

Rosalind Chalmers

Rosalind Chalmers was born in 1923 in Selkirk, where her father was English master at the High School. When he joined the B.B.C. they moved first to Glasgow, then to Edinburgh. After attending various schools in and around Edinburgh, she joined the W.A.A.F. as a radar operator in 1942.

In 1945, she married a navigation instructor in the R.A.F. Her husband is now a public analyst in Birmingham, and they have two children, aged fourteen and seventeen. Mrs Chalmers became disabled through polio in 1950. In November 1964, she went to live at the Greenacres Cheshire Foundation Home at Sutton Coldfield, Warwickshire.

Mrs Chalmers was always interested in writing, and wrote her first story at six. She says she loves reading, archaeology, France, discussion and chipples; and dislikes arithmetic, Blackpool, cocktail parties and fish.

Victim Invicta

(Chapter 2 in Hunt, P. (ed.) 1966: Stigma: The Experience of Disability, London: Geoffrey Chapman).

POLIO CAUGHT me in 1950, an epidemic year in Birmingham, so I have been a 'Victim' for fourteen years now and really ought to have evolved an adequate working philosophy. It's odd, how the epithet 'Victim' is so often attached to people with polio: other diseases have sufferers, accidents have casualties, but we are Victims, and somehow the word has undertones other than physical: 'Victims of rape', 'Victimization at the factory', 'Victims of persecution'; these seem to contain moral

implications hardly applicable to polio. But polio is recognized as a disease of civilized countries, which have improved their hygienic conditions to the point where many germs have been eradicated, and among them the odd weak polio germ which might have immunized against more severe attack. Perhaps there is' a moral application there.

It is possible to write about physical handicap without being autobiographical, but not without being personal. The case of a man without the use of his arms is different from that of a man without the use of his legs, and the situation of the latter is preferable, unless of course he happens to be a ballet dancer or steeple-jack. However, paralysis is seldom as tidily disposed as that, and there are other factors which are almost as important.

In many ways I was a lucky Victim. I had several advantages, the most important being a good husband, an inquisitive or enquiring mind, some education and some money. My interests lay in reading and writing, not in dancing, tennis or climbing. But in other ways I was unlucky. I was a solitary, and enjoyed spending a lot of time alone. I was lazy and perhaps too fatalistic; at the same time I liked doing things, for myself and hated asking for help. I disliked crowds, and anything more gregarious than the ward of an orthopaedic hospital it would be impossible to imagine. It was rather like living out an extended version of 'Have a Go', complete with 'characters', sing-songs, and earthy if not homely fun.

The problem is one of balance. It is disastrous to be too accepting (you give up trying), equally disastrous to be too dissatisfied (you don't make the best use of what you have. It is bad to be too dependent-obviously-but as bad to be too contemptuous of help, for a little at the right time is invaluable. But this correct balance is most difficult to

achieve even when you are aware of the necessity, because the mind takes longer than the body to recover, nor indeed can it ever be said to 'be 'normal' again. For there has been nothing less than a second birth another expulsion from the womb.

It was easy to die that first time. I was a happy person, with a little girl of two and a baby of five weeks, a bit tired perhaps after his birth, but with a great deal of tether to run before the end of it was reached. Most people can stand a lot more than they believe possible, especially when their reserves of endurance are untapped. It wasn't difficult for me, with a loving family and an interest in experience (for I still hoped to be a writer) to face calamity. I expected to overcome it and continue as before. This polio, which we had feared for our children, was certainly unpleasant but only temporary. Then when I lay gasping in hospital I suddenly realized I was dying, and was at first very angry indeed. It seemed, when there was so much to see and do to be entirely the wrong moment to die. Now, of course, I'm not sure; undoubtedly it would have been neater and swifter for us all. But the moment passed, and my anger changed into a determination to survive - at any cost. And God knows the cost has been high.

