

**Images of Ourselves: women with disabilities talking, edited by Jo Campling (pages 82 – 106 in the original text)**

**ELSA**

**Elsa was born in Northern Rhodesia (now Zambia) in 1939 and attended a co-ed government school there before going on to Rhodes University in South Africa to read Latin and English. She broke her back in 1957 (complete fracture at T11/12, which means she is paralysed from below the waist) and had rehabilitation at Stoke Mandeville, England. The following year she married. After the divorce she lived with her parents on a smallholding in Rhodesia. She has lived in East London for the past eleven years since joining her mate here (she was an old school friend).**

**Her chief interest is writing fiction, short stories, novels, plays in which fantasy and reality are set side by side, and she is a member of Gay Authors Workshop which tries to raise the standard and range of gay writings. She is a founder member of Gemma, which is a group of disabled and able-bodied lesbians, formed in 1976, to provide a linking and information service for isolated disabled lesbians as well as attempting to increase awareness about disabled gays among the gay community and society generally. Elsa also works locally with the Campaign for Homosexual Equality and with the East London Gay Liberation Front.**

A lot of this will seem contradictory because I feel differently about my disability at different times, in the same day I have several different reactions to it. I don't think I've accepted completely my body's state and difficulties; I get tired of the routine of looking after it even though I know that the smallest neglect might result in trouble such as a pressure sore; now and then I seem unable to resist the temptation to treat it as 'normal', to skip a routine inspection of skin, to expect more than is possible, e.g. sitting up too long even when I know the skin on my bottom is in poor condition.

When I was first disabled I wouldn't look at my body, especially the legs. I left off my glasses so that I couldn't see it when the nurses washed and turned me. Looking back I am surprised that rejection of my body began so soon after my injury, before the muscles atrophied. After twenty-three years of disability I don't feel wholly resigned to my body the way it is, thin unshapely legs, navvy-like shoulders and torso (just as if tomorrow it might somehow regain a more conventionally acceptable shape). Sometimes I hanker for clothes I could have worn before but which would be uncomfortable and impractical for me now. I look at catalogues and half-plan to buy, knowing perfectly well I will stick to my blouses and slacks which suit me both aesthetically and practically. I have worn dresses and skirts a few times but I don't feel at ease in them, my waist isn't narrow now and they hamper my movement. With trousers I can dress/undress quickly, get in and out of cars, on/off toilet, etc. more freely. When I do wear dresses/skirts it is only for a short time, like party-going, and it is like dressing up for a joke. For everyday life I need loose clothing that I can forget, easy to get on and off, and which hides my shape as much as possible. In this camouflage I suspect I imagine that my body underneath is the same as it was.

My image of myself is not clear because for so many years I avoided thinking about this. In one way I feel my wheelchair is part of me and I resent people leaning on it, fiddling with it. I accept it and I ignore it. I feel irritated when attention is drawn to it - 'What a nice wheelchair!' I suppose I should respond as sensibly as if a car or bicycle were being praised. It was quite a shock to me recently to discover my blind spot about myself; I needed a picture of a woman in a wheelchair from which I might make an illustration, and I was hunting through magazines for some time before it occurred to me I need only look in my own photo album - there I am, in a wheelchair. Why after so long don't I see myself as a wheelchair-user? It looks as if even to me 'wheelchair people' are other people and not me.

Early in my disability I had a rejecting attitude towards other disabled and have only just got rid of this (though not entirely, it would seem). I didn't then want to mix with disabled people, didn't want to be associated with them, I wanted to pass for non-disabled, as it were. I wanted desperately to be accepted as 'normal'. Having no information about gay people, I didn't even know able-bodied lesbians could have a happy purposeful life, and after my injury I rejected my sexual orientation and took on the role of being heterosexual. I saw marriage and children as the best way to prove to my family and anyone else that I was a 'real' person. I can remember a sort of terror at being allotted forever to the 'single' category, and at being pitied for being single. I wanted to be part of the herd, with a partner like other women. At school and college I had been a loner with few friends. Disability suddenly made this unbearable. I couldn't bear that my disability would seem the reason for my singleness. At that time it brought out the worst in me, senselessly and needlessly I was fighting a peculiar hurtful and selfish campaign for survival, I seemed to think that if I could pass as a housewife and mother everything would be all right. Fortunately I wasted only a few years in this dangerous way.

