

**Images of Ourselves: women with disabilities talking, edited by Jo Campling
(pages 35 – 57 in the original text)**

MAGGIE

Maggie, who is 31 years old, is severely deaf and wears a hearing-aid. She is a single parent with two daughters aged 7 and 3. Maggie works part-time as a teacher of drama to deaf students in further education. A feminist, who is politically active in the disability world, she is studying for a degree in psychology at the Open University. Her other interests are performing mime and growing vegetables.

I started to go deaf fifteen years ago. In the beginning my hearing loss was slight but looking back it seems as if the feeling of disability was far greater then than now, for it seemed to permeate my whole being. At eighteen, I was a lively, extrovert, intelligent and attractive drama student With very definite ideas about my future life plan which centred largely on a career in the theatre. I found I missed bits of conversation sometimes in noisy situations but this happened so infrequently that I attributed it to lapses in concentration and the Glaswegian accents around me. Little threatening thoughts that I might be inheriting the family deafness were dismissed until the college began to notice my difficulty and I was sent to an ear, nose and throat specialist. He diagnosed hereditary, incurable, progressive nerve deafness and said that I would probably be profoundly deaf in about five years' time. My first feelings were ones of enormous guilt at having 'let my parents down ' and I kept the news secret until the college wrote to them. But the guilt of being less than a perfect person remained and grew, as my deafness progressed.

I readjusted my life plan as one who has been told she has five years left to live. I found I could bluff my way out of awkward situations by acting the part of a rather scatty dolly bird. It wasn't that I couldn't hear you but rather that I was such a feather-brained, aspiring actress that I just didn't understand what you meant. It seemed more acceptable to be a 'normal' silly butterfly than an intelligent deaf woman. In this role I made no demands on anyone but I experienced a different kind of oppression which led me to my first awareness of sexism and the oppression of women in general.

When I thought about a future when I would be profoundly deaf I shuddered With horror. I wouldn't be able to act because I would lose control of my voice. All my present voice training would be wasted. I wouldn't be able to work at anything other than cleaning or assembly line work. I would have to give up my present social life and take up interests where I didn't have to mix With people. I could, of course, get married and take the easy way out of the employment problem. If I were a wife and mother I wouldn't lose my self-respect as it is fine for mothers to stay at home. But would any man want a deaf woman for a wife? Since my deafness was hereditary would I want to watch children of mine go through all this trauma? Would I wish a miserable deaf woman on any child for a mother? Whichever way I turned to think, the negative answer that I was deaf seemed to destroy any shred of hope. I can only think that I learned to expect so little from my future because I had somehow soaked up these prevailing attitudes towards women with disabilities as a hearing woman and taken them over to crush myself in my own deafness.

Five years later, I was married to a life-long friend and working as a teacher of drama in a comprehensive school. The frivolous butterfly had long since vanished into oblivion. I could still hear, with the help of an expensive hearing-aid, and could communicate with my husband and friends quite easily in one-to-one situations. In groups, such as the staff- room at school or gatherings in my own home, however, I was lost, since, by now, I had to see the speaker's face to lip-read as well as hear. People's heads toss and turn, mouths are covered by hands, so many consonants look alike on the lips and by the time you have translated one difficult word the next sentence has passed by unnoticed. I discovered that neither hearing-aids nor lip-reading were the miracle solutions they were cracked up to be. Being a woman made things 'easy' once again. I smiled and nodded my way through hour after hour, looked good and cooked nice food. In those days it seemed acceptable for the men to do all the talking and the woman to listen and play the part of passive admiring wives. My armchair interest in the growing women's movement told me otherwise but I couldn't see any way out. I could still ape 'normality' but the woman inside was in despair.

My ENT specialist told me not to worry .I would eventually come to terms with the change in my life. He gave me no indication as to how I was to come to terms with a world viewed largely through a plate glass window where other people live, laugh and suffer and barely know of my existence. Deprived of much positive feedback on the woman I really was, my self-esteem took an insidious dive. I began to mistrust my own perception of the world and the people around me. How could I be sure of my impressions when I couldn't hear? When the views of others differed I quickly adjusted mine. They were right because they could hear and my experience seemed invalid. I felt I had little to offer anyone and rather than face rejection, I avoided people. Grieving over the lively, gregarious woman I had once been, I felt very isolated.

I seemed to be near breaking point when one evening something happened that proved to be the beginnings of my birth as a deaf woman. I was in an Indian restaurant with friends doing my little smiling and nodding act when I noticed the people opposite. At first, I thought they were drama students because they were so lively and expressive but then I noticed the sign language. They were deaf like me! They were happy! They were laughing and talking and didn't give a damn that the whole place knew they were deaf. I stared and stared with fascination and found I could follow more of their conversation than I could the talk at my own table even though I couldn't follow the signs. My years of pretence seemed suddenly absurd. I had been making things 'normal' and easy for everyone except myself. I was a deaf woman. It was time to give up my mourning and come out deaf.

