Images of Ourselves: women with disabilities talking, edited by Jo Campling (pages 106 – 138 in the original text)

FRANKIE

Frankie, who is 50 years old, suffered an attack of polio when she was 27, married, with a little girl of 5. She was in an iron lung at first, but eventually became an out-patient at Stanmore Orthopaedic Hospital for eighteen months. She was left severely disabled, in layman's terms about 80 per cent disabled, although this has no bearing on her general health or life expectancy, which are both good. However, she is completely dependent on other people for getting up and dressed and for getting out and about. Within these limitations she leads a busy life, having worked as a telephone canvasser and she now gives weekly cookery lessons. She has travelled to Glasgow and Nottingham to talk to the British Association of Social Workers about physical disability and she gave evidence to the Snowden Committee on the Integration of the Disabled.

My husband, for whom I cared deeply, was called Leo, my daughter was named Gay, and my one aim in life was to make a comfortable, happy home for them - one they would want to come home to and bring their friends. I struggled desperately to be the same wife and mother to them that I would have been had I not had polio. I had to play my role, I never could bear the thought of being a person for whom everything has to be done or just an object of pity. This was not only with regard to Leo and Gay but with all my relationships, which then, as now, had to be on equal terms for me.

I have learnt to accept different kinds of help from different people, in fact letting them help in whichever way they prefer, whether it is what I require at the time or not. I try to ask the ones who like shopping to do just that. I have certain friends who are happy taking me out so I leave that to them and others prefer to help with jobs around the house. It is a bit tough if you need to go somewhere and the only one available is the person who likes tidying cupboards. But by and large it seems to even itself out. I have also made quite a study of human nature and I try very hard not to overload anyone person, if I can possibly help it. I do try to protect those that I live with from being overloaded, which is not always possible because when all the family friends and voluntary or paid helpers have gone it falls, once again, on those that live with me, and it is tough make no mistake!

What can I do for all these people in return? My main talent is cooking and I have developed quite an extensive knowledge of the subject. I find this is very useful to all my friends. Sometimes, if I have enough help, I can make things for people when they have a particular need for it; the telephone rings constantly for advice and for recipes.

Another talent I have is for sorting out my problems, which have at times been enormous. We had one period when my husband was having a nervous breakdown, my mother had had a stroke and was living with us and I was flat on my back unable to move with two slipped discs! I have had to look into things so deeply that I have emerged from it with a mind that is quite well equipped to help others see their own problems more clearly.

My husband suffered from very long periods of depression, which meant that it was really difficult for us to have much social life. Booking ahead was impossible, driving and parking in the centre of London was yet another problem, so we spent most of our time at home or with a few friends locally. The time when Leo came home from business was the highlight of my day and everything revolved around the meal I had prepared for him, but I had to find some way to occupy myself in the daytime so that I wouldn't be so dependent on visitors. I was also desperate to make some contribution to our finances however small it might be.

I did the only thing I could do lying down and that was to work on the telephone as a telephone canvasser. The work was boring and after a long period of it, became soul-destroying, but I didn't care, I was so thrilled to be working at all, and I had the evenings with Leo to look forward to.

In October 1976 I received, the catastrophic blow of all time. Leo suffered a fatal heart attack at the age of fifty-four. At forty-six I now had to face life as a disabled widow. How I was going to cope with this lot I just could not imagine. By this time Gay was married and had very little need of me except, of course, for the usual things that Mums try to do for their married daughters, those that were physically possible for me to do I mean, which shortens the list anyway; which could hardly be enough to keep me going. My whole purpose in life had gone. What was I to exist for? So much time and thought had gone into trying to keep Leo on an even keel that I could not imagine how I was to live without it. Quite frankly I didn't want to continue living. I lay on the bed having no reason to get up, and not wanting to anyway, until I became very uncomfortable. When I did get up to visit the loo, movement seemed to be getting more difficult and I suddenly realised that if I didn't start moving about regularly again I would soon be bed- ridden and lose whatever mobility I had. I became quite panicky about it because I had climbed those same hurdles in the past, trying to regain muscle power, and had found it horrendous. I had no choice but to get up and move about, for the alternatives were too horrible to contemplate.

I was left with a very nice house in not too good a state of repair and a lot of financial complications, which really meant that I was not too well-off. Apart from knowing that About this time a little miracle took place. An old friend of mine asked me if I would like to have her seventeen-year-old son, Howard, come and live with me, owing to the fact that they had a lot of problems at home. I jumped at the idea and it was no sooner said than done! Up until then I'd felt I had been cut off in the midst of life. At forty-six I knew I still had a lot to give. Why not let Howard benefit from all these circumstances and turn what could have been misery for all concerned into a happy, viable situation, giving both of us just what we needed. I am quite sure that Howard had no idea of the enormity of what he was undertaking in living with someone who is so dependent on others, but in return I have bent over backwards to see that he benefits in every possible way and I treat him exactly as I did Gay. It seems to have worked extremely well, the fact is that two years have passed, he is still here and we are the best of friends.

With Howard's help and that of a very dear friend I was able to start the cookery classes on one day a week and they have proved very successful. A lot of work goes into planning the lessons; there is the timing to work out and recipes to get photocopied, etc., to say nothing of the shopping lists and the food preparation on the day before. I do some day courses and some evening ones. The people who come to the day courses are given a little snack lunch, which also has to be prepared beforehand. I continue to swear that every time is the last for lunch but it seems to be so much a part of the enjoyment that I haven't the heart to stop doing it.