Disability forced me to talk more (hitherto I was not extrovert), I felt and still do feel that I have to keep proving I'm not mentally disabled as well. I still open conversations deliberately to dispel any suspicion I might be mentally retarded. I don't entirely approve of the chatty personality I seem to have developed for this. Since having a friend with Down's syndrome, however, I feel less the urge, to dissociate myself from mentally disabled people. So what if I am taken for one of them, they also have the right to go about the world. Now that I meet more disabled people, particularly other disabled lesbians, I enjoy some feeling of solidarity with them though I still feel I am not a 'proper disabled person'. I compare myself unfavourably with the stereotype, a disabled person who struggles against the odds to complete her education, get a job, play sport, drive a car, travel, etc., and do a good PR job with 'the public', explaining competently about disability. I feel myself inferior to this image and at the same time know it is ridiculous, we have the right to be the sort of people we are, disabled or not. It annoys me when able-bodied people hold forth about how we should be as independent as possible - of course we should be but I'd like to hear some talk about the able-bodied being a bit more independent too - how many of them even cut their own hair, for goodness sake, and how many of them with full use of all their senses can occupy themselves for twelve hours without resorting to laid-on entertainment. No wonder we're asked, 'What do you do with yourself all day?' I suppose you *read* a lot,'

or a patronising, doubtful, 'Well, you seem to keep busy.' This even if the disabled person has full use of hands, eyes and brain. Their inadequacies are projected onto us.

Not being expected to do a full-time paid job benefited me in one way; it meant I had time to devote to my fiction writing, art and handcrafts. Mainly for my family's sake I wish I had more material success in these fields, though I think that as soon as I was disabled their expectations of me ceased. I haven't told my family I work with the Gemma group - and I think they would regard this sort of work with a disabled group as very much second best - pretend work. I partly subscribe to this, observing how much other people dislike working and feel I have 'got away with it'. Work should be unpleasant or boring, and what I do is neither. I half believe even a tedious job would be 'better' because that would bring in money and be socially acceptable - illogically perhaps I would be proud of doing such a job, uncreative and stultifying though it might be.

When I came to live with my lesbian mate I felt a bit absurd about being gay *and* disabled. With her I was at ease of course, but I felt self-conscious about meeting other lesbians, I thought they'd see me as non-sexual, they'd think 'how can she be gay like us'. When I was passing for heterosexual it didn't occur to me to think I'd be regarded as non-sexual - I think this is because I saw heterosexual women as sexually passive anyway, whereas I see lesbians as sexual equals.

Since writing to and meeting other Gemma members I have become confident about my identity as a disabled gay. But I think it is well that this relationship (of eleven years' standing now) is the only one I want. I don't think I could ever embark upon another one. She and I had known each other for years before we lived together so I was close to her anyway. Even so, it was a gradual process introducing her to my physical problems. In the first years I wasn't happy about her helping me, for instance, when toilets were inaccessible and I had to use a bowl. Now I'm not embarrassed about it but I still wonder, is this really nice for her, could year upon year of this affect our relationship? These are only half-serious doubts. I have phases of asking her for reassurance (knowing I will get it), childish direct questions: 'Am I grotesque?' She is half-exasperated, half-amused. I trust her completely, I know she won't laugh at my body as one nurse did once. If we did separate I couldn't put the same trust in someone else, I could never start all over again, I'd be too afraid of rejection/disgust, it would take too long for me to get as close to someone else again.

I notice I have an ambivalent attitude towards more information about disability being generally available. On one hand I want everyone to understand more, yet illogically I find I don't want them to have the physical details of what *I* have to do each day, my bladder management, my manual evacuation. I suppose I shall grow out of this feeling of having lost privacy. Because I have many varied interests, perhaps because I associate my disability with the growing and developing part of my young adulthood, I don't long to be able-bodied again, except on a few occasions, when with uncongenial company and I wish I could escape quickly, or when I want some shopping in a hurry. I feel that when I was able-bodied I was a self-centred, inactive sort of person and that I would have continued in that way. It's as if being able-bodied were my larval or pupa stage and being disabled is the real me now. Though disability has probably shortened my life it has given me a good deal by changing its direction, forcing me to

communicate and sensitising me to other people's lives. It is one of the reasons I joined the animal liberation movement; seeing pictures of monkeys in restraint chairs, sows chained to the floor, makes me relive my first claustrophobic horrors when I had to lie as staff had positioned me.

In two respects at least I had to view my disablement positively. My adolescence was plagued with severe menstrual cramps, sometimes so bad I couldn't stand. With severing of the spinal cord I lost that nightmare of pain and only have a distant ache occasionally. It is good being free of the pain and nausea; doctors (male) were quite useless, some clearly didn't think it was that bad. In fact it was so unpleasant that if I had the choice of being able-bodied and having that pain back I would choose to remain paraplegic. Another immediate advantage was that during rehabilitation I became strong through gradual structured exercises. When 'able-bodied' I was weak and asthmatic. I still have the asthma but I now have muscles and strength, I was even taught to swim without bother. I still feel slightly resentful that I could only get this strength when paraplegic, my previous PE teachers had no idea of these techniques. In the last few years I find I'm afraid of further disability, I've become conscious of my good fortune in having a non-progressive disability. I'm afraid of additional injury or disease, and I'm very aware that my hands and arms are my vital tools, without them I become dependent on some- one else to get me in and out of bed, etc. I fear even as much as a broken finger because of the loss of independence it would cause me. Sometimes I feel as if this could become a real phobia. I also worry about disability in my mate, that if she were ill or injured we might be separated, but was reassured to hear of a paraplegic wife who cares for her disabled husband, and now I feel, I would be able to cope too.