We had been on the list of an adoption society for several months but as my first positive thoughts about my disability began to take hold I realised that I had been allowing my deafness to deprive us of so much. This body had a right to carry a baby and give birth. In saying our children shouldn't be born I was saying implicitly that I shouldn't have been born. OK so maybe our children could go deaf but with me as a mother they would have the finest possible expert to help them. Even if they didn't go deaf they were going to have a magnificent deaf mother. Not for our children the passive smiling noddy or the pretty cook. They were going to grow up seeing deaf

people treated with respect. It became my most important goal not only for my children but for myself and all deaf people.

Whilst I was expecting my first child I met some women who had been born deaf who introduced me to the most revolutionary hearing-aid ever invented - sign language. Lip-reading the clearest speaker is fine for half an hour but after that my eyes water and my brain becomes confused and I am no longer alert enough to continue. No relationship can be made or continued in half-hour stretches but if people can fingerspell or sign I can enjoy their company into the early hours of the morning without strain. It takes ten minutes to learn the fingerspelling alphabet and when people fingerspell the first letters of words I can lip-read them with ease. I find that, once fingerspelling has been mastered and a relationship established, people are more motivated to learn how to sign. There is something very special about communicating with deaf people which can terrify you or enthrall you depending on what kind of person you are. We look at each other when we talk and this looking plus more explicit non-verbal communication involves a high level of self-disclosure which is not normally present in spoken conversation where people hardly look at each other at all. Words can lie and cover up but the face and body rarely do. My special needs demand your honesty and glimpses of your precious inner self. 'I'm sorry, don't worry, never mind, dear', you say when I tell you I am deaf. But it is your face that reads 'fear' not mine. And it is your fear of my deafness I have to help you with when we first meet. Sometimes I fail and the pain of your rejection goes down to join the pain of a thousand rejections. When I succeed, I am Maggie, lively, intelligent and lovable. As a mother of two small children I can be excluded in subtle ways even by those who otherwise understand my needs. People will speak beautifully for me and then drop the signs and turn to talk 'normally' to the children. What are they saying? Is it trivial or important? Don't I exist any more? A child can be rushed from the room for a wee wee or a drink and I am left wondering what calamity has occurred. Ears have heard what my eyes were not allowed to see. Doctors and school-teachers address questions to the children which would otherwise be addressed to me. Hey, I'm their mother! What is it that isn't fit for my ears? I can't let such small things pass without comment, since my children are learning that it is easier to get what you want from people who can hear and too much effort to bother people who are deaf and who are not important anyway.

A recent visitor laughingly remarked, 'Your children speak to people as if everyone were deaf.' Yes, they do when I am there because they acknowledge my right to be included - my right to exist. Even when I am one deaf woman among a hundred who can hear it is still my right. When I walk into the busy staffroom at college or join a room full of friends and see them switch, as if by reflex action, to speaking and signing so that I can understand, I feel a glow of joy. This is how it should be because I am important and lovable enough to be included and when I am included I am no longer disabled.

BARBARA

Barbara, who is 31 years old, went up to Oxford in 1968, where she read English Language and Literature at St Hilda's College. She met her husband, Roland,

who was also a student, and they married in Oxford in 1970. In 1971 she gained a first-class honours degree in English and began teaching at Berkhamsted School for Girls in 1972. Later that year she had a car accident, swerving to avoid a dog, and broke her back. For a year she was confined to a wheelchair but now walks with a stick. She can only manage limited distances very slowly and tires easily. In 1974 she gave birth to a son, Dominic, and in 1978 a daughter, Corrina. Currently she is a tutor for Wolsey Hall Correspondence College, working at home.

One minute I held the tiller,
The next, the rudder's snapped;
A split second, and life's changed course.

Thus wrote Mrs K. Thomas, who was a nursing auxiliary at Stoke Mandeville when I was a patient, in a sensitive poem recording the impressions patients had given her of their reactions to disability. This sense of numbed shock, of powerlessness, anxiety and loss of direction, was my first reasoned response when the realisation that I was partially paralysed penetrated my brain. Initially, I had felt thankful to be alive - I had had a very serious head injury at the same time as I fractured my spine and was not expected to survive. However, this mood of unquestioning gratitude collapsed as I found myself forced to consider what quality of life was left to me. Anger - a feeling that my body was now flawed, no longer as God meant it to be - and frustration succeeded. I hadn't been *made* like this, why should I be expected to live like it?

