

**Images of Ourselves: women with disabilities talking, edited by Jo Campling
(pages 57 – 82 in the original text)**

RACHEL

Rachel, who is 38, has epilepsy. She trained as a nurse and midwife prior to becoming a ward sister of a busy surgical ward. Her interest in education grew when she was invited to take a post as a teacher of pupil nurses and from there she undertook a training at London University for the Sister Tutor's Diploma following on with a degree in psychology and philosophy. She is now a senior tutor in a London teaching hospital. Her interests include voluntary work for St John Ambulance Brigade and for this work she was admitted as a serving sister to the Order of St John in 1979. She is a member of the local parochial church council, a governor of a local school and an active member of the British Epilepsy Association. She lives in London with her husband.

Most professional nurses would agree that there are many rewards in their jobs other than security and promotion prospects. In my former work as a senior ward sister a fundamental psychological need within me was fulfilled. A desire to nurse had first entered my mind at two years of age and had remained with me throughout my career. At last after years of waiting I was doing the work that I had always wanted to do. I was happy and contented and working long and sometimes hard and difficult hours. The privilege one had of helping the sick to get well again or the permanently disabled to come to terms with their disability or the dying to die in peace and with dignity was the most wonderful experience for me and one that I felt I could do for the rest of my life. Deep down inside me I really believed that this is what I was put on this earth to do and I studied constantly to improve my knowledge and skills.

My home life was just as full and as exciting as my work. I had a house and a car, I did a lot of voluntary work for the St John Ambulance Brigade; took leading comedy parts in the local drama group and helped to run the Sunday school for the church. My health had always been good, with only five days' sick leave in my whole career.

On 7 December 1967 this life style came to an abrupt end when quite out of the blue whilst on duty one afternoon I had a grand mal epileptic seizure. Once the diagnosis of temporal lobe epilepsy was confirmed, matron informed me that I was medically unfit to nurse. The doctor had interviewed my parents, telling them that in his opinion I would possibly have to take anticonvulsant drugs regularly for the rest of my life. He advised my mother that I would be best living with someone who was willing to take care of me making sure that I took the drugs at the right time and that I did not get into places which might prove dangerous should I start a fit. Mother immediately said I was to go home and live with them. At the same time both my parents were extremely distressed at both the diagnosis and the prognosis. It was very traumatic for me to see my dear parents so upset.

I gave hours of intensive thought about what line of action I should take. The fits were frequent and irregular but I became quite convinced that at all costs I must endeavour to lead a normal independent life. I did not agree with the doctor's idea of the management of the case. Being basically an honest straight-forward sort of person I

told the doctor that I did not agree with him and consequently made an enemy for life. My request for a second medical opinion was agreed and arranged but once again concern was expressed about my apparent lack of acceptance of the epilepsy; this made me really quite angry because I failed to see how anyone could not accept it since the fits interfered with my daily life very much. The second medical opinion confirmed everything that had already been said with the exception that the second doctor said he could see no reason why I should not attempt to train as a teacher providing I understood that there would be restrictions on certain types of teaching. I asked if I could become one of his patients but he said he was shortly leaving the area to take up a post in Manchester. My fight was now on. I was going to train for a teacher and nothing was going to stop me.

The fits continued and I kept being admitted to hospital. Lying in the hospital ward I had time to think. I cried a lot because I was now really beginning to miss my job. I thought about some of my ex-patients who would be returning to the ward for more surgery. One evening three old patients called to see me. This was more than I could stand and they had to leave prematurely. I was at a very low ebb because I felt so horribly alone. The staff didn't seem to know how to talk to me. I tried to chat to the nurses but sister would call them away, she was still very angry with me because I had argued with the consultant and asked for a new doctor to look after me. One morning quite spontaneously I refused Holy Communion. The chaplain looked annoyed but said, 'That's all right.' I knew jolly well it wasn't all right and began to feel guilty, but at the same time realised that I must take a grip of myself. I must have faith in God if I was going to gain any strength in myself at all.

The anticonvulsant drugs made me very drowsy. If I sat in a chair I would fall asleep for long hours and then awake with a pool of wet and dry saliva down my front. Medical advice said that I had to choose between the control of the fits or a drowsy state. I decided to keep taking the high dose but to walk whenever I could, to stop myself falling asleep. It was very hard going but it worked. My first success at rehabilitation was all my own work. I felt elated that at long last I was achieving something. I was living in my house, doing my housework and shopping and getting in with society again. Within a very short time, I learned that society found grand mal epilepsy upsetting, distasteful, frightening and that I was becoming a local nuisance. My behaviour during a fit made people think of insanity because I made strange noises and after fixing my eyes would then start to roll them. Oddly enough no one in hospital had ever told me how I behave whilst unconscious. It would have been such a help if they had, because I did not wish to frighten people and when I realised I was doing just that it was very sad. Upon awaking from a fit people might be comforting each other or telling me in an aggressive way that I had no right to go out on my own in such a bad way.

