclined to believe that we could find enough books, paintings, equipment, articles etc., by, for and about people with respiratory paralysis to hold a mobile International Exhibition.

It was my firm conviction that this news-letter should never embarrass its readers by asking for money. I have been embarrassed by generous gifts towards the expenses of production and postage; but I would like to say that I have stopped being so possessive about this publication, and am extremely grateful for all gifts received. For this relief, much thanks.

Our theme for general discussion in the next Responaut will be Housing and Help. I need your letters urgently, as many Responauts have to return to hospital when their help position becomes impossible. Education and holidays - our subjects for the first two issues of the Responaut - were chosen as having a potential use for everyone with respiratory polio, in or out of hospital. In going on to the subject of Housing and Help, we are not forgetting those in hospital. On the contrary, we see nothing but hospitalisation is possible unless we can establish a realistic assessment of our House and Help needs soon.

While some people will never be able to leave hospital, I have been deeply distressed by the letters from people who have had to return to hospital merely because they do not get the help they need. Money does not entirely solve this problem. We need all the Welfare officers and doctors concerned to help us find the right kind of help.

Editor

POINTS FROM THE POST

Congratulations and sympathy from Members of Parliament on our lively publication.

Correction from ACE, whose publication is called Where - not Which, as stated in our last issue. Promise of help for all Responauts.

Education: A comment from a Responaut who prefers to remain anonymous.

'The local Education Officer was extremely helpful, and provided'

me with a daily tutor for a year, and later paid the fees for a correspondence course in free-lance journalism and short-story writing. This course proved one thing: my inability to write. This discovery in itself served a useful purpose, as I found writing a most exhausting and exacting profession.'

(I find the conclusion premature, as this Responaut wrote me the most lucid, beautifully set-out, long letter - with problems and solutions. I could do with many more like her! - Ed.)

This same Responaut has a valuable contribution to make on holidays:

Family Holidays: Just in case anyone doesn't know, there are the B.P.F. Lantern Hotels at Worthing in Sussex and Lytham St. Annes near Blackpool, as well as the Respiratory Polio Caravans at Portsmouth. The Worthing Lantern has not a suitable room for a tank respirator, but the Northern Lantern has. It is possible that the local branch of the B.P.F. may help with the expense of a holiday, and the British Railways are always extremely willing to provide a suitable brake van at no more expense than a normal fare. I personally prefer not to have a holiday at a special hotel for disabled people, as for some inexplicable reason one feels less conspicuous and self-conscious surrounded by able-bodied friends.

Co-ordination: The support from co-Responauts is magnificent. Keep it up - and we will have a publication as lively as any I know. I am deliberately keeping the outlook as positive and cheerful as possible, for I have had so many letters with urgent and depressing problems - such as:

The man who has been back in hospital for some time now following the break-up of his home. He wrote that he had lost a lot of heart during this past year ...

The man who returned to hospital last year after six years at home ..

These people need our urgent support. Hospitalisation is not enough. If £40 to £80 a week each can be spent to keep such people in hospital after a family break-up, then surely something approaching this figure should be available to keep whole families intact, and to prevent this appalling misery. Residual respiratory paralysis is more than enough for any one family. Thank God there are families who want to look after the severely disabled members of their families. The Government should give more power to their elbows by providing some ready cash. The

money alone will not solve the problem. I am sure that finding the right people to help with this important aspect of care is not beyond the wit and will of the officers concerned with Responaut welfare.

Other Points in the Post were made by co-Responauts (including the Toomey J. editors), able-bodied friends, and interested organisations - all wishing us well.

COMPETITION

A pound for the best collective noun for Responauts. E.g: A Dilemma of Doctors. A Gagggle of Geese.

A of Responauts

HOLIDAYS AND HOBBIES

For Responauts, personal preference must be sacrificed to physical limitation. If your family is keen on camping and caravans, and they do not mind all the extra work of looking after you and themselves, then obviously camping and caravanning are a possibility for full family enjoyment - especially with the advantage of being able to have meals when and how you like.

We spent an experimental week in Dr. Sandiford's wonderfully equipped caravans at Portsmouth. The following year we decided where we would like to go, advertised for bungalows and a nurse, and our own M.O.H. wrote to the M.O.H. of the town concerned. We were extremely fortunate. A sympathetic hotel manager invited us to stay with him, putting the respirator over the ballroom so that the noise would not worry his other guests. Hotel accommodation is extremely expensive for us in our straitened circumstances, so last year we stayed with friends: but we are hoping to go back to the same hotel this year, for it does give us the nearest thing we can ever hope to have for a complete rest. The joy of being a family together, and the bliss of not having to worry about the shopping, cooking and budgeting - as well as the feeling of normality - makes it a real tonic for us all.

Our earlier arrangements of separate holidays for myself, my husband and two young sons were not a success for us: but other families might have found them so.

Security, privacy and hygiene are our three major requirements for an enjoyable holiday. Other families will have other ideas.

For information about the caravans, write to: Miss Nagel, National Welfare Officer, British Polio Fellowship, Clifton House, 83-117 Euston Road, London, N.W.1.

As with holidays, so with hobbies. Personal preference has to be sacrificed to physical limitations. Recently I realised I had forgotten how to play, and that I expend all my waking hours working. I am not a martyr to work - anything but! I enjoy work, and am glad to be able to do it. My work of holding my home together consists of knitting together the patchwork of effort by other people's hands to meet my family's requirements at the right time. That I have to work to earn some of the money to pay for the employment of some of those hands has been definitely therapeutic - therapeutic agony.