This destruction of my self-confidence was the most significant and far-reaching effect my paraplegia had on me. I felt that I was no longer acceptable, let alone desirable. All around me in the ward, marriages and long-standing relationships were dissolving under the strain imposed by the woman's disability. Out of ten or twelve young women in the ward with me, of whom nine were married or engaged, mine was the only relationship that eventually survived, although only three or four actually broke up while the wife was in hospital. A marriage was not *expected* to hold together; one of the staff said to me, 'You're married, aren't you? Well, that won't last!' Indeed, I felt so imperfect and inadequate that it seemed positively selfish to expect my husband to remain with what I had become, so I tried to persuade him to divorce me. Fortunately, though bitterly hurt by my suggestion, he refused. Why is it that so many marriages, especially of younger women who become disabled, break up? Part of the reason may be that many men find the role of nurse and carer suddenly imposed on them by the exigencies of their wife's condition totally unacceptable, it often being necessary to help in emptying bladder and bowel and in changing incontinence pads and even tampons. To a woman much of this is more or less instinctive - we quickly learn to cope with a baby's nappies. The determining factor is perhaps the nature of the relationship, although the attitude of professionals and people around to one's disability is important, too. Young couples have had less time to form a bond, have accumulated less joint memories, and perhaps less joint responsibilities, in the shape of children and mortgages. If a relationship has been one where physical considerations are of the greatest importance, where shared interests centre solely around dancing and sport, and where the female's role is primarily to enhance the male's status amongst his peers, then obviously the disablement of the woman is going to provoke a crisis. (The only physical interests my husband and I shared were punting

and midnight walks along the tow-path - which we'd had to forgo on leaving Oxford, anyway!) The attitude of the two partners before and after disability to each other and to themselves is crucial, and that is why a damaged self-image can have such an impact. It took me a long time to stop (mentally) apologising to my husband for existing, and to stop regarding him, as others around me did, as something of a saint because he did *not* leave me.

One's self-confidence is subjected to much unintentional battering by the public at large, too. Suddenly, one discovers that one is imbecilic ('does you wife take sugar?') and quite possibly unemployable. I had been a teacher of English at a private girls' school in Berkhamsted, Hertfordshire for five weeks when I broke my back in 1972. I was shattered when they asked me to resign because it was going to prove too difficult to arrange for me to teach in one room on the ground floor as opposed to moving from class to class in the usual way. I felt totally rejected, not only was my body impaired, but it seemed that even my mind was no longer of any use. Another problem a newly disabled woman may well have to find a solution to is that of the over-protectiveness of her family and friends. Being treated (albeit with the best of intentions) as a helpless invalid, discourages independence, and can be very damaging to one's self-esteem. I also discovered that a disability renders one neuter. Disabled people are not supposed to retain the feelings and instincts of the able-bodied, and this is an attitude one encounters among the caring professions in hospitals looking after the newly disabled, when a person is most vulnerable. In a mixed spinal ward at Stoke Mandeville Hospital it is at the moment (I'm trying to change it!) considered quite acceptable, if not ideal, for male and female patients to use the same lavatories and bathrooms with only curtains, not doors, to screen them from each other. They are thus expected to perform intimate bodily functions with very little privacy, a situation that most able-bodied people would find quite intolerable.

The sexual problems facing the disabled have thankfully received much attention in the last few years. When I broke my back, the hospital gave me no help or advice at all. The nearest to counselling I received were a few coarse jokes and innuendoes which, though admittedly amusing, were not of much practical value. The women's sexual role is supposedly largely passive, and while I appreciate that the impact of sudden impotence on a young man, whose conception of himself is rooted in his virility, can be devastating, I think this supposed passivity of the female explains the lack of support and help most disabled women receive. The professionals simply did not realise the importance of sexuality to the restoration of one's self-esteem. It was not until some three years after my injury, when I had been seeing an eminent gynaecologist and sexologist, Mr Desmond Bluett, for some time on a private basis, and had been receiving from him the advice, practical help, and counselling not available at the hospital, that I began to function again as a sexual being. Mr Bluett understood the importance of this to me; until I could respond to my husband, I felt that I was no longer contributing anything to our relationship - my sexual failure had become a symbol of all my other imagined inadequacies. The rediscovery of my own sexuality restored my sense of identity, and my self-respect. It was nearly the most important factor in my rehabilitation.