Things were running pretty smoothly now and we soon decided to let another couple of rooms. With inflation it was necessary anyway. By this time I was running a pretty busy household, cooking a meal for three of us every night and doing the weekly cookery lesson. This makes me a far more valued, regular customer to the smaller shop-keepers that I have to buy from, simply because they can still deliver. It also keeps me pretty occupied but still leaves me some free time, providing we plan it well enough, to go out and about with my friends. I am able to go to the theatre, to concerts and restaurants as often as one can afford. I have quite a few single women friends of my own age, though when I first became widowed I felt rather isolated from them because they were more able to look for new husbands than I was. I was proved wrong because some of them were friends of long standing and they seemed to make time for me as well. Two friends took me on the Jetfoil to Dieppe for the weekend and what a memorable weekend it was' too! Physically I am better than ever because I go out so regularly. No more fighting to regain lost muscle power, I just don't allow myself to lose it.

Life is pretty hectic most of the time. The house is often teeming with people. Perhaps that is why when it goes quiet it really does go quiet - so terribly still.

MURIEL

Muriel, who is in her 50s, lives alone in Newcastle-upon-Tyne. She has been wheelchair-bound for over ten years with severe rheumatoid arthritis. She has a specially adapted flat with many aids, but nevertheless, despite her badly twisted hands, before her husband went into hospital, she was changing the bed linen at least once daily and often during the night, due to his incontinence. Now that he is hospitalised she visits daily and washes all his clothes. She has actually spent the greater part of her adult life looking after first her mother, then her husband.

Her contribution was tape-recorded by Anna Briggs.

My mother had a stroke when she was forty-eight which left her paralysed down one side. In those days, there were no home helps, no auxiliaries to come out and give you a hand to wash and dress her and you had all the washing to do yourself. There were practically no social services and you were expected to look after her, even though *you* were disabled. It was a daughter's duty. At the time I already had rheumatoid arthritis and although I could walk around I could only do it with great difficulty. The amount of washing I had to do was quite considerable, and in those days again there weren't things like automatic washing machines, even if you had the money, which we didn't. My mother had worked but there wasn't a great deal in the way of social benefits as there are today, so that we had very little to provide all the necessaries. A washing machine wasn't considered necessary. You were supposed to wash sheets and get them dried and put them on the bed, that was the normal way. So I got absolutely exhausted, I went down to just under six stones in weight, because I looked after her. She was my mother and there was no question of trying to put her away. Even if I had wanted to put her into care, at that time there was no way you could do it, it was a daughter's duty to look after her parents. A daughter didn't have a life of her own. When she died I got a job, not anything very glamorous but at least I did earn my own living, and this was the great thing. I think people don't realise the amount of dignity you get out of having a wage packet. I can remember getting a job in old money for £3 a week, and I had been getting £2.17s.6d. a week dole, so I was working for less than half a crown a week, but it was *my* money. *I'd* worked for it. One of the things I find very irritating is that people tend to look at you as you are now, in a chair, and they think that you've always lived on the state, but that's not true, there's an awful lot of disabled people who have worked, and worked very hard. We've worked at jobs that nobody else would take, low-paid, dirty, unpleasant jobs. There seems to be two standards of living, one for the non-disabled and one for the disabled, and the thing is, what is for the disabled will do, but if you're not disabled, it won't do for you. People seem to be surprised that you have a standard, because perhaps you can't get washed yourself, so they think it doesn't really matter, but I like my dignity, I want to be as clean and as smart as anybody else, and I find it very irritating. I'm only human, I haven't a lot going for me, but what I've got I like to make the most of, like every woman. They seem to think that because you're disabled you have no feelings, no emotions, nothing, you're just like a robot.

I met my husband at a club for disabled people, and this is another thing, that disabled people don't have a great deal of social life. People tend to think that they can put all the disabled together. Now you can put a group of doctors or a group of nurses or any kind of people together, it doesn't mean to say that because they've got one profession they're all going to get on together, and it's the same with disabled people, we're people first and disabled second. So that's how I met my husband. He has now unfortunately developed senile dementia, which is a very difficult disability to cope with for those who have to look after them. He became doubly incontinent, very confused, and rather difficult to deal with. If he smoked he would drop lighted matches about and set the place on fire, so he had to be taken into care eighteen months ago, but I go and see him every day. He'd had paralysis when he was a little boy, so he's got a double handicap now.

When we got married it was a dirty joke. This is what I mean about they don't think you have the same emotions, the same desires or worries, as able-bodied people. You fall in love, you love somebody, you don't see the disability in them, you just see the person. You don't see the crutches, or sticks, or calipers, or wheelchairs, you see a man, and like most women when they meet a man they like, you only see the good points in them. They would say to you, 'What are you getting married *for?'* in a rather sleazy, dirty attitude. The kinds of questions that strangers would ask, people that you didn't know very well - 'What will you do if you have a family?' 'What sort of a sex life will you have?' - I wouldn't think that they'd ask able-bodied couples things like that, and my husband's rather shy, he found it very distressing. I found it just annoying, your whole life is public, you haven't to have any privacy, they like to know every little detail of your life.