The iron lung contained its foetus. Unconcerned, I lay reciting poetry, of which fortunately I knew a large amount by heart, invariably becoming confused in the order of the verses in 'Ode to a Nightingale'. Why did Keats seem so appropriate? My husband made me a reading machine with a roll of Penguin books, for not being able to read was a bad deprivation. The moments of terror came only when the respirator was opened and I found the air cold and without breath. The world inside was circumscribed; I grew accustomed to it, and outside demands were few. Those began when I was expelled for the last time and,

protesting and terrified, had to accept the bigger world again.

We had a splendid ward sister. Brisk, confident and scathing she fought like a tigress for us and with us. I had the impression that any back-sliding towards death would not be tolerated. Obediently I improved a little. It was obvious to others but not yet to me that I was not going to make a complete recovery. I was too busy being a patient.

After a year in that general hospital, and a year in an orthopaedic hospital, I went home. Things had not been static there either, of course. Both my daughter and the baby had forgotten me. My husband had been a constant tower of strength from the beginning at a cost to himself I couldn't yet appreciate. And the hardest part of the battle was in front of us.

We moved to a larger house which we could divide into two and share with my husband's parents, thus being separate but adjacent. We engaged a housekeeper who would also look after me, and a nursemaid for the children. And we had someone coming in daily to help in the house. If we hadn't been able to afford this the whole system would have broken down, or could not even have been initiated. This happened to a friend of mine at the orthopaedic hospital: her four small boys were put into (different) Homes and her husband left. She could have managed a bungalow with some help from her husband: although in a wheelchair, she had very strong back and arms and could have looked after herself and the children. Her husband did not even try: but some did try and the strain and expense defeated them.

Our main purpose was to keep home together for the children and somehow we managed it for the next twelve years; until, in fact, the day before yesterday, when with

both children at boarding-schools, me in a nursing-home, and my husband eating with his parents, we have come to a full stop. Or it could be a semi-colon; we don't know yet. And we don't know either whether it was worth it, although I must think that it was. The comparison, after all, should not be with the norm, the happy Weetabix family on television (is anyone as happy as that?), but with my friend at the orthopaedic hospital, and others who lost everything they had, not just some things. This article is supposed to deal with the problems of the Victim, so perhaps those of husband and children are not strictly relevant. But it is impossible to study one person in isolation; no man was ever less an island than a polio or other severely handicapped person. Or is it only that his dependence is made visible 'and beyond argument, obvious to the casual glance? Basically his needs are the same as anyone else's; the difficulty is, how far is he justified in pursuing them at other people's expense? It is the question of balance. again. In my husband's case he had lost his wife, but she was not conveniently dead and buried. ('Daddy has three children,' said our daughter pertinently, 'Me, Peter and Mummy.') He had an exhausting job but could not rely on peace and comfort in the evenings; on the contrary, there was generally another crisis to be resolved. He had to appear bright and confident with me, the children and the succession of housekeepers and helps. Life had become merely a matter of making-do. As for the children, they had lost their mother. Instead of being desired for themselves they were someone's job of work which had to be attended to. Oddly enough it is the small things I remember most clearly and painfully. The children having to stop watching 'Toad of Toad Hall' in the middle because the nanny was going off duty; my daughter crying at the door and not being allowed in until the housekeeper was ready. When I heard one or other of them cry in the night I would try to judge the urgency of the cry to decide whether I should

wake the housekeeper, who would not be pleased, and thus not likely to be very patient with them. But they didn't cry much; perhaps not as much as they ought to have done. I had very definite ideas about how they should be brought up, but most of those had to go by the board; plain survival took all our and everybody else's time. It afforded me a certain bleak amusement when I heard of other people's children refusing school dinners and insisting on coming home instead. That could not happen to us. Yet no one was to blame for the situation. Housekeepers and nurses needed their time off, for they had their own lives to lead: No one was actively cruel to the children; some people were very kind. But one continuing, reassuring presence was lacking, and when they were hurt I couldn't put my arms round them.