I hadn't realised that I was causing all this unrest locally. Some people were very sympathetic and kind, some could not understand my attitude. My attitude towards the fits was that they were very inconvenient because they were so unpredictable and left one feeling absolutely dreadful in the sense that one felt drowsy, nauseated, thirsty, cold and damp. Damp because during a fit I am copiously incontinent of urine and sometimes incontinent of faeces. By-standers to such an event, quite rightly so, found this extremely unpleasant.

More important to me than my own attitude to epilepsy was the attitude of my friends and work colleagues. They were all very shocked about what had happened to me and basically could not see how I might manage a job or further training. I became very annoyed with this negative attitude because as a ward sister, whenever any of my patients had to cope with a disability or retrain for other employment, I not only encouraged them, but if they needed me to help or support, I considered it very much part of my role to do so. This sudden realisation that there were, in the National Health Service, professional people who could not see beyond the clinical condition to the psychological and sociological implications of the disorder, shocked me at first beyond words and then verbally I became very fluent on the matter. Thirteen years later I am still appalled at this aspect of patient care. I consider it the duty of all professional people dealing with disability of a long-term or chronic nature to meet the patients and their relatives and friends and to learn from them the needs of the patient. Professions must, before giving advice on 'aftercare' be taught by those who have a deep understanding and experience. Patient organisations serve a very useful purpose in this area. For me the British Epilepsy Association is doing this job with the utmost tact and efficiency.

In the early days most of my professional friends thought I was either highly ambitious or just plain mad when I talked of enjoying life again. I planned a trip to Scotland and stated that when I returned I would have decided upon a new life, going up, over or round any obstacle that got in my way. Talk got round that I was becoming aggressive when I discussed hospital care, self-centred when I talked of future employment and manic when I had learned to laugh at the various situations which I inevitably got into. I argued back, which in one sense was the worst thing to do, because before being ill I had been an extremely gentle and placid person. This all confirmed a change of personality. It was most frustrating because for me it was this new hostile environment that I now found myself in, which had brought about my reaction, not the epilepsy. Fortunately prior to 1967 I had never been in opposition to anyone.

It seemed to me that the doctors and nurses looking after me had a most appalling lack of insight into the problems of a patient with epilepsy and I told them so. I also told the matron, who told me I was just a trouble-maker. Her new deputy heard this conversation and came to my room later to tell me in a most gentle way, to keep my Christian faith and be patient, because I would not always be looked after by people who did not understand. I was amazed at what she was saying. In her quiet way she left me wondering if I had dreamed the last ten minutes. The deputy matron had also seen my mother and had likewise given my parents some positive comfort. When I see people now who are new to epilepsy I try to have that same approach to them as that deputy matron had to me and my relatives.

Sister, because I repeatedly kept coming back into hospital, suggested to my mother that I should stop trying to fight the inevitable. Mother became very distressed and it was obvious that the conflicting ideas of sister and myself were beginning to take their toll of her, so I went home with my parents. Doctor and sister explained to them I should lead a quiet life, free from anxiety because worry and anxiety might precipitate the fits. This time I really lost my temper with them. I refused to do this. I was going to lead a normal life and take my responsibility in the world like any other

fully fledged adult. It was true that I would take the drugs regularly as prescribed. I would not take alcohol or drive a car or put myself physically in any position which would prove dangerous to me should I fit. Apart from that I was going to be little old hard-working me, if only to prove them wrong! I cannot remember ever being so angry with anyone like this before. I told my consultant that I would use the media to try to give confidence to disabled people - to go out into the world and develop into people with the confidence to do their own individual thing in contributing to society, because I felt that the professionals would not help them in this way. My empathy for the sick had increased so much. I also told doctor this and he told me that I had got most things out of proportion again. I was livid.

Living with my parents was difficult because they saw too many fits. I had managed to keep the frequency of the fits away from them while living at my own place. My fits were bad. Sometimes I would fall all the way downstairs or bang my head on the nice oak furniture or fall in the street, so mother's neighbours started to talk, as my own neighbours had done. My parents did not sleep very well at night because sometimes I would fit in the night and they would hear me and come to me. Mother would come into my room every time she heard me turn over in bed, thinking that I was unwell. I sensed the strain on them both and returned to my house where they visited me frequently. My mother had developed an intermittent loss of memory which she still has.