With more and more remote control devices evolving, more possibilities of recreational hobbies will present themselves. With more and better portable respirators, outings and explorations will widen our horizons.

I think I have found that all Responauts are deserving of congratulations in their lack of complaint about not being able to enjoy the physically active recreations - especially those of us who are keen swimmers, dancers, and sportsmen of every description.

Music, chess, collecting and observing, painting and writing, reading and designing, radio and television, are enjoyed in various degrees by most of us, thanks to the fact that we are still able, mentally and spiritually, and that we were fortunate enough to inhabit a well co-ordinated body before the polio virus attacked us.

There is no profit in discussing whether it is better or worse to have inhabited an able body. I know of no Responaut who is not grateful for the able years.

PATIENT PENETRATION

(The following article, by Ann Armstrong, is reprinted from The Medical Officer, by courtesy of the Editor.)

March, 1962, saw the publication of my article 'The Cost of Polio' in The Guardian.

The support and encouragement in the letters which poured through our letter-box during the next few weeks showed that there was great sympathy and empathy existing for severely disabled people which needed to find expression in positive action.

My own cri-de-coeur brought several letters from other people in a similar position. My article was reproduced in The Medical Officer, and two BBC broadcasts subsequently followed. At the end of the broadcast the commentator said that Ann Armstrong was campaigning. The words came as a bit of a shock to me, but as they echoed round my head I thought: 'Why not?'

I had to do something, not only for my own family's health, but also because of the predicament of the other people with severe residual paralysis from respiratory polio. Apart from the people who wanted to stay at home, there were others who had not managed to set up homes, but had spent years in hospital since being pinned down by paralysis.

There is no national register of the totally disabled people, only a register of disabled people who are available for work. I am compiling one of the totally disabled.

The 'Thalidomide' babies caused much soul searching, and it was painful to hear how many people were advocating 'putting them down'. The uncomfortable feeling that it was thought we would be better off dead permeated our lives.

This concept of ending unendurable suffering is a humane one. In order to take any positive action in a campaign, I had to try to define scientifically the meaning of life and death. Insoluble problem!

I decided that I must study normal, or presumably normal, people to find out what they thought necessary to life in order to replace the diminished dimensions of the severely paralysed.

The dimension of existence must be established before the dimension of experience can be added. Experience has further subsections - and as I tabulated them, keeping them to the necessary minimum, I realised just how much we had all lost when we were paralysed, and our abilities and physical potentials were locked in a deep freeze, with our aspirations and destinies seeking alternative expression.

This part of my research was most painful to me, for I had refused to see myself as a paralysed person, the idea was so inconceivable. I had not identified myself with my paralysed contemporaries. It is exceedingly difficult to re-orientate yourself in a disabled body when you have spent many years as a well co-ordinated, active person: you find yourself wanting to help people as you once did.

Further along in my researches I noted that we make a physical gesture to convey our feelings. When we can no longer make these gestures the feelings are presumed to be non-existent. This is the basis of the belief that disabled people do not mind the slings and arrows of their outrageous fortunes.

As I compiled my register of disabled people, I thought sorrowfully of those of my year who had died. I speak of those of 'my year' as if suffering were some kind of qualification, and indeed I have come to believe that it is. Where you meet a person who has suffered most dreadfully you will meet a person ready to help you with your suffering: someone who has graduated in the scheme of things which we do not understand, for this work of caring for the family of the World.

Disabled people should have purpose-built homes, but they should not all be lumped together in one area unless they wish, as this can emphasise the disability. They should be sprinkled among the population in the normal ratio, giving the population a better chance of mutual benefit. Freedom is a fallacy. We all depend and contribute as members of the community from the moment we draw our first breath. Food, warmth, shelter, affection, communication, laughter, and something to do are basic necessities to us all.

My research has meant many letters to the National Fund for Research into Poliomyelitis, the Infantile Paralysis Fellowship, the Minister of Health, the Minister of Pensions, King Edward's Hospital Fund for London, and to people with residual paralysis and their friends. A fat file soon grew beside me, and I had to start making copies of all the letters because I was reading too much to be able to commit it all to memory.

Books about equipment, hospital services, charitable organisations, the international rehabilitation scene, the National Health Service Act, National Insurance and National Assistance territories, a book for health visitors, Ministry of Labour rehabilitation booklet etc.

have been consulted, but nowhere could I find any published official information about a plan for the domiciliary rehabilitation of people suffering from residual paralysis following respiratory polio.

This was new territory, and I realised that those of us who are performing the experiment of living at home with no guide-book, making our way by trial and error, are writing a new chapter in medical history. I realised that the National Health Service Act contained no arrangements for people in our predicament because in 1946 it was not medically feasible for a patient to leave hospital while still depending on a respirator. The relatives and friends of the patients all over the world have made tremendous efforts and adjustments in order to give 'respos' a chance to live at home.

In Denmark the sheer weight of numbers caused by the 1952 epidemic resulted in blocks of flats being built where responsible 'respos' could be nursed by a relative, or persons of their own choosing, who would be paid by the State. An emergency ward was built at the top of the building.

The year-long correspondence was terminated with a letter to every M.P. Our own M.P. had discussed us with the Minister of Health, who had no powers to help us, and he wrote that our position is weak because we are so few. I have found the effort more than I care to admit, and I could not have accomplished anything without the willing help of many able members of the community.

I hope that when the cry goes up in Parliament, 'Who goes home?' the answer will include all those of us who can resume living again with community care.

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