Putting oneself together again mentally after disability (which will serve as my definition of what rehabilitation involves) is obviously vital. Bitterness and self-pity

can wreck a person, and of course can ruin a marriage. So can constant self-abasement, because people tend to take one on one's own valuation. So if a woman is convinced that she is worthless and merits only a kind of condescending pity, then that is how she will be regarded. Two other subsidiary factors helped *me* to regain my self-confidence and so indirectly maintained the stability of my marriage. The first was the support and help of my entire family, especially my beloved father, and which one of my brothers translated into practical terms by finding me a job as a tutor with a correspondence college. This demonstrated to me that at least mentally I still functioned adequately. The second was the birth of my two children, the eldest, Dominic, within two years of my injury, and the baby, Corrina, some four years later. Despite some bladder and bowel complications caused by a particularly difficult first labour and delivery in a local hospital (which Mr Bluett, who delivered Corrina by Caesarean section, has only just after nearly six years, put right, since he alone appreciated that the problems I was experiencing were not spinal but gynaecological, resulting from the damage to my pelvic floor muscles in childbirth) I discovered that pregnancy and children themselves are a wonderful morale-booster. At last my body was acting as a female body was supposed to - I felt blessedly *normal* while pregnant, and doctors were interested not in my back, which I'd had, enough of by then, but in my developing baby. Once my children were born, I became almost immediately the centre of their lives, whose presence was rewarded by smiles and whose absence or anger provoked cries of distress. It was wonderful to feel so *necessary* !

Most important of all was the attitude of my husband, Roland. He instinctively struck the perfect balance between helping me, and allowing me to do things for myself to regain my independence. One example will suffice. Roland would never help me to stand up - in any case, unsolicited aid upsets my equilibrium, which is never very stable - but if I fell, he was always there either to catch me or to pick me up. To the uninitiated outsider, it must often have seemed that he was being heartless and cruel to leave me struggling to manage running our home as 'best I could crawling around on my knees. (Until I had an operation on my hip, I couldn't walk even with crutches, and it was impossible to get the enormous wheelchair the hospital supplied through the front door of our tiny cottage, quite apart from the lack of any space to manoeuvre it once it was inside.) Roland's attitude incited me to prove that I could still perform normal domestic duties, albeit slowly and clumsily. He showed a complete acceptance of the limitations and implications of my medical condition, coupled with a constructive sympathy to help me to come to terms with it. Because he made it clear to me that in all but the most basic physical sense I was still the same girl he married, I began to look on myself in that way, too.

This whole consideration of the psychological effects of disability on me raises the further question of whether my experiences were typical; whether in fact there are special problems attached to being a disabled *woman*. The crucial element seems to me to be not the *sex* of the disabled person, but his or her attitude. The greatest problem for a woman with a disability would seem to be that she may feel that she is no longer sexually attractive or lovable; her self-confidence, which is strongly linked to her conception of the image she wishes to project of herself and which represents how she intends society to regard her, is seriously shaken. She feels ugly, faulty, impaired and worthless. In my case, once my self-image was restored, I ceased to feel mentally crippled. Indeed, most of the friends I have made since my disability have to

make a conscious effort to remember that I am physically handicapped -it is a peripheral facet of me they frequently overlook, not something of central importance. Until a disabled woman learns, as I did, to place a higher value on herself and realises that to many men she is still personally attractive, she will indeed be doubly disadvantaged.

SUE

Sue, who is in her 30s, lives in an isolated village in Kent with Ian and her small son. She is taking a degree course in sociology at the University of Kent. She is a radical feminist and 'a very private person'.

When I woke up the morning of 1 June 1976, a normal day, I did not know it was to be the beginning of the end. The end of freedom, spontaneity, social anonymity; the beginning of fear, pain, existential isolation; the ambiguity of social ostracism/public property. I did not know it on that June morning but I was to become THE DISABLED; the beginning of the frightening descent into the world of the 'social minority'.

MS came suddenly, dream-like. On my usual walk down the lane which marks my country home, legs became heavy, the unconscious movement became conscious. I fell among the grasses and wild flowers, no real alarm yet, wondering. The strange consciousness of movement receded, I continued, but days later it reappeared. I went to the doctor. 'Er, Doctor, I-um-don't seem to be able to walk properly' - embarrassed, conscious of sounding silly. He eyed me bleakly and handed me some tranquillisers. I went home and threw them away. Symptoms continued and varied. I visited the medical profession again. This time he was not amused - look Mrs Housewife you are depressed/isolated/neurotic/female. Are you taking the pills? No? Exasperated, take *these* pills. I take the pills, symptoms persist. I go back to the overworked doctor. Repeat my story .He tries psycho- logical approach (after all, he's on duty at the local 'mental hospital' sometimes, he has an interest in psychology). 'Do you find walking easier when you are not with your husband?' 'No.' I am not being helpful. 'Do you find it more difficult out of doors?'. 'Yet - I keep feeling like I'm going to fall over (and there's no furniture to hang on to).' Ah hah - his face brightens up, he's got it - agoraphobia. I'm not at all convinced, I ask for an examination. Smile fades, he refuses, says its not necessary - I am agoraphobic. I don't feel any better, but I have a label. I go home and report that I am an agoraphobic. There follow months when I nearly kill myself, forcing painful legs on long walks, bike rides, in an effort to de-agoraphobic myself, combined with amateur psychiatry nights of 'where did I go wrong'. I couldn't get the feel of being an agoraphobic. I go back to the doctor; this time he's had enough. I am a hypochondriac - heated words - the patient answers back. I'm shown hastily out of the surgery shouting, 'Next time I see you I'll be in a bloody wheelchair.' Prophetic words. The next day I collapse, an embarrassed doctor (but covering up well with professional ethos) orders an ambulance.