On returning home I went through a patch of really long-lasting fits. This was new and worried me a great deal. Was it possible that I could be getting worse? It had never occurred to me that that could happen. Over a period of six days I had sixteen fits as far as I could count, then I passed into *status epilepticus* (passing from one fit into another without gaining consciousness). I owe my life to the very same professional people whom I had fought with so much. Their skill at managing the acute situation was, and still is, of the highest order.

I gained consciousness with their superb care and drug therapy. Sister came on duty and said, 'Hello, I see you have been misbehaving again.' I felt terrible but because they had saved my life, I could not bring myself to tell her that nurses did not speak to sick people as though they were public trouble-makers. Sister turned to a pupil nurse and said, 'Stay with her, she's really bad this time and we don't know if she will go into *status* again.' This time I couldn't contain myself, so I replied, 'We sick patients do not need to be told how bad we are, Sister. Such news delays our progress.' 'You be quiet and do as you are told', she said. The pupil nurse came in and she started to cry. She was the very same girl I had taught surgical nursing. Despite a drip in my arm and ECG leads on my chest, I managed to put my arm around her and give her a paper tissue to dry her eyes. 'Oh Sister', she said, 'Why did this have to happen to you?' At the name 'Sister', I started to cry. 'What is going to happen to you?' she said. 'You always will be my favourite Sister, I wish I could help you.' During this time the film *Sound of Music* was very popular, so I tried to comfort her by saying, 'Well, nurse, you know what it says in the *Sound of Music*, "When the Lord closes a door He opens a window". I am just looking for my open window, it's going to turn up some day and in the meantime, we must just wait.' A staff nurse was passing by, she rushed in almost shouting at the pupil nurse, 'What's this she is saying about jumping out of a window?' Nurse wept loudly and was removed by two nurses. Sister came. Staff nurse reported

that she had overheard me telling the nurse that I was going to jump out of the window. Sister said, 'We must inform doctor and matron.' The deputy matron came instead. The pupil nurse had told her the whole story and she said I was not to worry, it was just a misunderstanding. The ward lights were out, it was nearly midnight. She told me that the junior consultant whom I had worked for and herself were trying to get me into teaching. She said I was to trust them and to carefully consider going to London to train because she had contacts at the National Hospital for Nervous Diseases and she was certain that once I was living in London that hospital would be very willing to look after me. It all seemed very strange to me. I wouldn't really mind going to London, I would be able to attend the Old Vic regularly which would be super.

Next morning a new doctor called to see me and enquire about what I had said the night before about jumping out of the window. I told him what had happened and suggested that he contacted the pupil nurse. 'She's gone off sick,' he said. 'Are you a psychiatrist?' I asked, 'Because if so, I wish to see what has been written in my notes.' He showed me. A note had been added regarding a possible thought of suicide. He asked me if I was depressed, adding that if he had my little lot he would be. 'That just goes to show that you are more unstable than I. No, I have no intention of leaving this world until I have done something about the care that patients get to enable them to go out into the world with their disabilities and live active useful lives.' He left me without telling whether or not he was a psychiatrist - I looked him up in the medical directory later and found out that he was! Next day my own doctor called to see me and spoke to sister. 'Did Doctor - prescribe her any antidepressant drugs?' Sister said he didn't. 'I want her to have some when she goes home.' Six months later he told me how much better I looked and he felt it was largely due to the combination of antidepressants and anti-convulsants. I told him I disagreed because I had never cashed the antidepressant prescription and had no intention of ever taking any such drugs. I never went back to see him - I dare not go because he was so angry that day. I think I am bad for his health. From then on things got better and better for me. The fits occurred only two or three times per week, the drowsy state got better and every time I thought I was going to fall asleep I walked a mile or so and got over it. I was accepted by the first college that I applied to. The professor told me that everyone would be most helpful should the fits occur in college but for my part I had to maintain a high academic standard as no concessions could be given to me if my standard of work became poor. To be accepted was a terrific ego boost. In September 1969 I started. The newness of London suited me fine, very few people knew my medical history, I started to use my other christian name because I just wanted to forget the past. It all worked so well, I got interested in many things, joined various student clubs, started drama again, got elected to the local church PCC and made London my home - as it turned out for ever, because I later married a London man and we are very happy living and working within London. The National Hospital for Nervous Diseases look after me and their kindness and understanding is of the highest order. All that I am now, I owe to them, to my professor and my college tutor, I obviously could not fight on my own, I needed people who understood epilepsy and understood me.