It is a mistake to imagine that in such circumstances, and having to do so many things for themselves, children will grow up more independent than others. On the contrary, they will grow up less so. Having no basic security they lack confidence and grow timid and withdrawn, clinging to what little there is to cling to. It is the secure child who leaves his home and possessions confidently, knowing that they will be there when he returns. One tends, too, to load the child with material things, out of pity for him and a sense of guilt.

In theory I was in charge of the house. I didn't need much actual nursing and was in a wheelchair all day, but I needed someone to get me up, put me to bed and take me to the lavatory. I was occasionally ill (colds are a hazard for most polios) and they had to be in bed all the time. It is extraordinarily difficult to reprimand anyone when they also lift you on and off the lavatory like a baby several times a day! In addition I had to think of the repercussions on the children. It was hard to get housekeepers in the country, and a very little might cause them

to give notice, which would mean more changes for the children. So I interfered as seldom as possible in the running of the house, and if that too was humiliating for me I considered my humiliation to be the lesser evil.

Now that I am alone it is easy to look back and see what was happening then and how certain things could have been done differently. But at the beginning I was capable only of thinking of myself, and afterwards it was a question of struggling on without thinking much at all. At least the family remained a unit, albeit a shaky one. My own feeling of guilt springs from the knowledge of having ruined three lives, whether wittingly or not, and being at last fully conscious of it. However, guilt without action is sterile, and will only cast general gloom if indulged in for too long. It won't help anyone, least of all, yourself. But what will? There are several practical steps which should be taken to help disabled people and their families. The wife should be entitled to a pension, for her incapacity is as great a catastrophe as would be that of the breadwinner, and if paralysed in an accident she could receive vast damages, as indeed could a single girl. The cause of the disability is of no relevance to the family's needs, which have to be catered for individually by the State at far greater expense if the family disintegrates.

There should be someone with up-to-date information about gadgets and equipment who would see each disabled person before he leaves hospital. This adviser should know now about bungalows and how they could be acquired, about grants, and about holiday reliefs; he should also be able to give general advice about problems, with reference to how people, similarly disabled have coped with theirs. This service could be provided by the almoner, but we never found hospital almoners to be of the slightest use. They knew nothing and could do nothing. Snippets of information were picked up here and

there, from the staff and other patients, from friends and from articles in the press. An enormous amount of worry and despair could be prevented if all this information was pooled, together with the conventional medical advice, and made available before the return home from hospital. It is only common sense to give all the practical help possible at the very start, in case some families find the whole thing too much for them before they have even begun. Going home is an even greater emotional strain than the initial adjustment to disability.

This advisory service should be continued when the patient leaves hospital. Physiotherapy or hydrotherapy, if needed, should be arranged, and contact should be maintained either by the adviser coming to the house or the patient going to the hospital or office. Thus he could be kept in touch with new gadgets and ideas, or could just talk things over. Such a service might avert a few crises before they developed, and for some people it might be enough to know it was there in reserve.

I know it is no use advocating a register of domestic helpers as there just are not enough to go round; but it might be possible to compile a list of people prepared to help for short periods, over holidays, or to give the disabled person and their full-time helpers a rest from each other. My dream holiday would be somewhere on the Mediterranean in a room with a balcony where (almost) unseen hands attend to my intermittent needs. The delight would lie in not having to be grateful to the 'hands'-the person would receive an exorbitant fee-in not having to feel guilty because something else was waiting to be done, in not being emotionally involved at all.

I think the various organizations for the disabled could do more in trying to supply temporary helpers and gadgets instead of concentrating so much on parties and

pantomime trips. Of course in this matter I am prejudiced, being temperamentally ungregarious, but it seems odd that people are expected to enjoy being together merely because they are all incapacitated. They are probably as different from each other as people picked out at random from a crowd. Clinical details of my 'cast' are the last thing I want to discuss with anyone, but the temptation to do this is surely stronger when surrounded by others similarly afflicted. I am convinced that such dwelling on one's disease is wrong, and that the whole endeavour of the Victim should be directed towards getting back, if not into step at least into the company again at his own calculated pace. This means taking advantage of every practical aid available, and as much human help as is fair to the givers, in order to go on with the business of living.