As a woman, naturally I wanted children, but we made the decision not to because we didn't think it would be fair on the child. But we still had emotional feelings, we still gave each other strength and companionship, and a lot of people don't understand that, they think that you have got to be sort of producing and it wasn't quite nice for disabled people to produce children. Well that's up to the disabled person, if they want to go ahead and have a family it's got nothing to do with anybody else. What I had wasn't hereditary but there's more to children than having a baby. You see if we'd had children we both would have liked to take them to the country and shown them wild flowers, wild life, taken them to the coast and had picnics, take them bathing, do all the normal things that families do. Love by itself isn't enough for a child, it's got to have experiences, it's got to learn and to grow emotionally as well as physically and that would have been impossible with us. So in a way, we loved our children too much to have them. We sacrificed our children, so that although they wouldn't have a future they weren't going to have a rotten future with two disabled parents hanging round their neck. I don't think you have children to comfort you in your old age, yes of course, you expect that when you have children and you have a good relationship then you want them to come to you when you 're ill or you 're getting a bit old and you need some moral support, but you don't have them to sacrifice the children to your life, that isn't what having children is about, I don't think it is. I think that partly comes from my experience looking after my mother and when I've looked around and seen people, women, who because they've been the only daughter, or they've been the daughter who isn't married they are expected to sacrifice their lives to look after parents and sometimes the parents live so long because they're well looked after. By the time they die the daughters are so worn out there's no life left for them, and this is wrong, you don't have families for that, or I don't think you should. What is the alternative - and really women are blackmailed? As a woman I feel that I'm even now emotionally blackmailed sometimes into doing something that's really beyond my strength but I've still got to find the strength from somewhere to do it. Things like going to see my husband, I go up every day, he's dependent on me, he gets very distressed if I don't go up. People still think that I should go on giving myself, even though he isn't at home. It isn't that I don't want to give of myself, but we can all only give so much, and we do have a life, and so often we have to suppress our own feelings, I think, and this is where I think we're emotionally blackmailed because in a way I think we're brainwashed into thinking we should do it.

When I had to give up work, it was after my pelvis twisted and it left me with one leg shorter than the other, the doctor said I would never walk again and they wanted me to go into' care. I felt dreadful when I had to give up work, it was the most shattering experience I had had, because going out to work, you felt part of society, you were contributing, you were earning your own money. You also had your friends that you went to work with, and then suddenly you were cut off, you were in the house alone. Also of course financially you were worse off. You were lonely, you felt useless, on the scrap heap, finished, and it really was a very bad time. It wasn't only the idea that you could no longer work, it was the worry of what was going to happen to you, I wasn't married, had no family, no relations. What was going to happen to me? I was frightened. I thought it was the end of the world. Of course it wasn't, that's one thing about disablement, you do learn that you have a crisis but come through it, and so you seem to stagger from crisis to crisis, but you do get through. It is important for women to be able to work, I know you're needed when you're a housewife and at home, but you also have a social need, you want to be out and part of life, because life goes over very quickly and you want to mix with your own generation, there's something that you don't get at home that you get outside at work.

I married about five years after that, and slowly I got back on to my feet. I had one leg shorter than the other but I could get. around. We were married for about seven or eight years when I became ill and then it was just impossible for me to think of working again. When I got out of bed, both legs had just gone, and again, you see, I thought that was the end of the world because nobody thinks they can live from a wheelchair, but by gum you can, you can do a lot from a wheelchair. I think there's a great lack of counselling for people who become disabled and have to go into wheelchairs, I don't mean people who just have a limp, I mean really disabled people. Up to a point of course, you have to get through on your own, it's your own personal decision which way you take it, but I think if only there was somebody who would understand the frustrations, the way you feel, your anger, your bad temper, your aggression. There's nothing worse than somebody who's fit and healthy slapping you on the back and saying 'You'll cope' and you look at them and think 'What the hell do they know about it, they're walking around!' but you can take it from somebody else who's in a chair because they've gone through it and they know.

I think disabled people are not used enough. I think that many disabled people do become lethargic, lazy, couldn't care less, and it is not always their fault. They become this way because so often it is quicker for the able-bodied to push them out of the way, to push a wheelchair along, to do things for us, till you come to a point where no matter how strong-willed you are, you give up, you say 'Let them get on with it'. But I think there is a great source of energy, not really physical energy, but mental energy that isn't being tapped, and I think we could relieve able-bodied people by this energy , because we *could* do counselling, we *could* understand. We understand the way disabled people think. So often you get committees, you get all these people who, I know it sounds dreadful, they think they are doing so much good, but they never stop and think 'Right, what do the disabled themselves think?' They go ahead with all these magnificent plans, and of course as far as we're concerned it's a right mess-up, and then when you say something, they get really very hurt that you are criticising all their hard work, which I can understand, but if only they would have stopped first and said 'Let's consult the disabled' because we're not all idiots! I don't think things are changing, not a lot, there are some areas where it's a bit better, but I still find the tendency for a lot of people to shut the disabled out, or what is just as insulting, like the statutory woman, have a disabled person on sufferance, but they don't really want to know what you think, they just want you there to make the numbers up and just be seen.

Clothing is getting to be quite a problem for me because as my physical condition gets worse I am finding it rather difficult to manoeuvre clothes. It does annoy me when a well-meaning occupational therapist says, 'Well, get a size bigger.' I don't want to look like something that's come off a dustcart. I want my clothes to fit, it's important to me to look nice, as nice as I can. I'm not going to sit around looking like something that's come up from a jumble sale. Why should I? Would any other woman? The electric wheelchair improves things - one of the advantages of shopping with the chair is that there's nobody behind me when I choose what I want. There's none of this 'What does she want, what colour does she want?' That happens when you're being pushed around by someone. This is a common complaint amongst disabled people in chairs. They always say the assistant *will* ask the person who's doing the pushing, as thought you were a halfwit. I find it marvellous that I can go into a shop and buy a pair of tights for 25p or a three-piece suit for £25 and nobody knows but me how much it cost, where I got it from, and this is great. It gives you such a great feeling it's just between you and the shop, how much you paid for it. Before that, somebody knew, and no matter how good a friend you are, you don't always want them to know how much you pay for all the things you buy. It's your privilege to tell them or not to tell them, but when they're standing there and they know exactly what you've spent, this is part of the thing that I don't like. Especially for disabled women, it's just not expected that you want any sort of privacy in your life at all. The home help goes to the post office, she gets your money, she takes your rent, so she knows how much you've got coming in and how much rent you pay, it isn't really that I want to be secretive, but I do want just that little bit that somebody doesn't know about. It's private and it's part of me - it's like living in a goldfish bowl that everybody can see and know what you're doing. I think we all need to have that little bit of ourselves that's shut away, that nobody else knows about.