## **JILL**

**Jill, who is blind, is 40 years old, married, with one daughter and lives in Westcliff-on-Sea, Essex. She is the public relations officer for the National Federation of the Blind and secretary of her local branch. She is also chairperson of the Southend Federation for the Handicapped, a co-ordinating organisation of thirty-two different groups. Since going blind she has learned to swim, to horse ride and she goes dancing. She is a member of the United Reform Church and recently took part in a special service for the blind, reading the lesson from braille. She broadcasts on the 'In Touch' programme on Radio 4 and has appeared in many radio and television programmes on the work of the National Federation of the Blind. Jill tape-recorded her contribution.**

I was born fully sighted, but on my first birthday developed measles, followed by pneumonia, which led to the removal of my left eye. I should have gone to a special school, but my mother did not want me to leave home, so I was allowed to go to the small local school. I was able to take part in all the same activities as my fully sighted friends. When I left school I went to Southend Technical College where I obtained City and Guilds Certificates in hotel and catering subjects and eventually became director's cook for a large company.

During my nine years at college and work, I was a normal teenager, taking part in activities, such as dancing, sailing, going to the cinemas and theatres and mixing with boys. I met my husband, Michael, when I was eighteen and saved up for five years to buy our house before getting married. On the eve of our wedding, my right eye went a bit bleary, so my father called our doctor who said it was nerves and that it would be better in the morning. That day was to be a landmark in my life. I awoke to a bright, sunny morning and opened the eighty-six wedding day cards that had been sent to me. After breakfast with my parents I caught the bus to the hairdressers and then returned home to get ready for the wedding. My own dressing table had already been taken to our new house so I changed in my bedroom without being able to look at myself in the mirror. Before I had a chance to go into my Mother's room and have a look at myself, the photographer had called me into the garden for photographs and, because of the lack of time, I never returned indoors to look at myself in the mirror and so I never actually saw myself as a bride. As I walked down the aisle to the altar, I can remember seeing many friendly faces of people I had known for many years. After the wedding, we came out into the bright sunshine and I was still able to look around and see all my friends and relatives. Then we left for our reception and it was as we went into the hotel that the change of light started to make my eye go funny again. For the next few minutes I was very muzzy and I had a pain starting over the top of my eye. My husband led me to the table where we had to pose for a mock photograph cutting the cake and it was as we finished that my eye went completely. We started our meal and I didn't tell anybody but as we finished the first course, I began to feel sick and so my mother took me out to the toilet where I was sick and the pain over my eye got much worse. I told her that I didn't want anyone to know and so I returned to the table and carried on with the meal and then with the wedding reception. After a couple of dances, my eye was hurting so much that we thought we perhaps ought to leave early to go down to Eastbourne where we were to spend a week's honeymoon, hoping that my eye would be better again by the next morning as the doctor had promised.

I really don't remember much about the journey. I know we were taken by car from the hotel to the station and I can remember getting on the train. It was a very crowded train and I was very conscious of the fact that everybody must have been looking at me like most people look at newly weds, and the fact that I couldn't see them looking at me was very upsetting. By the time we arrived at Eastbourne, the pain over my eye was very bad but we still kept hoping that by the morning the pain would go and I would be able to see again. It didn't. Instead it got worse and I became quite ill, so that my husband had to phone the doctor during the night and I was admitted immediately to Eastbourne Hospital with glaucoma. On arrival at the hospital, I can remember hearing the sister saying 'Oh, she has still got confetti in her hair' and this was so, because I had just been too ill to even wash or comb my hair out. My mother and father travelled down to Eastbourne the next day and, after consultation with the doctors, it was decided that I would have to have an operation to try and save my sight and I was transferred to Southend General Hospital where I had been treated since I was one year old. I spent the next three weeks in hospital, where I had the operation, but it was not successful and I remained blind.

I had never ever met a blind person and just did not know how I was going to cope with the normal things of life like getting washed and dressed and doing my housework. My first reaction was that I would not be able to do any of these things

now, and after leaving hospital I returned to my parents' home to convalesce. It was during these early weeks that I began to find out that I could do things for myself and I tried to be as independent as I could. The knowledge that I would not be able to go back to work, and therefore, we would have half the income budgeted for, was an added mental strain. We decided to go back to the house that we had saved up for five years and see how we could cope. The days seemed to go quite quickly as it used to take me such a long while just to get up, dress and wash and to do my housework. During the first year I had my daughter Jacqueline. The first reaction of doctors when they knew that a blind person was pregnant was that I should have an abortion, but after consultation with the gynaecologist, it was agreed that I should continue with the pregnancy. Just before Jacqueline was born I had asked the gynaecologist if I could go on the Pill after the birth, but he said that this would not be suitable for me with my eye condition and that it was not advisable to have more children. Although I had not yet accepted my blindness, I agreed to sterilisation. Obviously the doctors did not think that a blind person was capable of bringing up a child.

