

## **Roger Glanville**

Roger Glanville was born in Slough in 1935, the first son of an unemployed Cardiff glasscutter and a Rhondda refugee. He went to the local grammar school at which he says his only outstanding achievement was the cultivation of huge weeds in his garden. After a year in hospital for treatment of rheumatoid arthritis, he went to Bristol University here he edited the students' newspaper and as the only limping undergraduate became well enough known to win election to the post of Vice-President and Honorary Secretary of the Union.

Mr Glanville's first teaching post was in a very large mixed secondary modern school near Harrow, his second in a small grammar school in Northern Nigeria. His present job is teaching Liberal Studies at Slough College. He has a wife, two children and a mortgage.

### **When the Box Doesn't Fit**

**(Chapter 6 in Hunt, P. (ed.) 1966: Stigma: The Experience of Disability, London: Geoffrey Chapman).**

I HAD BEEN teaching a term and a half and in my quiet opinion knew all there was to know about the job. There was one boy who was giving me a certain amount of trouble, so one night I kept him in as long as possible to see if I could break down his front. At ten to six a cleaner unlocked the door. The boy ran. As I caught him at the door and relocked it, he shoved me up against the wall and glaring down at me (from five-feet-eleven) he said, 'I'd smash your bloody face in if you weren't a cripple'.

That word.

Cripple.

How did he know I was a cripple? What is a cripple? We both sat down. I continued the marking I had been doing and about half an hour later I let him go home. The detention did not do any good and at the end of the term I willingly passed on to the next teacher a boy and a class to whom I had taught absolutely nothing.

But it bothered me to think that this boy considered me a cripple. After all, I had beaten him to the door in spite of his flying start.

During the following year I saw the boy occasionally in the corridors or playground - it was a very large school - and we exchanged casual greetings in the normal way. I have not seen him since but I should think he is a highly successful Fruit and Greens man proud of never having learned a word of French.

In one quick fracas he taught me that words not only have meanings, they have charge. 'Cripple' is highly charged. A cripple is a tiny, ancient, defenceless, screwed-up prune with freedom of movement in only two toes and one forefinger, around whom is a circle of happy fleshy plums enjoying the sunshine.

Why did the boy - I am afraid I have forgotten his name - call me a cripple when there are so many other powerful expressions he could have used? Obviously he was blazing with fury at the loss of his four-thirty birding time and he had to try to say or do something that would make him feel easier. He could have explored the many combinations of four letter adjectives occasionally heard by the secondary school teacher but he took an easy way out and said what had perhaps been in the back of his mind all the time. If I had been black and the nicest fellow in the British Isles, wouldn't he in the same circumstances have called me a nigger or a wog?

It is easy to understand the difficulty of a fourteen-year-old in coping with the nasty situation that I had put him in, but in my experience the average adult in this country cannot cope any better with people who are crippled, or deformed, or disabled, or in any other obvious physical way not normal. I am twenty nine and have had rheumatoid arthritis since I was fifteen. Although it has not been active for some time it has left me a fairly stiff left hip and a slightly shortened leg, but in most other places I look 'normal' (dare I use the word?). I also feel normal.

Most people know nothing about rheumatoid arthritis in the young, or Still's Disease as it is called, because there are very few cases of it. There are fewer still leading a normal or anything approaching normal life, so the average person in his average day does not meet a sufferer.

Nor does he meet in this average day someone who has had any other crippling disease. What happens when he does? One reaction is to ignore it and pretend the disabled person is normal; but that sometimes causes problems.

For example: we were just leaving the Students' Union Bar after a few drinks when I noticed my shoelace was undone. I stopped to tie it up while the others, about a dozen, continued to walk towards the flat which was a couple of hundred yards away. Being so close to the Union, the flat which I shared with three others was a never-shut coffee bar. By the time I had tied my lace the others were fifty yards ahead and I started after them at my top speed, their cruising speed. Unable to gain a yard, I began to feel irritated. Why couldn't they wait a few seconds? They all knew about my leg! Then I was suddenly overwhelmed with an abysmal loneliness. I was

abandoned, an outsider, a cripple: I was being treated as a normal person and it upset me.

'You stupid twit,!' I thought. 'You are just jealous of their ease, of their Rugby, of their fun, of their normality.'

By the time I reached the flat, the coffee was on and the fags were going round. Someone prodded me and said, 'Where did you get to? We thought you had gone round to the Union office.'

Though they had wondered where I was, they had not waited and I still felt a little left out, but not quite so much. I wondered what it was that I wanted of them; enough special consideration, I suppose, to make me feel that I was one of the group. But since they did not know how much 'special consideration' was needed, they could not boost my lack of confidence.