I get a bit despondent with the way things are, and they don't seem to be getting any better. I think that one of the things I would like to see changing is the attitude to aids which are very important for disabled people. The powers-that-be, like the local authority, have a set idea of what there is. They haven't got a wide enough horizon. With the silicon chip coming there are going to be many more so-called luxury goods but they're going to be fantastic for disabled people. But local authorities don't want to know because they are luxury goods that only rich women should have. I wonder if it would be the same if I was a man. I need a different kind of telephone in the bedroom but if I had it put in, it would cost me £10 per quarter more because it's a luxury! The very fact that it is a necessity for me doesn't come into it, it's a luxury. I'm fortunate I suppose because I've got a dishwasher, not because they're a luxury but be- cause my hands are too bad to wash dishes. And people say, 'Oh, fancy you having a dishwasher' and 'Aren't you lucky, I can't afford one'. And I know it's not very nice but I say 'Tell you what, give me your hands and you can have my dishwasher' and they take offence, but why should they if I'm not supposed to take offence at being told that I've got luxuries? People still expect you to live on a lower level and if you're a disabled woman, somehow you're supposed to cope, you 're not supposed to get tired, bad-tempered or frustrated or want to throw something through the window. You're not supposed to do it, you're a woman, and that's your job, and you're supposed to have some inner strength and you can go on and on and on.

I think disabled men get supported more, I know by experience, I've seen men who were not half as disabled as a lot of women and my goodness they're run after hand and foot, because 'It's not nice, it takes their dignity away', that a *man* has been disabled, that a *man* has been the bread-winner and therefore it's a tragedy if he becomes disabled. If a housewife becomes disabled, she's somehow expected to carry on, it's not a tragedy. In some people's eyes it's a bigger tragedy because if a woman is taken out of a house, that house will collapse. A man, I know you miss his money, you miss the man but let's face it, how many women have to cope on their own, not only cope on their own but cope with a disability and very often children. It's surprising how many men just can't face the fact that their wives are disabled and they just go off and leave them with kids and all to fend for themselves. I think that's very common - I know quite a few women who've been left in the lurch just because they've become disabled, and yet I know women who have stuck to their husbands and wrecked their own health looking after severely disabled husbands and in turn the women are now really disabled themselves and they've gone on years and years and years, long after they should have given in and said 'I can no longer cope'. I tried to cope for too long quite frankly and I thought that when my husband did go away I would get my strength back but it isn't working out that way. I've spent that strength and there's no way I'm going to get it back. But you see you were his wife and you were expected to cope, as a woman that was part of being married, and to me it isn't, there should be equal shares. I don't want more shares than anybody else, but I want my share of rights, I want my share of dignity and compassion and there's not a lot of it around for women.

WYN

Wyn was born in County Durham in 1924. She studied, nursing at the General Infirmary at Leeds where she qualified as a State Registered Nurse. She did midwifery training at Northampton General Hospital and the South London Hospital for Women, becoming SCM, and returned to the General Infirmary at Leeds as ward sister, then assistant sister tutor and finally night superintendent. During this time she studied for limited periods at the Royal College of Nursing in London, obtaining Ward Sister's and Nursing Administration Certificates.

After marriage she became Assistant Regional Nursing Officer, Leeds Regional Hospital Board. In 1957 she won a British Commonwealth Nurses War Memorial Fund Scholar- ship which enabled her to study nursing in Canada and the USA. In 1961 she had a baby daughter, Anne. Following maternity leave she returned to her position at the Leeds Regional Hospital Board. When Anne was 1 year old, she left home in her usual way to drive to work in Harrogate. She was innocently involved in a head-on car crash as a result of which she had multiple injuries including damage to the spinal cord in her neck. This resulted in her becoming a tetraplegic with complete paralysis from her neck downwards including all four limbs. In addition there was loss of sensation to all these parts so she has no control over her bladder and bowels. After three years in the Spinal Injuries Unit in Wakefield, she returned home to be cared for by her family and the district nurses. She has continued in this way for the past eighteen years. Although unable to return to work she leads a very active life, lecturing on the problems of disability to a wide range of audiences from medical staff, nurses and physiotherapists to all kinds of public bodies. She also does much work for the Spinal Injuries Association of which she is vice chairman and takes an active part as a Member of the Bradford Community Health Council.

She has written a large number of articles for various journals on aspects of disability and has also appeared in several BBC radio and TV programmes.

Prior to my being severely disabled I took a great pride in my appearance. I soon learned, after my accident, that having to rely on other people to wash me, dress me and maintain the appearance to which I had been accustomed was, and still is, fraught with great difficulties and frustration. The first time I looked in a mirror after my accident I hardly recognised myself. For practical reasons I was dressed in trousers with a pair of f1at-heeled lace-up shoes. Since I had usually worn dresses or skirts and high-heeled court shoes, my new appearance demoralised me beyond words.