Ever since J Jacqueline's birth, I have tried to prove these doctors wrong, and show that a blind person can bring up a child as well, if not better in some cases, as a sighted person. I have to be very careful not to over-protect Jacqueline but at the same time, prevent accidents from happening. Apart from the normal routine visit from the health visitor, I had no special training or help in bringing up Jacqueline. After my post-natal, my GP visited me and asked me what help I was receiving. At that time, I had not received any help at all, only from my mother and father and my husband, so he asked me if I had a home help. I didn't even know what a home help was, so he arranged for one to come in every day to help me with my work. He also arranged for a social worker for the blind to visit me. This was the first time that I had been visited by a social worker since I had been blind. I can remember it very well. I was sitting holding Jacqueline, who was then six weeks old and they asked me if I would like to learn braille or if I would like a white stick. I said that the only problem that I had was the difficulty I had to measure out Jacqueline's milk and had they got an aid that would be able to help me. They said they would find out, but it wasn't until about four years later that I found out via the 'In Touch' programme on Radio 4, that such an aid existed. By this time it was too late. With a six-week-old baby to look after and a large house to run I certainly had not got the time to learn braille, although if I had been encouraged to learn it and given the incentive, I might have started at that time, but it was not until I met another blind person three years later, who told me that you could get knitting and cookery books in braille, that I started to learn it. I was not aware at that time that you could write as well as read braille. I was not told anything about guide dogs or about rehabilitation centres. I had taught myself how to cope indoors but I had no confidence to go out. It was not until I acquired a guide dog seven years later, that I regained my confidence. It was Topsy, my black Labrador guide dog, now ten and a half years old, who gave me back all the confidence that I had lost. Although she now guides me all over the country, I still appreciate most of all that I can go out and do my shopping whenever I want to. This was something that I had missed very much when I first lost my sight, the independence to pop round to the shops. Now Topsy will find whatever shop I want. I just have to say to her 'Find the butchers or greengrocers' and she will find it.

The natural things that a woman takes so very much for granted, like looking in a mirror to brush and comb her hair or to put her make-up on, or when she has got dressed to look in the mirror to see what she looks like, I still miss very much. It was the simple things of life that upset me most of all, like washing, dressing and doing my housework. One of the first mistakes I made was to clean my teeth with my husband's haircream. This was because the haircream and the toothpaste were in the same sized tubes. I very quickly learned I had got a nose and now automatically I just have to smell to check that I have the right tube. Dressing is a problem, knowing the difference between colours and now that my daughter is the same size, knowing whether they are her clothes or mine. I very seldom use make-up but I can put lipstick and powder on quite successfully. Although I go to the hairdressers on occasions, I normally wash and set my own hair. This has not created any difficulty for me since I lost my sight as I find rolling up the hair is just as easy as it was when I was sighted.

Over the years I have learned to accept practical guidance from friends when choosing and wearing clothes so that I can keep up with the fashions. Now that my daughter is fifteen, she is an excellent person to take shopping. I enjoy going round the large shops and feeling all the different types of clothes as this is how I judge the fashions. By feeling something I can usually get a pretty good idea whether it will suit me.

Although I had my home help for the first twelve years that I was blind, I have not had one for the past four years, since the cost went up. With a large house, I have to work to a method to cope with my housework. I miss being able to walk into a room, look around to see if the room is tidy or not. I have to go into the room and feel all round it and make sure that there are no cups or papers and other items left from the night before. This takes time and energy, even if the room does not need cleaning. To make sure that the whole room has been cleaned thoroughly, I have to work systematically, so I start by removing all objects from tops of sideboards, dressing tables, etc., polishing the complete piece of furniture, then replacing everything. I then start Hoovering from one side of the room to the other removing every piece of furniture which can be moved. Coping with washing was very difficult before I had a washing machine because there was no way that I could be sure that the washing was clean. In the past year I have bought an automatic washing machine which has braille markings. In the first few months I was too nervous to venture into the garden to put out my washing even though my husband had fixed a line for me from just outside the back door, but gradually I did go into the garden. Ironing has never really caused me any difficulty and right from the very beginning I always did my ironing in a spare bedroom, so that if anyone should call, or especially when Jacqueline was a baby, there was no chance of her having an accident. As soon as the doorbell or telephone rings, I just switch off the iron, come out of that room and shut the door with no danger to anyone and no inconvenience to people coming into the living room or kitchen. Although braille adaptations are available for irons, I did not know these existed for many years, so coped with using an ordinary iron, learning by touch where the pointer should be, treating it very much like a clock. I can feel quite easily with my fingers where the creases are and I remember the correct way that I was taught at school to iron a shirt or dress, etc., and work in the way that I was taught.