As the teacher training came to an end I had to start looking for work, someone tipped me off that a school in London had a principal whose mother was epileptic. One

person on the interview panel was not at all happy about employing me, but the principal won the argument; three years later I got into the London teaching hospitals. I know now that to be stretched in one's job is right. Drugs have to be taken with absolute regularity in order to maintain a uniform blood level of drug, no alcohol can be taken. The latter is really quite tough because at parties one remains stone cold sober and consequently observes all sorts of behaviour and eventually gets bored with it all! Sometimes people try to encourage one to indulge, once or twice I have discovered my fruit juice laced with alcohol. That annoys me very much. I take my pills regularly in the loo because it saves answering questions or being said to be very neurotic. Actually they taste dreadful so I would prefer to take them with a nice cup of tea.

For years now I have had an aura before a grand mal fit. The aura is tingling in my left arm, and I lose consciousness about two minutes later. This gives me plenty of time to get myself into a safe place and hopefully a place on my own. I can then lie down on the floor, pull my skirts up to prevent them becoming wet with urine and then wait. Mostly I can be back in circulation within 30 minutes. It is better however, if I can lie down for a little longer because I feel pretty rotten. In the daily routine it is not always possible to rest. My fits now are very well controlled and have occurred during the night mostly. I am also prone to petit mal fits. These fits are very short absences, i.e. of a few seconds. One does not even fall to the ground and no bodily harm is done. Most observers would not even be aware of anything happening. However, from a practical point of view it can be a great inconvenience because during an absence one is not aware of what is going on. For example, listening to a lecture, if a petit mal occurs, the message will be interrupted, thus altering the meaning. I have now learned to overcome this by, at lectures or meetings, taking meticulous notes and then comparing them with other facts on the event. Petit mals occur much more frequently than the grand mal. Therefore, it would be quite wrong for me to attempt to drive. If I have a petit mal when walking downstairs, I usually end up by falling down the rest of the stairs. Fortunately, people do not think of the basic problem being epilepsy. If I have a bad week, people may comment about my clumsiness but that is certainly the lesser of the two evils.

JUNE

June, who is 38 years old, is an only child and was born and lived for the first five years of her life in India. She has severe cerebral palsy, incurred through injuries at birth, and can live in the community only with the continual help of attendants. She has a BA Honours in psychology and a postgraduate diploma in youth and community work. Her work experience has included being a warden of a hostel for homeless boys, running a night shelter for boys, a club for 'Hell's Angels' and a spell in a drug addiction centre. June now lives in Manchester. She is a part-time tutor with the Open University and a full-time mother.

'How could you do it?' was a question which had many nuances and was put to me by many people, during and after my pregnancy. The GP wondered how I could have had intercourse in my 'predicament' (as a good friend invariably describes my situation).

The gynaecologist wondered how it was socially possible for me to bring up a child, and social services merely stood on the side-lines, not offering any practical help but making me feel they were wondering how I would maintain myself and my child in the community, waiting for the first opportunity to take my child away from me. I went so far as to ban the social worker from the house after my baby was born because they had been so unhelpful to me during my pregnancy and I did not wish to support their professional voyeurism. You see, not only was it immoral to be an unmarried mother but it was doubly immoral to be an unmarried mother AND a severely disabled person daring to produce a child - a normal, healthy, beautiful child.

However, they were not the only people asking questions - my head never stopped buzzing with them. The first question was the physical safety of the child and myself if the pregnancy was to be continued. I arranged to see my orthopaedic surgeon in Sheffield. His genuine pleasure and reassurance when he heard of my pregnancy gave me great comfort at a time when the only word I was hearing was abortion. This man, Mr Sherrard, has my greatest admiration for his sensitivity, patience and compassion. Once I was assured of the safety of the baby and myself, my friend's words rang in my ears and my resolution to have a very wanted but unplanned baby was made stronger.

The gist of the discussion we had had a few years previously had been that one should not wait for 'the right moment' to have a child for this 'right moment' rarely came. My friend, who was not disabled, had her child two years before I became pregnant. She, like myself, was not married. While thinking of her words I remembered the numerous times I had been told I could not do something and had proved everyone wrong - for example going to university and living in the community with the assistance of an au pair and fellow students. However, I did not minimise the difficulties that would face me.