Whilst my hair had been kept clean and washed by the nursing staff it had not been cut for about three months with the result that this did nothing to enhance my appearance. The nursing staff were very co-operative and they organised a hairdresser to come to the hospital. That improved the situation but hair remains a perennial problem. Until four years ago visits to the hairdressers were a major operation. Having to be lifted into and out of a car and trying to get into salons which were often difficult from an access point of view added to the problem. It took two people to tilt my wheelchair back so that my hair could be washed in the basin. After washing and setting it commonly happened that the manhandling necessary to get me into, then out of a car and back into my wheelchair undid all the good work that had been done. In addition I was not independent to that less stress need be placed on them thus reducing the number of times I have to ask friends to replace broken zips. As I have no control over my legs nor the ability to adjust them should they be in an ungainly position, I find long skirts which conceal them to be more practical. Long skirts also have the advantage of concealing the leg drainage bag for urine and thus I wear this type of skirt for day, evening, summer and winter. I stick to a basic pattern and bring in variety by means of colour and texture. I do not find it necessary to wear flat-heeled shoes as I find that court shoes with stiletto heels have the added bonus that the heels can be made to fit behind my wheelchair footplates thus preventing the involuntary spasms in my legs from moving my feet and scraping them on the footplates or other objects. I should point out here that a small scratch or abrasion can be very difficult to heal in a person with paralysed limbs. In my own case damage to my ankle from a small abrasion has taken up to a year to heal. My appearance is even more important now that I am confined to a wheelchair as I am usually more conspicuous and also I am not independent to slip away and adjust myself if I feel that my appearance is in any way in need of this. This reduces the pleasure of going out.

I like to use some make-up even though only a minimum. My choice of lipstick container is one which I can use my teeth to remove the case and then use the trick movement of my wrist to push up the lipstick. My chin can be used to press on the top of a perfume atomiser so that I can apply some myself. A brush comb inserted into a leather strap which I can push over my hand enables me to comb my hair. After a lot of shopping around I found a beauty case which has a mirror in the lid. This is needed as most cloak- room mirrors are too high for a person in a wheelchair to be able to use them.

The female anatomy adds to the difficulties of the severely disabled woman. When I became disabled I lost control over my bladder and since then have relied on a self retaining catheter for urine drainage. As the urethra and vagina are in close proximity to one another it is not difficult for someone inserting a new catheter to place it by accident into my vagina instead of my urethra. When this happens the catheter has to be discarded, causing delay in catheterising me and extra cost to the NHS as catheters are quite expensive items. The reverse situation has occurred when I was being treated for a vaginal infection. On that occasion a pessary was inserted into my bladder via my urethra instead of into my vagina. Tampon cartons and cotton wool swabs have also been lost by being left in my vagina. Suppositories intended for my rectum have also been inadvertently inserted into my vagina. Many people think that it is impossible for events such as this to take place but I can assure them from personal experience that it has happened. Insertion of anything into one's bladder is liable to cause infection and this is far greater when the object is not intended for that area and hence not appropriately sterilised.

Many able-bodied women find that menstruation is a nuisance. For the severely disabled woman it is a major difficulty. Firstly I have no sensation and therefore have no idea when I start to menstruate. Secondly it is impossible for me to insert a tampon or fix a sanitary pad in position myself. Thirdly I am unable to change myself. Thus once the nurses have inserted a tampon and applied a pad I must remain like this until I can be put to bed again in the evening. In order not to stain my clothes and increase the amount of washing I try to guess when I am due to menstruate and ask the nurse to insert a tampon as a precautionary measure a few days before the expected event. I also feel that the iI:o3ertion of tampons is a very personal thing which since it cannot be done by myself should be done by a nurse or a female member of the family and not by my husband who in fact frequently has to do it and is quite competent at it. Once menstruation is established the nurse inserts two tampons and applies a pad. I then hope that I am adequately protected until I can be changed that evening. If I wish to go to a social engagement this adds to the complications since I have to try to find two people to lift me from wheelchair to bed, change my tampons, re-dress me and lift me back into my wheelchair. The menopause increases the difficulty if one is suffering from heavy menstrual loss and cannot change tampons. If such heavy loss is due to hormonal causes the situation can be controlled by taking hormones to stop the bleeding. With the best possible planning, however, accidents still happen and one is faced with an embarrassing situation on finding oneself lifted from a wheelchair revealing a bloodstained cushion. In turn, one's clothing proves to be soaked in blood which passes the stain on to the bedclothes on to which one is being lifted.

Men who have lost control over their bladder can in some cases use a urinal or a condom. Unfortunately a satisfactory urinal has not been produced for women. It is necessary therefore for women to use a permanent self-retaining catheter. This brings with it the danger of introducing infection, promoting calculus formation and in turn causing damage to bladder and kidneys. I have had to have three major operations on my kidneys for this reason.

No longer is it possible for me to do the household shopping or take part in any of the normal household duties. This adds to one's frustrations. It means that the family in addition to looking after the disabled person are confronted with all the household duties including shopping, cooking, laundry, etc. Domestic help is both difficult to obtain and expensive and this can add to the financial difficulties of the situation.

Psychological barriers play an important part in my life. An early example of this was six weeks after my accident when I saw my year-old daughter. My immediate reaction was to try to pick Anne up and give her a hug. The loss of power and movement in my arms made this impossible, added to which my loss of sensation prevented me from feeling her next to me. It has also been a constant source of distress to me that I have not been able to tuck Anne into bed. To see everyone else doing this is a most frustrating and depressing experience particularly when one realises that it will never be possible to do this normal human motherly task. The physical lack of awareness of contact must to some extent be set against the following gain. I have always had time to listen to any of Anne's problems and share her accounts of her doings. When our domestic help suddenly left, Anne, who was only seven years old, had to be guided verbally by me as she prepared simple meals. It was not easy to sit helplessly by, watching her cook, serve the meal, cut up my food into small pieces and even feed me with certain items of food. I found the latter most humiliating. Had it been practical, my daughter and I would have enjoyed shopping expeditions for clothes but these had to be kept to a minimum from a practical point of view.