As I had been trained as a cook, it was very frustrating for me when I lost my sight and could no longer see when the Yorkshire Pudding had risen or the roast potatoes

were cooked. I can remember the first cake I made for my Mother's birthday sank in the middle because I had not weighed the ingredients. I had always used scales that I looked at and did not know that weight scales were available. After my husband found a pair of weight scales for me, I had no problems and cake-making is easy once again. I did not know for many years that braille adaptors were available for my gas cooker and relied on the raised knobs already fitted on my cooker, but now I have braille adaptations to the regulo. Eventually I found out about a kitchen timer and now use that when cooking. While there are some gadgets to help blind cooks, most of the way that one has to operate is by using your other senses and working methodically and tidily, sorting out cupboards so that you know what is inside each tin. I once made a rice pudding with pearl barley because it had been put back into the wrong cupboard and another time when I opened a tin of pineapple instead of baked beans because it had been put on the wrong shelf. Washing up has not really created any problems for me except that I have to be told when cups or other china have stains and to prevent his happening I put a little bleach into my water once a week and soak all cups, and hope the stains have been removed. Many families stop their blind relatives from washing up in case they might break something, but this never happened in my family. Knitting was one of my hobbies before I went blind and I found I could knit better afterwards than when I was partially sighted. It was a lot easier once I had learned braille and could read knitting patterns for myself, as having to wait to have patterns read to me was very frustrating. I had always enjoyed sewing but I had never been very good at it as I was not able to see to thread the needle very easily and could not machine straight. When I entered my daughter for a fancy dress competition, when she was three, it was with some reluctance that I attempted to make her dress. With help from a friend to cut out the pattern, I completed the whole operation by myself and found that I could now machine straight and even thread the needle for myself. I taught myself to make a crepe rose and attached one hundred to Jacqueline's dress and entered her as a lively lady and was very pleased when she won first prize.

A question I am often asked when I give talks at schools is, 'What is it like being blind?' and I always reply by saying, 'It is very tiring.' I think this is more true of a woman than a man, and being a blind housewife and a mother is an added strain. The psychological effect of having been sterilised does depress me at times when I feel that I should have had the opportunity of having more children. Now that I am forty, I am sure that my feelings and attitudes are no different from any other woman who is forty, except for the limitations society imposes on me because I am blind, but not because I am a woman.

## **ANN**

**Ann Macfarlane was born in Norwich, Norfolk in 1939. She had six months' formal education before the onset of Still's disease at the age of 4 and has had over 120 operations on all joints. In 1961 she gained membership of the oldest short-hand society in the world and in 1962 began giving private tuition in shorthand and typewriting. After seven years she closed the business and found open employment as a medical secretary to a consultant physician. During ten working years, she travelled three times to British Columbia, New Zealand, Israel and Austria. She is now actively involved as honorary Secretary of the**

**local Association for the Disabled and chairman of the Kingston branch of Arthritis Care. Ann is a member of the United Reform Church. She lives independently in a purpose-built flat with assistance from the community nursing service and help from parents and friends.**

Newspapers and magazines take great delight in aiming articles specifically at the obese woman, and if the woman happens to be less than physically perfect the dart has scored a double bulls-eye, injuring further not only the disabled body but piercing the soul also. A woman is persuaded to 'sip an infusion of herbal tea three times a day', 'submit her body to cosmetic surgery', 'indulge in a holiday on a health farm', or 'peruse slimming diet cook books while enjoying a lazy weekend in bed'. While a woman is photographed in a bikini gently caressing a wheat sheaf with one arm and holding out a packet of 'slimming' biscuits with the other, a man rarely features in the 'battle of the bulge' unless he happens to have suffered a coronary or sports a paunch. A woman seems the main target, all aspects of her femininity being attacked, until she stands, or sits, feeling totally inferior, humiliated and a social outcast because of the additional centimetre lurking round her bosom, waist or thighs.

Obesity, plumpness, overweight, fatness, a surplus of flesh - call it any name you choose - dominated the first half of my life. During my teens and early twenties I felt not only unloved but unlovely and my status as a woman was reduced to a minimum by a mountain of fat, definitely not helped by the scores of people who murmured, 'You'll grow out of it', 'You can't help it, it's because you can't move', 'You look perfectly all right to me'. They meant it kindly. They were attempting to calm my active brain which was attached to a body buckled by rheumatoid arthritis. I did my best to avert their eyes from my five-foot frame surrounded by sixteen and a half stones by frequenting the hairdressing salon and laughing a great deal in order to convey that my disability and weight were of no significance whatsoever. At times I would appear deaf, shutting out the whispered, 'Don't push her wheelchair, you'll slip a disc', 'We can't take her on the outing, we'll never lift her up the coach steps', and, 'We can't get involved, it's a pity she's so heavy - such a drawback'. These remarks were true and were often uttered by women whose own weight was less than ideal but because they were active their problem was not accentuated in the same way.