By contrast, when the average person meets a disabled person he can be over solicitous, which might make the disabled person feel persecuted. The first time it happened to me, I was standing on a bus going to school. I had not been out of hospital long but I was strong enough to walk about and jump on and off buses, and being newly in the Sixth Form was trying to be the smart young gent. An acquaintance of my mother's sitting half the bus away turned and saw me.

'Hello, Roger. How are you now? Would you like my seat dear?'

'No thank you. I'm all right,' I said firmly.

'Do you think you will be able to stand all the way?'

'Yes, thank you. I'm fine.'" .

'Are you sure you're all right dear?'

'Yes, thank you.'

'Well, 'you just let me know if you want my seat, won't you, dear?'

'Yes, thanks,' my broken voice and spirit mumbled into my tie. Twenty-six passengers on the lower deck, and the other four standing during the rush hour, turned to look. Ten million eyes. No-one spoke but I heard their thoughts. That little boy is going to collapse. Wonder what's wrong with him. He doesn't look too bad. Has he had an operation? Do you think it'll be in the papers? Which hospital was he in? He looks a bit skinny, doesn't he? I lived through it. I even put on a bit of a limp for my audience when we reached the terminus!

What the normal cripple needs is just a little consideration, just a little help up the mountains (even if they are merely kerb-stones), but not the fussing which so frequently accompanies genuine concern. A quiet, relaxed, 'Are you O.K. mate?' works wonders. Somehow people find it very difficult to relax and offer help at the same time. This seems to be because the opportunity to help happens so rarely that people do not get practice. When my wife and I went to Nigeria we were immediately shattered, as all Europeans must be, by the horrifying evidence of disease-blind beggars accompanied by their 'eyes', tiny girls singing in shrill voices; crippled children with pencil-lead legs, literally crawling along at the side of the road; old, young, tall, fat, thin, thinner, skeletons; black pathetic faces without noses, round feet without toes, scratching at the flies and mosquitoes with fingerless, elbow-clubs. With my walking stick and slight limp, I soon became 'Ngurugu'-the cripple. Although my knowledge of Hausa is very

limited, the word 'Ngurugu' seems to have a simple, bald meaning without emotive connotations. Why does the word in that language not carry the mixed fear, sympathy, pity, horror, disgust that its equivalent in our language does? Disease, and its damage, is so much part of daily life in the tropics that it is accepted as simply as are trees, sand, rain and sun. I was struck by the fact that I was never asked what was wrong with my leg. This was not that my acquaintances hesitated to ask something personal; they were not tardy in any other direction! I think they were just not interested in what made me limp. If they were interested at all it was in me, the whole me, and if there was a little bit chipped off, it made no odds to them.

Whether lack of practice in dealing with the disabled is a factor or not, relationships with people are further aggravated by the difficulties encountered and the barriers thrown up by the disabled themselves. It is obviously a tremendous task to come to terms with oneself, particularly if the disability occurs after a normal life has been established. When at last one begins to feel able to cope with a newly restricted pattern, resentment against the injustice, the 'big chip', has to be dealt with. One has to try to -find one's real character, to deal with other people in a reasonable way, to react normally to all situations, to harbour no bitterness, to be ordinary and normal. On those days when coping is impossible, the barriers go up again; but when one finally succeeds in living with oneself, these barriers collapse completely because they are no longer needed to protect one from everyday high-speed life.

During the period of adjustment one needs more than anything to feel that there is some meaning in life. Relationships with other people play an important part in finding this meaning, but in order to achieve mutual understanding, communication with- out tension is

desirable. Yet, at the same time one's disability makes one feel not quite right, a little ill at ease, and therefore tense: so the other person's primary task is to combat the tension and spread a little relaxation around. Fit people (the ones with duodenal ulcers, varicose veins, or blood pressure but no outward manifestations of abnormality) find it difficult to be normal with the disabled. They are tense before they start. The first thing they want to know is, 'What's wrong?' And then, 'How long? Never! I thought. My aunt. ..! Have you tried. ..? mud, codeine, turkish baths, vegetarianism, bee stings, cortisone, corks in the bed, real leather shoes, ACTH, rest, exercise, prayer?' When these questions have been answered, they relax and sometimes turn out to be quite nice people; just thought they were helping. It is of course easy to generalize, and there are many people capable of being genuinely relaxed and interested in a disabled person without being concerned with his disability. But my assertion that the average man is hampered in his dealings by undue tension and irrationality is supported in my experience by the inability of various institutions in this country to be reasonable (i.e. what I consider reasonable!).

Because people find the establishment of personal relationships with the disabled difficult to achieve, when they are acting on behalf of some organization their formulation or implementation of the official line reflects these personal difficulties. It had always seemed rather peculiar to me that my first provisional driving licence was over stamped 'Disabled Driver'. How could I be a disabled driver when I was driving a normal car? If the over-stamping had read 'Disabled Person' this would have been partly acceptable, but if the disability did not affect the driving then obviously no over stamping would be required.