Travelling by car is still an enjoyable experience for me as I have no recollection of the precise circumstances of my accident. However it takes two people to lift me into and out of the car and I usually end up in my wheelchair with my clothes in a state of disarray. I often feel humiliated and wish that I could independently adjust my clothes. The situation is even more degrading if there are a number of people waiting to meet me by the car and I am unable to make myself presentable.

Life is a constant struggle trying not to feel different from able-bodied people. Even the simple use of a serviette illustrates this. My serviette has to be clipped to my blouse or dress collar so that it is held in position and is thus able to protect my clothing. I try not to spill my food but the fact that my fingers are paralysed means that I am unable to hold cutlery normally. So from time to time food is spilt, and in order to save washing my clothes each time it is more practical to have my serviette clipped to my collar. This makes me feel different to other people and I object to it. Being unable to handle an ordinary teacup it often happens that someone will attempt to give me a drink from one. Now in the first place the liquid may be far too hot but once some- one else is pouring it into your mouth you are unable to speak to tell them to stop. If the situation becomes really unbearable one has to attempt to withdraw one's mouth with the result that the hot liquid invariably cascades down one's chin, neck and clothes. Oddly enough the person assisting with the cup usually wonders why I have been stupid enough to do this. A similar situation can arise even if the liquid is of drinkable temperature. Someone kindly lifts the cup to my lips and pours the liquid as fast as or even faster than I can drink it, into my mouth. Eventually I am desperate to stop drinking to take a breath but the assistant does not realise this and I am unable to stop the flow of fluid in order to speak to them. In the end I am forced to stop and the liquid cascades down the front of my dress. A slight variant of the hot liquid episode is when I have on occasion been given a very hot drink from a cup or beaker using a straw or a plastic tube. All goes well at first and I suck the liquid up in the small amounts needed and then swallow it. Either to assist the process or quite unconsciously, the person holding the beaker gradually raises the height of it. Suddenly it happens that having drawn it into the drinking straw and obtained the required amount in my mouth I find that ceasing to apply suction no longer has any effect and the scalding hot liquid pours in a continuous stream from the straw into my mouth. The reason is that the beaker now has a higher liquid level than the top of the straw in my mouth. Under these conditions, once started, the flow of liquid continues to siphon from beaker to mouth without any assistance or control from me. Again the disastrous sequence of events can only be broken by my opening my mouth and thereby spilling the contents down my clothing.

The fact that I am always seated in a wheelchair with limited neck and hand movement causes me both embarrassment and difficulty. I dislike the situation in an audience when everyone else stands for some reason and I am unable to do so. Also when the audience applauds and I am unable to join in as I am unable to clap my hands together. Few people realise how difficult it is for a person in a wheelchair when a group of people stand nearby and hold a conversation in which the wheelchair person is supposed to be included. In the first place it rapidly becomes uncomfortable for me to tilt my head back all the time so that I am looking up towards them. Also it is difficult to understand, in such a situation, that the person in the wheelchair has great difficulty in hearing conversation directed at the other people several feet above one's head. Perhaps the greatest insult one feels in this type of situation is when one has been pushed into a shop to make a purchase. All too frequently the shop assistant addresses the remarks concerning the purchase, not to the purchaser in the wheelchair but to the companion pushing it. When one member of a family is seriously disabled, the whole family is disabled. As in my case it may well mean that the family has one income instead of its former two. To me also it is very frustrating that when my husband comes in from work in the evening I cannot have a meal ready for him. Instead he has to start and prepare the evening meal. Then if I am in need of any form of attention during the night my husband has to get up and attend to me. But despite having had his night's sleep disturbed he has to go to work as usual the next day. Despite the difficulties of being a severely disabled person I think that life is still worth living. I have a loyal understanding husband. Our daughter unknowingly has brought us untold pleasure. My voluntary activities and giving lectures on the problems of disability to a wide range of people from NHS staff to voluntary organisations keeps me fully occupied and I find that I am very busy with little spare time.

DIANA -II

Diana, who is now 60, lives with her mother of 92 in London. A stroke in 1967 left her paralysed down the right side and completely unable to communicate in speech or writing. Her speech is now adequate, although halting, but she cannot write. Her difficulty with writing is not caused by the fact that her right hand is paralysed, as she had learnt to use her left hand for this function, and she can copy write efficiently. The difficulty is that although she knows what she wants to write, she is unable to recall the words she wants to use. This is the same problem as her speech and both her spoken and written language are agrammatical. Furthermore, although she can recall the word or sentence, she is unable to write it down because she cannot recall the letter shapes which go together to make up the words. Earlier Diana was unable to write single letters to dictation but this is not a problem now. However she has only a very small written vocabulary. Her contribution to this book was the result of the combined

efforts of Diana, two of her 'scribes' and Margaret Freeman, LCST, Chief Speech Therapist of the Middlesex Hospital.

Diana was one of the founders of' Action For Dysphasic Adults' and she inspired and helped to set up a network of speech clubs throughout the country and abroad. I n 1978 she was awarded an MBE. Her book *Living After a Stroke* (with Barbara Paterson) was published by Souvenir Press in 1980.