Not a little time was wasted on my part by blaming my obesity on to drugs, institutional 'stodge' and my disability. Immobility was a factor, as was a tendency to gluttony and boredom due to the fact that, during those early years, I had not learned how to utilise my time and the opportunities for disabled people in society were almost non-existent. My femininity was draped, like an alabaster bust, in a short, curly hairstyle and sack-like dresses. I made my own clothes because I developed a phobia in the various maternity departments and 'outsize' clothes shops. I sat at the electric sewing machine, operating the foot pedal with my hand, and churned out the required number of shapeless garments, all on the long side to hide my fat, diseased frame.

I was born into a loving family where food was prepared to be enjoyed and where rejection of a second helping was a rejection of love. Through a childhood spent mainly in the company of medically qualified adults I was constantly warned, 'Eat up your dinner because, if you don't mummy won't love you or be allowed to visit you.' As I grew older the emphasis was shifted to, 'You'll die if you don't eat', 'You must eat

or your blood will deteriorate', or 'Your joints will become more deformed if you don't eat properly'. Nobody considered my feelings as a child, a young girl, a woman, or even as a person - a unique human being. Always, and because it was an effortless pleasure in a world of uncertainty, I did as I was told and, later, lived many a day regretting my obedience to authority. I not only burst out of my made-to-measure bras but out of my wheelchairs, the metal skirt guards breaking away from the main structure. I was not just a soul in torment but I was lumbered with a diseased body suffering additional physical distress. For years I was generally unwell as I stumbled from one diet to the next, with a craving to be slim. The fact that I would never have a body beautiful did not upset me but I longed for a few of the attributes of femininity and especially to clothe myself attractively.

A day arrived which was to transform my life. It started out as an ordinary day on which I had to travel to London for a routine check-up and when I entered the consulting room, I was greeted by a young doctor whom I had never seen before and whom I was never to see again but to whom I owe a substantial debt. 'You look pretty fed up,' he remarked. 'I'm tired of always feeling unwell,' I muttered. 'I'm sure it's because I'm so fat.' He asked me a few questions and said he could understand my attitude when I had had so many years of hospitalisation and surgery. 'You wait there, I've got just the diet for you.' He bounded out through the door and returned half an hour later holding out a bottle containing vitamin pills. 'Take these daily, they should do the trick.' 'Where's the diet sheet?' I enquired. 'Diet sheet?' he echoed, 'You can't lose weight and eat.' He summoned his nurse to wheel me from the room.

The doctor had not mentioned blood disorder or dying if I did not pamper my already gross body with food and I returned home to convince my family that I had to starve in order to survive. I reckoned I was about to launch out on a discovery of myself as an individual but, on that momentous day, I had no idea of the far-reaching consequences of that anonymous doctor's advice.

Not a morsel of food passed my lips for five months. I would have fainted on many occasions if I had not been blessed with a permanent seat. I spent hours counting and recounting my minute calorie intake each day, learning about carbohydrate and fat units, and flooding my mind with dietetic information while depriving my body of steak and fresh cream meringues. As the months passed and my gigantic proportions dwindled, I emerged as a butterfly from a chrysalis. I became truly happy, confident, daring. At the end of three years I had attained slightly below normal weight and my whole eating pattern had changed. Because I, personally, felt better without it, I ate little meat and, fortunately, really enjoyed vegetables, fruits and cheeses.

In *Fat is a Feminist Issue*, Susie Orbach suggests 'that women fear being thin. ..fat has its purposes and advantages. After an initial joyful experience of seeing themselves thin they contact feelings and ideas associated with thinness that make a woman feel cold and ungiving, angular and self-involved; admired to the point of having expectations laid on them.' The writer goes on to say that 'they feel there are no longer any excuses for the difficulties they face in their lives' and 'that when they are thin they will have no room to feel blue, and that no one will see their neediness'.

Perhaps, after all, I was hiding behind my fat in order to avoid work and social contact because of my disability. People would think my condition had improved with my 'new look' and my appearance would command less attention and sympathy. For me each day had new meaning and I was more aware of everything around me and within me. Of course I still had 'off' days and felt misunderstood but, to compensate, I enjoyed the advantage of a slight increase in energy and gained confidence to pursue ambitions. People took me more seriously and, although my disfigured body faced them square on, they appeared to accept my disability more easily, making it less of an excuse to help me, the secondary issue of fat now being discarded.