Other questions passing rapidly and constantly through my mind were from where I would obtain my helpers, how I would pay them and how I would accommodate them adequately. I realised that I would have to employ two helpers - one to look after me and one to look after my baby - and that the two-bedroomed private flat I rented at the time would not be adequate for four adults and a baby. My boyfriend was living with me at the time. Thank God, I was surrounded by staunch long-standing friends and relatively new ones who were morally and practically supportive. They spent many hours in libraries looking up charities I could apply to for extra money and many more long hours helping me to write letters to them, my MP and social security. I also put my name down immediately for a four-bedroomed council house, as I felt that the two helpers deserved their privacy as their hours of work would be long and the emotional and psychological stress would be great. In fact, I received a three-bedroomed council house when my son was eighteen months old. Eventually, when I felt it was psychologically bad for my son not to have his own 'personal space', my helpers had to share a room thus reducing their privacy and their 'personal space'. This produced its own traumas and eventually led to an irrevocable crisis which has only recently been satisfactorily resolved.

My applications to numerous charities proved fruitless and initially I had to rely on the extra - but inadequate - money my MP obtained for me from social security. Later with the aid of a sympathetic and relentless welfare rights officer, to whom I am much

indebted, I embarked on a long and complicated battle with social security which has only just ended in a final tolerably satisfactory payment for myself and helpers.

The next hurdle was finding the helpers! Fortunately for my baby and myself a friend in the block of flats where I was living was an English teacher and had taught and made friends with an au pair the previous year who wished to return to England during her summer holidays. She was German, clean, efficient and capable. She gave my baby the best start in life for which I could ever have hoped. After Ursula, who became a good friend and the baby's godmother, had left, my unending search for au pairs began. Only two agencies, out of the many I contacted throughout the country, were sympathetic to my specialist needs. Au pairs are only allowed to work five hours a day and I and my baby needed constant attention. Ursula also worked hard in Germany, finding me an agency, who supplied me with suitable girls at spasmodic intervals. There followed an ever-increasing number of girls - mainly French and German, with an equal number of crises, before the arrival of one or the departure of another. Some were excellently efficient, others tried hard, while a few were totally incompetent. Their period of employment ranged from nine months to one week, while recently two eighteen-year-olds beat the record by staying the course for the great duration of three hours! They were, in fact, from the Italian Riviera so that Moss Side, an Inner City area with a high immigrant and generally poor population, must have been quite a shock for them! Finally, the agency from whence came these girls retracted their invaluable service in January 1980 and I was left with no other sources to which to turn. Fortunately, a long-suffering friend came to my rescue and offered to help out for a short while. Seven months later, not only is she still here but she is looking after myself and my small son, virtually single-handed, while a long and arduous battle has ensued between myself and social services.

When my au pair source 'dried up' I turned to a voluntary organisation, Community Service Volunteers, who run a 'one-to-one' project with disabled people, helping them to live in the community. However social services are reluctant to make a small monetary commitment. This is very frustrating as the contribution they are being asked to make is a mere 'drop in the ocean' compared with the commitment they would have to make if they took my son and myself into care!

My pregnancy was normal and healthily boring. I had no strange cravings, high blood pressure or any of the other symptoms associated with pregnancy, which I was expected to have. The only discomfort I suffered was 'night sickness' for the whole nine months and not being able to drink alcohol. This latter affliction caused great frustration to myself and great merriment to my friends. There is nothing more frustrating or irritating than seeing drunken friends through sober eyes at parties, wishing you could be equally drunk and equally stupid. I was, at the time, at college doing my postgraduate diploma in youth and community work.

Being pregnant did not stop me from doing any of the things I was used to doing - from hitching down to London during my fourth month, to going out to parties and generally socialising, or working on placements. I felt that being pregnant was not a reason for opting out and many arguments ensued with my tutor, who felt that I should not exert myself doing placements because it was bad for my health and unfair on the baby. On the contrary, my arguments were that as I had never felt healthier or more fit

it was ludicrous to sit around languishing and brooding when there were so many interesting things to do and so little time in which to do them. Besides this, not many mothers or 'mothers-to-be' could afford the luxury of lying around being pregnant. I was even more aware of this than usual because I had just finished working with single-parent families on a council estate. My placement had been to 'set up' a club for them, with the help of another student on our course.

The real stress during my pregnancy was of an emotional and psychological nature. Although both my boyfriend and myself did not believe in abortion and I had made a positive decision to give birth to and keep my baby, we were both very very 'scared' about the future and how we would over- come the problems mentioned above. His natural reaction was not to talk about it or plan for it in any way -in fact to pretend it wasn't happening. This was partly my reaction as well because when I thought of the future I became panic-stricken and overwhelmed at the enormity of what I was 'taking on'. However, at the same time, I felt resentful at not being able to enjoy my pregnancy and plan together with him the coming of our baby. I confided this to a nurse, during my last few weeks in hospital. She assured me that this was very normal and that throughout her pregnancy all her husband wanted was a dog! I had to have a caesarian section and although my baby was a healthy Sib 13 1/2oz boy, it was hospital policy to keep caesarian section babies in an incubator for twenty-four hours. Thus the only person to see him in the first twenty-four hours was 'his dad'. After gazing at his son for twenty minutes he tore himself away to announce that he was the most beautiful baby he had ever seen.