By the time I was forty-seven I was, I think, successful in my career and leading a very full and active life. My work, as Manager of the Education Liaison Services for a computer company, was challenging, as the computer industry was still just developing. I was involved with several committees and had written two books and a number of articles on my subject. My social life was equally full; I loved the theatre and concerts, parties and sport. I had stood as a candidate in local government and parliamentary elections. I was independent, active and I loved to talk! Suddenly everything was changed by a subarachnoid haemorrhage. Even when it all began, it seemed not too bad. I had surgery and remember three days of visits, laughter, cards and flowers and then I had a stroke. That time is hazy for me, but my mother and sister have a clear memory of me, paralysed down my right side and unable to speak. The doctor told them I was a hopeless case and that I was 'virtually an idiot' now. Thank God, they did not accept his verdict. My mother was convinced he was wrong; she says she could tell from my eyes that I was alert, but my lack of speech confused us all.

In the first three months I made a lot of physical recovery. My arm and leg were still paralysed, but with physiotherapy and occupational therapy, I began to walk and dress myself. I didn't feel the arm and leg were a problem, though; my lack of speech was far more worrying - all I could say was 'tonight and tonight and tonight'! No one seemed to know what to do to help and their lack of understanding made it all far worse. I have a clear memory of doctors and nurses standing near my bed talking. ..I felt left out. ... I wanted to talk. I couldn't even communicate my basic needs. They thought I was incontinent when I wet the bed but it was because I couldn't tell them when I needed to go to the lavatory. There was not even a bell or a buzzer so I could call for help.

The frustration of miscommunication was overwhelming. I lay in that bed comparing my previous competence with this new and frightening state. I have always had strong faith and I felt that through this experience, God was giving. me a new goal. He was telling me to work for others who had problems and I vowed that, in every way I could, I would use my skill with speech to campaign for greater understanding of people with speech disorders. I've worked hard to keep that vow but I am still amazed at the number of people who rely on their speech, reading and writing skill in their work - such as MPs, government departments and journalists - who are ignorant of the devastating effect of speech impairment! My mother and sister had to fight first, though. They fought and fought and fought to get me to a rehabilitation centre where I could have speech therapy. It took three applications and many letters to all sorts of influential people to get me admitted, but I was finally taken to the Wolf son Medical Rehabilitation Centre. It was there that Michael Jackson, the speech therapist, told my mother and sister what had happened to my speech. I didn't understand the explanation then, but I was delighted that at last someone understood me and knew I was *not* an idiot. It was a great relief to know that I was not the only person to ever have been like this -there were eight people like me there at the time.

It was lovely to feel safe in the hands of the speech therapist. The joy of producing even a few words and the relief of knowing I could get better is still a vivid memory for me. It was very bad speech but never mind, I could say something! At that stage, I used three phrases constantly 'it's madness!' 'wonderful' and 'but, but, but'. They may be symbolic in a sense, but in fact a speech therapist would label them as recurrent utterances, a sort of 'prop' phrase which came out more easily than the more meaningful speech I actually wanted to use. But it was progress and I was happy.

Then, all of a sudden, the Wolf son discharged me. I returned home to live mainly with my mother, sometimes with my sister Jacqueline and her husband, David. I was distressed and devastated by this sudden change and all I could do was cry. I *did* have private speech therapy twice a week at home from Joan Ellams, a speech therapist from Camden Rehabilitation Centre, but it was not enough. I knew I needed more and although the family tried constantly to help, I still felt desolate. My mother especially refused to give in although after five minutes of her work I would be tired again and weepy. The closeness of my family and friends kept me going during this time. My mother in particular continued to be an indomitable driving force; it was so typical of her to keep going even though she must have been exhausted. (She was seventy-nine when I had the stroke.) Her refusal to let me give up helped me find my own fighting spirit again; we are very similar in character. At home, alone, she would talk constantly, asking me the names of everything in the room and demanding answers. When friends came, she insisted that I should be kept in the conversation although it was hard for me to follow a lot of talking. My sister and her husband also worked hard; David, my brother-in-law, played dominoes and cards with me and even found a one-arm card-holder so I could play one-handed, even though I could only manage 'snap'.

I think it was at that time that I realised how much had changed. I knew it was not only my speech or my walking, etc., but my independent life style was in jeopardy. I was decidedly slowed down in every way. Before, I walked briskly, talked quickly and was a very active person in my work and in my social life. Many of the things I loved like the theatre, concerts and parties are no longer so pleasurable. Where I used to have boyfriends, now I have friends who are men. My periods stopped and, though I enjoy kisses and cuddles, any interest in sex disappeared too. My brain works fast but the messages take longer to be acted upon.

My family's hard work at that time was continuous. They campaigned for more rehabilitation and, after several attempts, I was admitted to Camden Rehabilitation Centre for therapy every day of the week. After six months of being at home, Camden provided so many, many challenges! First, it has a lot of stairs - and very peculiar stairs, almost between each room - so it forced me to be very active and independent. Also, I met other patients who seemed far worse off than me and many who were far more active, so I found it hard to feel sorry for myself even if I had time! My greatest delight of all was speech therapy with Joan Ellams *twice a day*. We worked on all the problems associated with my basic disorder of dysphasia and dysgraphia.

The weekdays were completely full but I was very happy as I knew my physical independence was increasing. My speech did not show the same improvement but my motivation to keep going stayed strong. At weekends, my mother kept up the pressure, helping every way she could. The biggest problem now was with friends, when they visited. They continually directed all conversation to my mother and not to me, so that mother frequently had to ask them to talk to me. I thought them very rude but it didn't stop me from trying to join in. I started to use the telephone at this time and enjoyed it, even if I could only say 'but, but, but'. Strangely, though, I can often speak better on the phone than face to face with people. The telephone is my lifeline.