In an article I read recently, a woman in her sixties believes that 'plump can be pretty' and 'big can be beautiful' and a photograph proves her to be smart, immaculately-groomed and attractive, standing poised and relaxed in a tailored dress. That lady would be hard put to it to relate her 'outsize' story to a diseased figure. A disabled woman often does not have the financial resources for good grooming and tailored clothes. As for poise -watch a fat disabled woman getting into a wheelchair, climbing stairs on crutches or struggling into a car.

Over the years since I lost my surplus stones I have achieved numerous ambitions and goals whilst experiencing a deterioration in my physical condition. It is now more difficult to perform physical tasks in the home, more effort is required to surmount the physical barriers such as transferring from crutches to wheelchair, steering the wheelchair, mounting steps and getting into a car. Thinness has not made it less painful and awkward to dress and apply make-up, less exhausting to have my hair shampooed and styled, but once the physical effort is over I feel better, confident, and at ease with disease. My ability to deal with the emotional barriers as a disabled woman in a society where the male, albeit to a somewhat lesser degree, is still classed as the superior being, has been strengthened. I have a great love for life despite disability and the ongoing burden of mountainous fat would have stifled it, even ended it. I have a 'seen' disability, but both male and female, from every walk of life, respond to me in a far more positive way because the disability is manageable, whereas in my gross state they tolerated me at arms' length for fear that they would become involved with the problem of assisting my overweight body. They saw only the flesh and little of the spirit.

## **KAY**

**Kay, who is 46, lives in Newcastle-upon- Tyne. She is married with three grown-up sons. She has had multiple sclerosis since just after the birth of her first son. Before her marriage she worked as a display artist in a departmental store. When her children were young and she was confined to the house, she designed and made a large variety of toys, which carried the label 'Kay Crafts'. She was secretary of the Newcastle Disablement Income Group.**

When we were first married, I felt that I was a prized and treasured girl. My husband had saved, and bought a house to start our married life. He thought I should give up my job once our wedding was arranged and just look after our home once we were married. Eventually, in two years' time, I was looking after our first baby as well, who

I breast-fed for nine months. Following this I found that I was unable to walk steadily, and my doctor said it must be calcium deficiency and prescribed some tablets. It cleared up in a fairly short time. In another two years I had our second son and once again took calcium tablets, having had a slight numbness in my hands. Our third son was born after four more years and I was with a different doctor, as the previous one died. I asked if I should be taking calcium pills as before, but he said, 'Oh no. there should be no need for that.' Obviously he thought something else must have been responsible for the trouble. Unfortunately, I had to have a breast abscess lanced two months after this baby's birth. This is when everything changed dramatically. My condition deteriorated, and I saw a specialist. He diagnosed multiple sclerosis, but told me that I was suffering from neuritis. My GP was informed of the diagnosis and passed the news on to my husband. He was advised to tell me when he felt the time was right. I had put two and two together myself and tried my best to get my doctor to admit the truth. I told him that I was having speech difficulties, thinking, 'Now he has to say what it is', but neuritis sometimes did have that effect. It was not until I had two wisdom teeth removed in hospital, that a doctor on weekend duty, not realising that he was not supposed to mention it, blithely asked how long I had had multiple sclerosis. I just burst out laughing, 'I knew. I knew that was it.'

I regarded the third baby as being a consolation prize. I was confined to the house for three years, relying on friends to take him out. I was unable to walk any distance with his pushchair, and was then provided with a three-wheeled invalid car, so I could once again do my own shopping. But I felt that was such an obvious sign that I was a disabled person. I appreciated it of course, but I could not take my three-year-old son with me, as I had taken the other two individually on the back of my bike. It was not the same pleasure looking after a baby, and two older children, when you are disabled. I was not able to go out anywhere with them, with the baby still in his pram. I don't know how they felt, or even feel now, having their mum in a wheelchair. I have discussed their behaviour with other mothers whose children are the same age, and they just say that it is just their age. All teenagers go through the same stages and can be even more of a nuisance. Our boys are most unhelpful, which means an even greater load falls on my husband's shoulders. This does cause quite a lot of argument and I can only hope that things will improve when they are older.

The eldest found other accommodation as soon as he came of age, and just comes back at odd times. None of them did very well at school. Art was the best subject for them all and the eldest studied photography for three years in Bournemouth. He is now trying to find a job. Then the one next to him left school intending to go back after a year to sit some 'A' level exams, again. He worked in an office, on probation for a year, then after eighteen months gave it up, feeling it was not the right job for him and he is now unemployed. Our youngest son left school as soon as possible, after sitting his 'O' level exams and has not yet worked.

My husband is now unemployed. He was a salesman, and a very good one at that. Since we married he changed the firm he worked for only once and, of course, this was because of my illness. It is distressing to realise how well he would have done if it had not been for me. He couldn't take a job that would have meant that he would be away from home even for one night. He was made redundant last June and there is very little chance of getting another job when you are over 50 as he is now. I feel

horribly responsible, being the one he was determined to provide for, but not intending to end up in this situation as a result.