It seems essential to a man's self-respect that he should find himself of use, and it is no less necessary for a woman. On becoming disabled the man or single 'woman has probably lost the power to continue his previous job, and a wife the power to look after her family herself. Both are traumatic experiences, and something else to do must be found as soon as possible. Anything will do at first. Obviously the degree of paralysis affects the ease with which suitable tasks can be found, but there is always something. I used to encourage people to discuss their plans for the future with me, and it seemed to help them to sort out their ideas. Later, when the Victim improves or his condition stabilizes it is time to look round for more things to do, and to try a few until it becomes clear which one is the right one for him. (I doubt if basket-making would ever be the grand solution, but for some reason occupational therapists are mad about it!)

Even bedridden people should not allow their lives to dwindle to mere television watching – unless they intend to criticize it for the local paper. One possibility for them is

to learn a language from the radio or long-playing records, and it might be feasible then to do translating work, perhaps using a dictaphone.

Of course if the Victim improves enough to go back to his own job, this is fine. He will feel an increased satisfaction in it, probably in ratio to the extra effort needed. But if it has to be a new venture it is important that this should be something which he can do by himself, or nearly so. I thought once I might do some cooking, but as that would have entailed so much collecting of tools by others and putting away again afterwards it wasn't work it; not to me, for I wasn't that keen on cooking, and not to the household. In a specially constructed kitchen it might have been possible, or in a bungalow I might have managed some other chores, but we wished to go on sharing a house with my husband's parents, and we had to have a housekeeper anyway.

I know really that the one talent I ought to exploit is that for writing, and I try to, in the time not spent worrying about the family, knitting and mending.

Occasionally I imagine that the whole thing is some macabre joke, as in 'The Monkey's Paw', when the woman had two wishes granted, and then retracted them with the third. I can remember wishing, when the children were babies and I was so tired, that I would like to go to bed for a year. I did. And I also wished, though even less seriously, that I could be shut up somewhere-a hermit's or prisoner's cell perhaps-so that I could get some writing done. And I have been. I haven't had a third wish, and if I had I would be chary of using it. Didn't someone say that the worst thing that could happen to a man was to have his wishes come true?

I have said that no one, after emerging from a serious and cataclysmic illness, is the same person again. He might think he was or would be, but for good or evil he would be different. The components are still there, naturally, but reassembled, some diminished and some enlarged, until the result is! a variation on the theme of his old self, which until he is familiar with the score he has to play by ear. At the same time he has the same family and commitments as before. They do not change.

The Victim's most important task is to put himself into perspective and, eschewing the king-like role of the patient, become merely a person again. His world-shattering experience has in fact shattered only his and his family's little world, and there are millions of people and millions of worlds. However, his attitude and behaviour afterwards can spread circles of influence far beyond his immediate situation, whether that is contained by four walls or not.

From the months in the general hospital my most vivid recollection is of the first time I was taken out of the ward and downstairs to the nurses' hostel to have a cup of coffee. On the way a door was open to the garden and I saw the grass. We stopped, and I stared at it in astonishment and exaltation. Its greenness was of a quality beyond memory' and beyond imagination. I drank it in, and it was as though my body had lacked some mysterious chlorophyll of its own which it now recognized and absorbed. That moment should be put on the scales against all the previous pain and frustration and humiliation and I think the scales would balance.

Of course the moment passed, like the bad ones. Not many Victims are destined for the life of a mystic or philosopher-saint, which is just as well, as it would be very hard on their relations.

Nevertheless, such an opportunity to see everything freshly again is not easily forgotten. It is something to carry forward into the mundane struggle and days of inching progress, when, like Alice, it seems to take all the running you can do to stay in the same place. You have felt yourself, however briefly, to be linked to the universe, which would be the weaker if that link were broken. And you want to exclaim, with the woman to Thomas Carlyle: 'I accept the universe!'

Only, I hope, to receive the same reply 'My God, she'd better!'