I am in hospital. Hospital, where people go to get better, doctors in white coats are gods of medical science and technology, patients are models of gratitude, subservience and stiff in the upper lip and everybody is happy. Ladies in nice nighties,

smiling, pretty flowers surrounding the bed of pain. Men in white coats who stand at the end of those beds don't actually speak to the case in the bed, don't actually look at the case in the bed, especially if you have something nasty they can't bring themselves to tell you about. I'm transferred to another hospital. I prefer this place - at least it's more honest for my type of patient - no more pretence that everything is all right. No more ladies in nice nighties, no more sweetness and light; the hopeless cases. An old workhouse, institutional green with pipes running down the walls. The staff leave you alone, no more forced gaiety and 'interest'. I remember facing one young doctor saying, 'I've got MS, haven't I?' (I still don't know where that idea came from as I had no real idea what those words meant.) He, looking embarrassed and surprised said, 'Yes.' Then I said, 'That's curable isn't it?' 'No', he said, 'It's incurable.' These gods in white coats, whom as a child you always knew would make you better, who could make test-tube babies, transplant hearts, kidneys, could not help me. I was incurable; one of the hopeless ones. But that young doctor could not face telling me I was one of the hopeless so he said I would get better, I was the type of case who never, but never, had another attack. I was reprieved, saved, and until I started reading about the disease I was now bound up with, I believed him (almost).

The day started at 6 o'clock with a nice cup of tea, but not for me. As I had just managed to sleep a few hours previously and had nothing to do all day except lie in bed, the prospect of being awake was not appealing. They gave up on me, merely muttering angrily and rattling the tea trolley. Not so fortunate were the older residents, who were got out of bed and sat in a chair for the next 13 interminable hours. Woe are those who are powerless, helpless and helped. An older woman who had one of the most beautiful and dignified faces I have seen, sat immobile in her chair day after day, refusing to be alive to what was happening to her, except when her husband came at night and loved her, and she became human again. Porridge time came around one morning and in bustled one of those guardian angels, a nurse. 'Come on dear,' said the 20-year-old to the 70-year-old, 'Eat up your nice porridge.' The woman sat unspeaking while the nurse tried to push the spoon in to the unwilling mouth. The ward was quiet, the helpless looked away while the helper forced in the porridge. The woman turned her head, wordlessly, tears streaming down her face. The nurse, momentarily defeated, angrily turned to the helpless for support, 'She's got to eat it, it's good for her.' Man's inhumanity to man. But then when you are the helpless, dignity is a luxury you cannot afford.

I finally left that place of hidden pain and despair and got back into the mainstream of life - but with a difference, I was now 'disabled'. I was entering the world of 'normal' and 'abnormal' and I was soon to find that I was firmly on the side of the 'abnormal' divide. It's a strange and frightening experience to leave hospital 'different' from when you went in. I somehow expected the world to have changed because my experience of it had, but it was just the same, it was I who had changed. Hospital was horrible, but at least you had a place in it, everybody was ill, but out there you were on your own. Life somehow became relegated in the mind as 'then' and 'now'. The splutter of interest I had received on my initial going into hospital, interest in my diagnosis from the medics, 'hope you get better soon' from friends, quickly dissipated. The medical profession figuratively pulled down the blinds on my case, told me it was all a matter of attitude and departed, and friends, ah yes, friends, I didn't find I had any, not at least so as I would notice.