I have a great feeling of inadequacy when it comes to helping him and the boys. How much more could I, and would I, have done, if I had not been disabled? I think I failed miserably training the boys, perhaps because there were too many other things occupying my mind. You cannot just carry on doing what you intended to do, when your life is changed completely. The boys have not been nearly as close to me as I would have liked, and I don't know what might be causing this division. Could it be that I was different from their friends' mothers? Is it just that I haven't said the right thing at the right time?

When our youngest was nine, the Government provided me with an adapted car with hand controls. This was a wonderful help, as long as there was someone to put the wheelchair into the car boot when I set off, and take it out when I arrived at my destination. This car came to the end of its economic life last year, and how I miss it. I feel imprisoned in my own home. On occasions now, my youngest son, now sixteen, pushes me out in my wheelchair and we can do shopping. I do go out once a week with my husband, to do some shopping and have coffee in the town, or to do local shopping, but for the rest of the time I just carry on doing the same repetitive jobs. I used to have a great feeling of satisfaction when I did any cooking but I'm afraid I don't do so much of that now. I can't work nearly as quickly as I did at one time and it takes me far longer to do such a small amount. My husband doesn't seem to understand that I enjoy it, and just says I spend far too much time in the kitchen. When there are so many things that you are unable to do, it is essential, I feel, to do something that satisfies you. This is when I feel sorry for my husband as he tries to understand, and certainly does all he can to arrange outings for me. But I am denied any freedom of choice. You cannot just decide 'I'll go to so and so today' or 'I'll go and see such and such a person'. You are dependent on someone else's help whenever you go out.

My husband and I have benefited from the Chronically Sick and Disabled Persons' Act, which obliges local authorities to provide certain services for disabled people. The first house we bought was quite unsuitable for me, and under this Act our local authority would have provided a bathroom on the ground floor, if there had been room. So we began the search for another house, in the same area, with room to make the necessary change. We were lucky as such a house did come on the market, but it was in a very bad state of repair and needed a lot of money to be spent on it. There was a utility room just beyond the kitchen which was ideal for conversion into a bathroom, plus a sitting room, living room, a dining room which would be an ideal double bed- room, and a kitchen all on the ground floor without one step. So we decided that this was for us and agreed to pay the asking price. The Social Services department went ahead with the bathroom, very soon after we bought the house, and since then have fitted the kitchen out with everything at the right level for me, with a split level cooker, and a ramp down to the back garden. Unfortunately my condition has deteriorated somewhat since the bathroom fittings were installed and I can no longer get in and out of the bath myself. This is something that really upsets me. My occupational therapist was very good and got me an auto-lift installed, and some rails beside the lavatory, which are now essential. Taking a bath is an entirely different

procedure now. It is no longer a personal, feminine, pleasure. The bathroom looks more like a shipyard. I still need my husband's help, not lifting me now, but operating the lift, and I still find it rather humiliating. Not being able to do my job as a housewife has been most irritating. We did get help from the council for this, but their home helps are so variable. Some are excellent workers and are most pleasant, but there are others who will disappear upstairs, where they know you can't follow, and please themselves what they do. Sitting in a wheelchair permanently has a very bad effect on my state of mind, and also on my clothing. Every sweater I wear has a hole in the top of the left-hand sleeve by the metal screw on the back of the chair. Clothing is important to most women and more so, I think, to those who are disabled. I cannot wear shoes now, as my feet were swollen as a result of the side-effects of cortisone injections. I was on a course which went on far too long. I thought it was doing me good, but I think my doctor should have known better. I now depend on an old pair of sandals for winter and summer. I feel cold even in warm weather and always need the heating on in the house, with an electric over-blanket left switched on every night. I wear warm trousers all the year round, which is not the most feminine of outfits. The major aim of the Disablement Income Group (DIG) is to have a comprehensive allowance paid to cover the extra costs of disabled living. I would certainly be relieved if this meant that I would not be such a burden on my hard-working loving husband.

I love my husband dearly and we have managed to keep a good sexual relationship. All the roads in our suburb have been holding street parties since Jubilee year. I enjoy these especially as I can take part in them. This year a very good jazz band came round, on a lorry, stopping and playing for a while at each party and those who wanted to went onto the road to dance. My husband and I used to love this kind of music and he asked one of our neighbours to dance with him. I tried my best not to be affected, but I'm afraid I was very jealous. I always enjoyed dancing with him, and to see him enjoying dancing with another woman was just too much. I also love my three boys dearly and I have occasional glimpses of a similar feeling being returned. My greatest pleasure now would be for my husband and three sons to be able to get jobs which would give them good wages and fulfilment.