The first letter I received from the County Treasurer's Office in answer to my enquiry about the legal significance of over stamping was perfunctory and terse. It referred me to Motor Vehicles (Driving Licence) Regulations 1956 and 1962. At the local police station a very helpful policeman and I went through a substantial wad of regulations with no result. I tried the Clerk's office at the Magistrate's Court and we could find nothing about over stamping licences. I pointed this out to the County Treasurer, and this time received a pleasant, full and very helpful letter, which did not go so far as to apologize but did admit that the previous references should have been 1950 and 1963. It now turns out that my licence should not have been over stamped as I was not restricted to 'a certain class of vehicle for any reason of disability'. It seems quite reasonable to me that people make mistakes, and occasionally licences are issued incorrectly. It seems unreasonable to me when clerks, in official correspondence, imply that I am irritating them and wasting their time by raising such- trivial issues, when five minutes extra care in the preparation of their reply would obviate the need for further correspondence, and do wonders to my attitude to the local authority. In the long run this is a matter of public relations.

Insurance companies raise my temperature, and my reaction to them is based on three incidents from my own experience. The first was when I was in West Africa, but the location makes no difference, as it was a British company and the people taking the decisions which I bemoan were British. I bought a car soon after arriving in the town where I was going to teach and, through the garage who were agents for the insurance company, made an application for comprehensive cover. The application forms contained the usual questions about my physical condition and my approach to these was, and is, to put simply that I have a limited movement in the left hip



as a result of rheumatoid arthritis which is now dormant. My view is that there is no point in providing a detailed medical history when the companies do not specifically request one, and if the information I provide is inadequate the company will ask for more.

In this case the company did not request further information, but the local manager, rather embarrassed, told me that Lagos insisted on a compulsory £50 excess. That meant that in each and every claim I would have to pay the first £50, without getting a discount off the premium. I refused these conditions, pointing out rather vociferously that the company had not explained the reason for the excess, that the information I had given about my disability was inadequate as a basis for determining the amount of the excess, and that I had just passed a driving test on a normal car. A few days later I received a letter asking me to agree to an excess of £25. The local manager told me that the company usually placed an excess of about £15 on new drivers anyway so I agreed to the new amount. Twelve months later I insisted that the compulsory excess be cancelled in view of a claim-free year, and the company agreed.

The second incident was after my return to England when I wanted to buy a house. I made an application to a different company for a With-Profits Endowment Policy to be used to finance the house purchase. As it happened the doctor the company asked to give me a medical examination had been my G.P. for twenty-five years and knew the full history of my case. After passing half an hour discussing his teenage son's rebellious attitude to authority I was hoping to escape with a mere brushing with the cold end of the stethoscope, but he checked meticulously each detail of the report form and I was there for a further hour. The report the doctor submitted was as precise an appraisal of my physical condition as the

insurance company could expect to get from a non-specialist. The result of my application was that I was refused a house purchase policy (which had been my only reason for applying), but was offered an endowment policy with no cover for the first five years.

The third incident concerned yet another company. By the time I made applications to this company I had bought a house with the help of a local authority mortgage and a private loan, and I wanted a Mortgage Protection Policy. I had a medical examination with a very sympathetic doctor who knew the Director of the Special Unit for Juvenile Rheumatism where most of my treatment had taken place. The examining doctor suggested to me that he should refer the insurance company to the Unit, on the grounds that with rheumatoid arthritis a single medical examination could not determine future progress. My application was refused, but the company stated that if I cared to reapply a year later they would reconsider the application. The Director of the Unit had not been consulted.

A year later I reapplied. The note acknowledging my application was accompanied by a form requiring me to state that there had been no change in my condition since the first application. I filled in, signed and returned it. I then received a letter informing me that Head Office required me to be medically examined by their local medical attendant, the same doctor who had examined me a year earlier. At the second examination we determined that there had been no change in the intervening period, and since the reference had not been taken up by the company the first time, I asked him to put a note on his report that I specifically requested reference to be made to the Director of the hospital unit. Again this reference was not taken up. The company offered me mortgage protection cover at four times the normal premium. I wrote to ask why and how this figure had been arrived at. The

reply stated that an explanation could not be given, but that if I required medical knowledge concerning your medical examination I could ask my doctor to write to the Chief Medical Officer of the company. It was pointed out that the Medical Officer would not reply to me direct but only to my doctor.