I was confused, I still felt fundamentally the same. My body was different, I knew that all right, but inside it was me. Normality after all is what you know. The male who is very short is normal to himself, it is other people who make him aware of an 'abnormality'. The 'ugly' female is 'normal' to herself (try denying your own being), it's the others who make her 'abnormal'. After all if we were all very short and ugly (decide for yourself what that means) a person unlike that would be 'abnormal'. 'Normality' and 'abnormality' are socially defined. It also has to be a relative concept, we are all normal/abnormal to the social norm, in varying degrees. Disability can and sometimes does interfere with the practical running of a life, but it is the reaction and non- action of society which causes disablement. There is no such thing as THE DISABLED, there are just people. On leaving hospital and finding the mantle of 'disabled' placed firmly upon my unwilling shoulders I entered a world which was alien, absurd and ultimately defeating. My weak grasp on my identity was no real match for the massed forces of society who firmly believed themselves as 'normal' and myself just as firmly as 'abnormal'. I found myself inhabiting a stereotype. I became my illness, I was. of interest only because of it. And as a person in a wheelchair I illicited embarrassment, avoidance, condescension, personal questions. With a growing sense of unreality, I noticed people were not talking to me, only to the person who was standing on their own two feet behind, and if they did they were inexplicably embarrassed, or talking loudly. I became public property, anyone could come up to me (being friendly of course) and ask me 'What's happened to you dear?' and they all seemed to know somebody or somebody who knew somebody who had MS and then proceeded to tell me in graphic detail what happened to them.

Friends either departed or tried manfully to ignore what had happened to me. I was surrounded by a conspiracy of silence. I discovered the topic I wanted and needed to discuss was taboo. Talk about broken affairs, politics, etc., was OK, in fact socially desirable, but my fear and pain of my experience was not. Such attention as I received was jocular and curiosity from the insensitive (of which I found many) and embarrassment from the more sensitive. When I did mention the bewilderment I felt at the treatment I was now experiencing I was told, 'They are embarrassed, they cannot cope.' So I had become an embarrassment! They cannot cope, but they don't have to, I felt like screaming, I have to and they are making it impossible. I discovered the 'sick role'. The 'sick role' is society's niche for THE DISABLED. You must behave as 'the sick' at all times but never complain about it. You must allow your person to have good works vented upon it, it makes THEM feel better, accept with a gracious smile the fuss, offers of 'help' you don't need. It puts you in the 'sick role' the good feel good, everyone is happy. 'They are just trying to help' -but whom they are actually helping is supposition in need of analysis that these good souls would never attempt.

Going out became a nightmare, I was public property. People either staring intently into my face, or quickly looking away. I have been told by friends that the notice I cause is due to the disparate images I present -'I'm young and attractive, I don't present the "disabled" image expected' (you work out the implications of that one). Places I had taken for granted became inaccessible to me, cinemas, restaurants, many shops, people's houses, etc. We devised unorthodox methods for combating society's thoughtlessness (and subconscious efforts?) to exclude me, I went piggy- back (feminism gone wild!). In need of some light relief we decided to storm *The Life of*

Brian - it's amazing when you think about it that people who logically need cheering up and entertainment are the very people who are most often denied it. (Cinema modern, many, many steps, no lift.) We managed to get in at a slack time, and after the film, sat in our seats like a couple of fugitives, hearts beating, waiting to make a break. Now - it would be quiet - made our way to the foyer only to be confronted by a huge queue, mouths agape, who watched our every movement into the chair, which had been carefully hidden away in a cupboard as an unusual object. Implicit in the crowd's behaviour - what's a person like you doing in a place of enjoyment? Moral tale: Know your place - but then I always have had trouble with that one.

So, I wheel through this wonderland which for me, by accident, has become a nightmare, a living embarrassment. I'm told I'm lucky, Ian is told how wonderful he is, I am told how wonderful he is and how lucky I am. It's great for the self-esteem (it's a well-known sociological/psychological fact that we 'disabled' have low self-esteem). Implicit implication; he's wonderful/a saint for staying with an undesirable property like you. You (disabled) are lucky not to be alone, unwanted in an institution. No one has ever said he is lucky (unthinkable), or he obviously stays with you because you give as much as you take. But then of course, that's an unthinkable proposition, isn't it?, After all I'm only one of THE DISABLED.

PS. I realise that a lot of what I have said will be unpopular, or that I can be dismissed as bitter and twisted. Dismiss me if you will, as society has dismissed the feelings and protests of blacks, Jews, gays, women for centuries. Historically it has been proven that powerless groups are not given recognition until they demand and fight for it. Like- wise I am not asking for my rights and humanity to be given a place in this society, which like it or not, I belong to - I demand it.

PAT

Pat, who is in her early 30s, contracted polio at 2 years of age which left her paralysed from the waist downwards. She walked with the aid of calipers and crutches until recently but is now confined to a wheelchair due to spinal difficulties. She worked as a secretary for a number of years with the Civil Service until she obtained a place at college and later university. After university, Pat worked for the Royal Free Hospital as Co-ordinator for a Research Project in diseases of the heart, as a secretary for the National Bureau for Handicapped Students and currently full-time Advisory and Information Officer for the Disablement Income Group, where she advises on the financial problems of, and for, disabled people. She was awarded a Winston Churchill Travelling Scholarship (1980) to study self-help housing schemes in Alberta, Canada, for mentally and physically handicapped people. She is on the Management Committee of the Crossroads Care Attendant Scheme and Chairperson and Founder of the Islington Disablement Sports Association.