The hospital staff were incredibly sympathetic and spared no efforts to help all three of us. The gynaecologist, after he had lost his two-hour-long abortion battle, refused to co-operate on any issues with me. I was fortunate because two of my friends were pregnant at the same time as me and were able to advise me. When I asked my gynaecologist for a prescription to prevent my sickness, his answer was, 'That's what being pregnant is all about, and you wanted to be pregnant!' He was also horrified because I expressed a wish to breast-feed my baby and categorically refused to allow it. However the nursing staff said it was none of his business and promised to do everything in their power to assist me. I think all the staff were pleased to be witnessing such an out-of-the-ordinary type of confinement and, thus, were only too eager to help me in any way. I was also fortunate in that there were not too many confinements and births at this time so that the staff were not rushed off their feet. Also, I was in hospital for six weeks before my baby was born, owing to premature contractions, so that the staff were familiar with the situation.

When they brought my baby to me I just could not believe that this tiny perfect being with a mass of dark hair, tiny clenched fists and a little red face was really mine. I had helped to give him life. I had nurtured him for nine months inside me and now here he was, a reality, the most precious gift I had ever been given. Suddenly I knew that all I had gone through to make him possible and all that I would go through in the future to ensure a happy, healthy, loving and fulfilling life for him was worth every effort. I had no problems in breast-feeding, apart from finding the best position to hold him. He was a very adaptable baby and I successfully fed him myself for three months. For me, this was one of the most wonderful experiences of my life and created that bond between us that might otherwise not have been formed, because of the sheer

practicalities of the situation. I could not do one physical thing for my son unaided. For a long time I could not really believe that I was his mother and that he was really my offspring. I think most mothers feel this during the first post-natal months but the constant attention required by a new-born baby soon makes this a reality, because, I am sure, only a mother could do this. Now my child is nearly four years old and the wonder of knowing he is mine is no less. Now the physical attention he needs from others is less, and the emotional and psychological support he needs from me is greater. Thus the bond between us becomes stronger daily.

The future is uncertain for everyone but for me it is a hundred per cent more uncertain and from long and bitter experience I have learned not to look too far into it. However, there are a few things of which I am certain. No one will ever take Frank away from me. He will grow up in a happy and loving environment and will be as secure and as well adjusted as any other child with two 'able-bodied', parents. He will, however, have the advantage over other children because his sensitivity and tolerance will have been heightened by his environment and hopefully, he will learn to live life to the full and be sensitive to the plight of others. My last wish for the future is that although Frank is the most precious thing in my life, when he is old enough to lead his own life he will feel free to do so and not be pressurised by feelings of guilt or misguided 'duty' to stay at home and look after me. I have led a full and relatively happy life and this is the legacy I would like to give to my son.

DIANA

Diana, who is 39, had a very severe attack of polio when she was 13 years old. She was paralysed from head to foot and spent four weeks in an iron lung. Her next three years were spent in hospital at Oxford, where fortunately there was a hospital school. From there she went on to a college for disabled people to do a secretarial course and eventually into her first job. Over the years she has gained a great deal of independence and now drives an ordinary adapted car. However, she has only one working arm, very weak legs and shaky balance. She can only walk short distances on crutches and is much safer using the back of her wheelchair when she can sit or walk as she pleases. She now lives and works in London and has recently married.

For the disabled woman who is career minded or just wants to work, the difficulties placed in her way are not only the physical ones of coping with the disability linked to the access problems, but more often the subtle psychological ones that can have a far greater effect on confidence and her own awareness and understanding of her disability. My first job lasted for twelve years, by which time I was aching to move on, and had achieved a degree of independence that would allow this. The low expectations of the Disabled Resettlement Officer (DRO) I sought help from in this attempted move made me realise she had no idea of what I could do and without actually saying so implied I should stay put as I had a good job. My second job led on to a great deal of confidence building by my boss which finally allowed me to apply for a job which would mean commuting in and out of London each day - something my family frowned on, but allowed me to really test out my capabilities, leading

eventually to living in London.