My next letter was aimed at the Managing Director and made three points: first, I could not see why my doctor should be involved in my insurance correspondence; second, my medical reference had not been taken up; third, I thought that the figure offered was not based on statistics, and was so high that it was unlikely to be accepted. The reply set out to justify the figures, and so far I have consulted two Senior Lecturers in Accountancy (both of whom by coincidence are part-time agents for insurance companies) and a lawyer, none of whom could explain the logic of the explanation. I am now blinded by science, and uninsured.

Two points emerge from these examples. The first is the very obvious difficulty an insurance company has in translating a physical disability I of an uncommon type into cash risk. The compulsory excess of £50 imposed on my first car insurance could not have been reasonable if the company were prepared to cut it by half when I refused to accept it. If it were still a calculated risk the company should have refused to cancel the excess after one year. The endowment insurance being offered, with no cover for the first five years, seemed farcical in that the nature of worsening rheumatoid arthritis would make me a far worse risk (i.e. more accident prone, slower off the mark or off the road) in the second five years, in spite of the accumulating reserve. I regard the last example as the worst in that very little effort was made by employees of the company to explain exactly and clearly why I was being offered insurances at the prices quoted, why the

Medical Officer would not write to me, why the references I made were not taken up. Since a disabled person, knows that the insurance company is primarily in business to make money, all he wants from the company is a fair deal; and here is a good example of the need for the deal to be fair and to be seen to be fair.

The second point which emerges from the examples is the speed with which responsibility is passed on to some higher authority. My enquiry about my driving licence was interpreted, according to the Ministry of Transport regulations. In Nigeria the area insurance manager conveyed to me a decision made by Head Office in Lagos. My endowment policy information brought by a local agent was: 'They have decided not to ...' Referring to the last insurance the local branch wrote: 'We have been informed by Head Office that they require you to be medically examined. ..' And yet in any case where I have approached directly those in authority the answers are blunt and genuine and responsible, even though maybe not to my taste. Where some difficult situation is to be tackled or a decision is to be made, few people have the responsibility, or perhaps commonsense, to do it.

I sometimes feel this is nothing to do with normal disabled relationships, but just part of the trend. towards conformity, pattern standardization, stereotyped people. Everyone goes to the office, pinstriped Monday to Friday, and thorn-proof tweeds on Saturday. Turn up on Thursday in tweeds and they will send you home for a doctor's note. Dye your suit pink and see if you can get into a dance. Be black in a white area, or be white in a black area. Walk backwards down the High Street pulling a twin tub, and note public reaction. As soon as it can be determined that you are a nut, a psychiatric categorizer will say that you are a certain type of nut. If you don't fit admass, eggheadmass, two-ulcer-job-one-ulcer-man-mass,

another mass type must be found for you or people don't understand, and what they don't understand they fear, and when they fear they avoid. If you are disabled, you don't fit.

I do not mind that I do not fit, but it is very encouraging to be given the benefit of the doubt when doubt exists. As a teacher I have had three medical examinations connected with my jobs. In each case the doctor was not a rheumatology specialist, a fact which he pointed out as soon as rheumatoid arthritis was mentioned. The first was when I started a Teacher Training year. The doctor was a local authority Medical Officer of Health. Towards the end of the examination, he said, 'ok, I've got to decide which group to put you in; A, B1, B2, C or D. If I put C or D they won't let you do the course. What you think?' He twisted the Private, Confidential, Not to be Shown to the Candidate, form round for me to read. I said B1 as the nearest fit. 'I don't know what's going to happen to you in the future,' he said. 'You may be completely crippled, you may get a lot better; but I don't see that it's my job to stop you doing this course. But that'll do.'

I finished the year's course and went into hospital for a six week reconstruction job that ran on and on and on, and eventually took up five and a half months. Weak and white I limped to another medical three days before the beginning of the Spring term. Unsmiling and worried, another M.O.H.

'How do you find you get on when you are teaching?' he said.

'I don't know. I haven't started yet.'

'We'll see how it goes.'

I taught for two years without missing a day through illness. My third medical was with a sweet old gent! man who had spent many years in mission hospitals in the tropics and in China. He was fascinated, but very upset that research into rheumatism had progressed so slowly and that no simple six-penny-packet cure had appeared. He thought I was wonderful to want to go to Africa to teach and suggested the heat might be good for me. Each of these men understood my physical difficulties and understood the need for me to be allowed to try to do my work.

A friend of my father's was partially deaf for many years, which he found a strain. His hearing then disappeared completely leaving him in utter, stone silence. He now reads lips, talks quite well and is buoyantly, boyishly happy. Sometimes I feel stronger and the future looks bright. Sometimes I feel grim and the future looks grimmer. In such circumstances I can hardly expect others always to be able match my needs. But I hope that people will come to rely less on norms, types and categories for their attitudes, and will attempt to bring more flexibility to their dealings with the individual.