'Your mummy has gone to heaven', said my aunt and with that phrase I knew I had become an orphan. My father had died shortly after I had contracted polio when I was two. I was ten and my brother fourteen years old. Family life had thus ended when

mother went to 'heaven'. When she died, we had been living in Essex and, being disabled, I attended the local mixed school for mildly handicapped children. My brother went to a boarding school in Suffolk. Attending different schools, in different areas, meant we came under the care of two different education authorities and this fact changed the pattern of our lives. It meant we went into the care of two different authorities with different ideas on how their charges ought to be cared for. My brother was fostered with one set of relations during school holidays, whilst I was to be shared between two families. I was whisked away to a special boarding school for both mentally and physically handicapped girls. Rather than catering to the particular needs of each disability, the school was more of a dumping ground for society's outcasts. As far as the school was concerned, the common denominator was disability. The fight for survival as an individual was on.

Being females, we were not, unless very bright, expected to amount to very much and the level of teaching was to the lowest and slowest of the class's mentally handicapped. For example, I was a particularly good reader. Reading lessons consisted not of individuals reading aloud or to oneself but a clock-wise session of each individual, whatever level of reading ability, struggling to read a passage. I used to carry on at my own pace and ignore or forget where the last one had fumbled to. Consequently, I became a target for 'not paying attention' and not finding my place in a book. I had often read it more than twice by the time the class finished it and had lost interest. Taking parts when reading a play proved disastrous and pathetic, as there was no semblance of continuity or cohesiveness.' For '0' levels, the teachers had to tutor the four of us by postal course. It was dull and uninteresting and no one had time to explain 'homework' - whatever that was. Their expectations for our future were either continuing in residential care or being a seamstress. At all costs it was essential that we learn to appreciate a Victorian view of being a woman, sit passively listening to classical music, if possible learn to play a musical instrument, be able to sew the most intricate things and have courteous manners. The norm was passively to obey, at all costs, one's elders. The rebel in me was thus born and forged. I resolved that I was not going to become a seamstress or a 'cripple' in a home. I was going to shape my future or die in the attempt. As I went through my teens I found I was not expected to have adolescent feelings of sexuality or wish to wear pretty things. A disabled woman was a neutered sexual being and a dependent on society and always to be 'grateful' for what was meted out. The burden of passive oppression was crushing. For example, a small thing that incensed me. Every time visitors, particularly the governors, came to the school, we had to remove the awful pinnies that we had to wear at all times, brush our shoes and be ready for inspection and 'answer up' to questions anyone might ask. I was nearly expelled when I smuggled the pinnies back into the class and made everyone put them on just as the governors came into the classroom. The pinnies never fitted and were always marked with slops by those who had difficulty with eating, and by the general debris of the week. It was a shock-horror situation and when asked to explain my actions I tried to explain what it was like to be viewed in a cage, be talked about as if deaf and that people ought to see us how we really were - pathetic creatures shut away in a cupboard of society. One became valueless without shape or form. Every year the RAF held Christmas parties where everyone was treated as an idiot child. Once, when I was thirteen years old, I chose a cuddly toy off the present list and the man who gave it came up to me and started talking to me as if I was four years old. I told him to 'sod off' and was marked as an ungrateful being.

In my school holidays I was beginning to realise that I was not individualistic and self-assertive as I thought and that I had no choice about my life style. The education authorities only allowed school uniforms at all times. My friends at home wore pretty things and were gradually having ideas for their future. My future loomed before me as a struggle to shed the bonds of anonymity. My brother was taking his, 'A' levels and laying the foundations of a successful career. Our single reunion every school holiday showed me he spoke well, had a sense of dress and knew where he was going. I felt ashamed. He would tutor me, on his visit, through a book on how to pronounce words and spelling. The school was asked to give me particular attention in these areas but after one or two lessons, it was decided that it was unnecessary! I was expected to do nothing and fulfilled their expectations but with a burning desire to prove everyone wrong. My brother was expected to do well and he did and eventually slipped into his university place.

As a young girl, I was keen to wear fashionable clothes but the two visual images of womanhood were denied me: that of bodily beauty and a sense of fashion. I was plump and as I rarely had any clothes and only those decreed to be 'practical' I did not develop any dress sense. In fact I can remember the two dresses, two jumpers and the three blouses I had. Society quietly decreed that I need not bother to become a 'woman'; my disability precluded such a luxury. But what was worse, it placed me, as I developed, into the Catch 22 syndrome. That is, I could not choose to opt out of a sexist role -if I did my choice was not recognised as a positive decision but just part of being 'disabled' and therefore my style of dress was not important. Consequently, the silent pressure by society towards my non-sexuality forced me to take a sexist role in order to demonstrate my womanhood; in fact I needed to be ultra-feminine to appear 'normal'.