My work has always been in the health service in the rehabilitation side, for the first years in a spinal unit, where I found myself identifying problems that newly disabled people and their families needed help with in helping themselves, and then into a mental handicap hospital where I saw similar problems. As this was a small hospital I had a lot of contact with the families of mentally handicapped people and learned a lot about their difficulties. From here I went on to develop in London the newly formed Spinal Injuries Association and had the opportunity to try out some of the ideas that had been gathering in the back of my mind whilst working in the spinal unit. I now work as part of a team looking at the needs of mentally handicapped, mentally ill, elderly or physically disabled, most of my work being concerned with physically disabled. Whilst the onset of disability seriously disturbed my own school career, the experience gained through various jobs and my own personal experience of disability help me in my present post. A lot of this work is concerned with attitudes to disability not only of professionals to disabled, but of disabled group to disabled group. My recent work has included a small project looking at employment for handicapped school leavers, and in talking to both these young people and the professionals helping them it has thrown up some interesting things about attitudes to the employment of handicapped people and the experiences of both professionals and employers.

My own first promotion came only because they were unable to find and keep a senior secretary prepared to take the rough and tumble of a busy medical office. After three girls had come and gone, and I had six months of combining my own work load with that of the consultant needing the new secretary, I ventured to ask if I could have the job. It had until that time never dawned on me that they had not noticed the extra work and administrative tasks I had absorbed and carried out without asking an undue number of questions, or things going wrong. I remember being a bit hurt about this, although it was something I was used to, as when being employed on a trial basis I had had it impressed upon me that I would have to work well with the others, this working well often meant I got the most of the 'nasty' jobs - not being able to run meant that I was left sitting when such a 'job' was seen coming towards the office. However I made my request, getting a surprised look and the comment, 'Oh, do you think you could manage?' followed by, 'But it must go to the Hospital Management Committee for their decision.' I remember being upset by this, because I knew that no such decision was made on the other girls who had been employed for such short periods. I was also hurt that of the four girls in the office I was one of two who had secretarial qualifications and I felt strongly that this should mean more in my favour than it obviously did. I remember also thinking over the fact that the comments had been made that I would not be able to run certain errands, i.e. get x-rays, make office tea. These were all little things that appeared to be raised because of my chair, the fact that I got through more desk work on occasions than others seemed to get forgotten. The other thing that did disturb me and made me wonder if I was difficult to get on with was that I accidentally heard one of the consultants checking out how another felt about me having the post. This, I felt, said little for the doctors working in this rehabilitation unit dealing with disabled people, from where medical papers often appeared criticising other employers outside the health service. One thing I had always insisted on at work was that I was no different from the other girls. I took my fair share but it seemed to me that my simple request for the upgrading on the grounds that

I was doing the work anyway had led to a full investigation within the office as to how I got on with people.

In the event I got the upgrading, and suddenly became aware of my own abilities and the fact that I could achieve much more, despite the fact that the other girls felt I should not have had the job and its responsibilities. It was OK while I was filling in, but once I was given the post - 'well, she's disabled isn't she!'

Some four years ago the hunt for jobs led to a very distressing interview which made me stop job-hunting and ask if I could rearrange my London job and hours to fit in with personal and family commitments. It also served to remind me that in some quarters 'things ain't changed'. I had gone for interview for an administrative assistant, again in the health service. By the time I got to the interview board I was feeling a bit tense because I had had to spend half an hour trying to find the office in the hospital, not even the receptionist at the front door knowing the interviews were taking place. Additionally I had had to get help to get down a flight of steps. I should have been warned by this that although they had the information 'wheelchair user' in front of them on the application form, no concessions were to be made.

I am not certain if all disabled people feel it, but one is often aware if the person talking to you is at ease or obviously discomforted by your disability. I always expect to be dealt with in the same way as other candidates at interview, but it was very obvious these three gentlemen were not at ease with me. The board consisted of a young personnel officer, the area personnel officer and the doctor in whose department the job was based. Most of the talking was done by the younger personnel officer. He could see nothing but my chair, worse still he could not even say the word wheel- chair, pointing at my chair and saying, 'How will you manage in that thing?' We progressed through the mechanics of how I would arrange my office furniture to how much help the DRO would give to make the front door of the office accessible. My information on the help that employers can be given on this subject seemed to be totally opposite to that the personnel officer had, and after gently correcting his information once (I had only recently given up a job that included running an information service which included this subject, information this gentleman had in front of him) and getting an icy stare from the rest of the interview board, I found myself closing up. I sat through his comments on the fact that I should have been registered as a disabled person, 'It makes my job easier'. On questions about the actual job I received a sharp 'What do you know?' on an area where I had admitted my experience to be limited, and this was followed by, 'We have young male candidates anxious to gain experience.' I remember wondering at this point whether Oxford and having heard of my marriage and what had happened to me in the past twenty years, wrote saying that they had never realised I could achieve so much. This statement linked into the comments made by one disabled girl I had interviewed on school leaving, confirmed my feelings that expectations for girls in wheelchairs leaving school (unless they are intellectually high flyers) are set very low.