When I left boarding school at fifteen I went to live permanently with one family and attended the local ordinary school, where I flourished and became a studious pupil. The contrast was so very different. I was expected to study hard, take exams, complete homework and participate in all school activities. Although I could not actively join in with gym, I was expected to attend and sit on the side-lines catching up on homework. This was a delight to my school chums who used it as an excuse to 'keep Pat company' but the gym mistress soon caught on! Outings to factories were part of the school curriculum and in my class I became the focus of a threatening classroom strike. The class were off to visit a paper mill but when informed that I was not going because it would be too tiring for me, the class decided none of them would go. No one had asked me and the class decided I ought to choose for myself. Naturally I wanted to go and eventually, we all went and had an enjoyable day!

As I was still in the care of the education authority it was decided that I should play the other strong female role, that of being a secretary. As I was fairly bright it was felt that the future was a good one. Unfortunately, I had no intention of becoming one and the thought of spending my days in an office gave me claustrophobia. It was decided to send me to a secretarial training college. The college specialised in retraining for those who had sustained mild industrial injuries, consequently the emphasis was on hard work and high job expectation. I underwent the course and it did prove useful over the years but college also taught me other things. I was already 'courting' and as

female students were in great demand, I realised sexuality was a viable commodity for companionship and good fun. Also, I learnt that I was expected to hold down a job and look after myself. At 17 years the education authorities decline responsibility for their charges and leave you to fend for yourself to find a home and a job. Although it had always been considered that I needed special care and attention because I was disabled, once I had reached the age barrier all responsibility for my 'special' needs ended. I found a job and living quarters in London where I repeatedly tried to break from the secretarial mould. I was too late to gain further education, I was told, unless I persisted at evening classes. My social life was so full of sports and people that I had little time to study at night. As I had had a poor education, I really did not know how to study or write an essay. Eventually I learnt that there was a women's college where one could study without 'O' or 'A' levels. I applied and was accepted. During the course, I developed a burning desire to go to university. An aunt of mine said that this time 'I really had gone too far' and was too ambitious for my disability and educational abilities. There is a very firm belief by those in authority that a disabled person should, at all costs, have a 'secure' although boring and dull, job and once this has been secured then that is one's niche for life. I knew that I could never live such a fate and keep my sanity. I resolved to redress the imbalance of my early education. This proved a formidable task.

There are very few technical colleges that will accept a student without 'O' levels and certainly not if they are a poorly educated and disabled person who already has a good job with the Civil Service. I applied to college after college, went to interview after interview. Sometimes my lack of education was used as an excuse for those not wishing to take a disabled student. I was told that I could not climb the stairs involved, despite having just walked up them. Some blatantly stated that I was lucky to have such a good secretarial job in the past particularly being disabled - I should be grateful, should forget wanting to be anything else and would not get into university anyway. Eventually I went privately to a career guidance centre to see if I was overreaching myself. The analyst said I had potential to do 'other' things but that my disability precluded these and secretarial work in the Civil Service was the best place for me as it was secure. Rather than pacifying me and encouraging feelings of security, it only added fuel to the burning desire to 'better' myself but I did not know how or what form it would take. I felt I was moving down a long black tunnel with no light at the end and no one willing to reach out and help.

I have been blessed in my life with extraordinary good friends and these have always been my life-lines and without them I flounder. They encouraged me to reach and fulfil my own expectations despite my disability and poor education. Eventually a technical college took a chance and decided to enrol me for 'A' levels. I am sure the head of department felt sorry for me having applied to so many places and failed. My friends encouraged me to apply for university even if it meant going to one and banging, literally, on the door and demanding acceptance. I had been brought up to think that I had nothing to offer the world but to accept the role that society decreed, with pity thrown in for good measure. I could never bang on anyone's door and demand entrance but I resolved that I would have something to offer so that I would not be refused.

I gained my 'A' levels and the following year entered university as a mature student. It was worth every inch of the battle. I discovered myself intellectually. Everyone is worth something however small and nothing is so satisfying as self-fulfilment. Although society cares to give me the stigma of being a disabled person, my own self-fulfilment allows me to lay that aside as an unimportant matter. For many disabled people who have never been encouraged to succeed in anything and are forced to wear such a label, it can often take them over so that all one sees is a disability and not a person. Everyone in life needs encouragement and needs to gain confidence in themselves and for me, university was that watershed. Whether one feels oppressed by the stigma of disability, forced into a sexist role or whatever, the important thing is that one is never alone and others can and do feel the same. But above all, one must be oneself as much as possible.