KAREN

Karen was born in Salisbury, Wiltshire, in the 1940s, the eldest of four daughters. She was a perfectly healthy baby until the age of 2, when she developed a tumour on the spine and she is now a paraplegic. Her formal education did not start until she was 9 years old. Then she went through the usual process of special education, except it was perhaps more radical than most, in that she was encouraged to excel academically and became part of the community of the children's home in which the school was based. Four years in a residential centre/workshop for the physically handicapped followed until she 'escaped' to do a secretarial course.

In 1969 she came to London and lived on her own for the first time, working in the education and training department of the National Association of Youth Clubs. She was accepted to do a community and youth work course at Westhill College of Education in Birmingham in 1972 and looks back upon this as the most stimulating period of her life to date. On leaving Westhill she spent four years working for National PHAB (physically handicapped/able bodied), an organisation concerned with the social integration of the two groups. From there she ran a full-time youth centre for an outer London borough, but at the time of writing had dropped out to do her own thing. Karen has made a 3,000 mile trip across the United States in a Greyhound bus. Her addiction is making and flying kites and this has included going up sixty feet on a man-lifting kite. Her unfulfilled ambition is to go hot-air ballooning.

As a child I was never really aware of the fact that I was different from a large percentage of the population, certainly not until I was a teenager. If, on occasion, I was treated as someone special because it was thought that I would not make old bones, my ego was such that I assumed it was because people thought I was a nice person. I often think that it is a pity that kids with handicaps are allowed to get away with anti-social behaviour by virtue of their disability. With the onset of adolescence and all the things that go to make the early teens an unhappy period - acne, a flat chest and the 'curse' - came also an awakening sexual awareness, and the idea that perhaps I was not quite the same as other girls. My unawareness of my disability until that time can be attributed to the fact that all the pupils in my school were handicapped, and the able-bodied children in the home where the school was situated were so used to seeing us around that it didn't seem to make any difference to them.

However, as an adolescent I realised that boys do not react in the same way to a girl in a wheelchair as they do to other girls. It was when I left school at seventeen that this awareness really hit me. However, it was tempered by the fact that I was in a residential centre for the handicapped and was beginning to date boys who were also physically impaired, although occasionally I did also date able-bodied boys from the town. My mother did not help me during this period, telling me to think of higher things, to look for spiritual relationships, because any man who appeared to be attracted to me must be perverted. I am sure that as a mother she wanted to protect me.

In those far-off days of unenlightenment, it was considered impossible for paraplegics to enjoy a sex life, that we should not even think about it, and if we did, then we were not normal. Finally, at the age of twenty-one I experienced real love for the first time and suffered a year of agony and ecstasy. I wanted desperately to 'make it' with the boy

in question, but I never did, for two reasons. Firstly, fear of rejection was now beginning to take hold, and secondly, if you lived in a residential centre you were unlikely to have a room of your own. So the fear of rejection together with the possibility of being caught in the act were very powerful preventatives and eventually we both went our separate ways. Another real problem for a person who is physically impaired by paraplegia, apart from certain physical deformities, is that you are likely to be incontinent and the thought of having an accident whilst making love can be very inhibiting and takes away any spontaneity. For me this obstacle was removed at the age of twenty-two, after an extensive medical review revealed that I could be bowel and bladder trained. How this had not been discovered before I don't know, but the psychological barriers were lifted and my independence improved.

A variety of romances followed, none terribly serious and some more of a platonic nature. During this time I also left the residential centre, came to London and became involved in youth work. I finally lost my virginity at twenty-eight just before going to college. Even so, it took the guy in question six months of sensitive and gentle persuasion and then the occasion was for me a joyful and enjoyable one, coupled with a sense of relief. Most important of all, I was not rejected. I believe that because we took so long we knew each other well and my physical appearance really ceased to be of prime importance. After four years of living together we broke up finally not because of sexual incompatibility but because of my boredom with him. I simply fell out of love. It was a feeling of guilt, and perhaps failure which made me stay with him so long. Acquaintances who did not know me well assumed, as is often the case, that he had left me and not the other way round, because I had a handicap and he had not. I did learn from the relationship that I did not have to feel grateful because a man loved me, and that a woman can, if she wants, call the tune in a relationship. I am still an incurable romantic and idealist, but increasing years have made me realise that if I did settle for one man, he would need to be the sort of person who would allow me to continue in the freedom I have gained in the last few years. Disabled women have the same spectrum of emotions able-bodied women have, but they, and other people, don't always realise it. You have to believe in yourself before others will believe in you.