As for Camden Rehabilitation Centre, it is a superb place. The staff put themselves second and the patients always come first. I had one whole, lovely year there. I made a little progress with my speech - a tiny amount! Suddenly again I was discharged, but this time we managed to arrange a lot more speech therapy. I knew I was benefiting from speech therapy despite very small gains and I had faith and determination to continue. With all the speech therapists, I could say quite a lot and I wanted to carry on until I could say even more. I wanted to talk to my family and my friends, but my long-term plan was to talk to the public and to the media. My writing is still totally limited to copying, but we found a way round that problem. The Patients Guild from Camden Rehabilitation Centre suggested that I find 'scribes' who worked with me to write to everyone, from friends to the Income Tax. It is a long and complicated business, but it works. The scribes have to work hard to interpret my meaning and it can take up to half an hour to produce the right sentence - the only way is to laugh, make guesses and laugh again, until we find the right words. Using this system, we wrote the letter to the *Daily Telegraph* which began the Speech Clubs. I didn't know how many people had problems like mine but, whatever the number, I was determined to help them and their relatives. Two hundred replies told of as many tragedies. This strengthened my conviction that my stroke was meant to take me into helping others. Later, this same combination of my faith and recognition of the needs of others led to the organisation of the now annual inter-denominational service for people with speech disorders.

The stroke has totally changed my life. I am restricted in many ways; I can't use public transport, so I walk or rely on friends with cars, or taxis. Going to concerts or church services is difficult because I need to spend a penny every half an hour; it's easier not to go! I now visit churches out of service time and pray for a few minutes and my mother and I have communion at home. Being unable to write when I'm by myself is still a great frustration. When I have a good idea I can't jot it down and I may forget by the time a scribe comes. It is difficult to store everything in my head and I dislike not being able to be more systematic.

Despite all the trials, I have continued my campaign for the speech handicapped. I have spoken about the problems and the need for increased speech therapy services on the radio and television several times. I feel it is most vital that doctors, medical students and all paramedical staff know their responsibility to people with speech problems. I am frequently included in lectures to all these groups and, despite some problems with travel, always make this my first priority. I manage to get my message across effectively even though my speech is halting and my sentences may include a jumble of tenses and words which may start off quite mixed up.

I feel frustrated by my lack of fluent speech and writing, every moment of my life. This drives me on to be always doing something for others, as well. So many people have helped me to live a full life again. My mother, my family and my friends, all have shown me incredible love and understanding. Many speech therapists and all of my scribes have worked hard with me and for me. We may not have a big voice yet, but there's a lot more I want us all to do. I think we *can* do it, as well!

MARY

Mary was born in Newcastle-upon-Tyne in 1907 and lived there until she was 35 years old. She contracted severe polio when she was 3 1/2 and did not go to school until she was 10 1/2 . She ran a shorthand and typing school in her own home for fourteen years and then began to get restless and moved to London. She worked at the then Ministry of Works during the day, attending the London School of Economics in the evening where she took her BSc (Economics). She then went on to Birkbeck College, also in the evenings, where she took her MA in Industrial Psychology.

After retirement she campaigned for the acceptance of the disabled into the community and in 1973 she received the Harding Award for her services. She has been honorary director of the Disablement Income Group (DIG), chairman of the Legal and Parliamentary Committee, Central Council for the Disabled, chairman of the Snowden Committee sub-committee dealing with welfare aspects of the integration of the disabled, and founder of the Association of Disabled Professionals. Nowadays she is 'just a private person'.

It all began when I was three and a half years old. Until then I had been just an ordinary little girl. A little girl, not even a tomboy. I was an only child and my mother was 'good with her needle' and so I had pretty clothes. I had fair hair, golden hair, and my mother had a polished round piece of wood about a foot long and an inch in diameter around which strands of hair were brushed when my hair was washed, and again each time it was brushed during the day. And then, suddenly, within in a few hours in fact, my hair was cut off, not bobbed, cut like a boy's and the pretty dresses were never used again. I had contracted polio. Seventy years ago if one had a fever one's hair was cut off: it was assumed, or believed then, that one's hair consumed one's energy, or so the story went. My mother had had her hair cut when she was a little girl when she had scarlet fever.

For some years I was massaged every day with olive-oil - when the polio itself subsided I was completely paralysed - and therefore everything I wore became stained and impregnated with oil, and so I always wore plain white nighties, which soon became browny-grey however well they were washed, and over my nightie I wore a navy blue boy's jersey. It must be remembered that in those days little girls always had long hair and never wore jerseys, and in consequence there were not pretty coloured jerseys.

On one occasion a new doctor came to examine me and in that irritating way grown-ups often speak to children, and indeed often speak to other grown-ups who are sick, he greeted me in jovial tones w1th, 'Well, my little man, and what are we going to do with you?' Apart from the fact that I didn't want him to do anything with me, doctors always did nasty things, I was outraged at being taken for a little boy. This was the ultimate humiliation for me: I answered, with all the scorn I could muster, 'Mary's a girl's name.'

I still have two photographs, taken about that time, within six months of each other. One shows a robust little girl in a bathing costume with a curl over her left shoulder, hand in hand with two little boys standing on the sands with the sea behind them. The other, the later one, shows a thin little creature sitting in a baby pram in a jersey with cropped hair: surely a peevish little boy? The peevishness wore off with the years, and the hair grew again, but the gold and the curls never returned, it was straight, straight like wire and an indefinite mousey colour. And it was many years before the pretty dresses returned.

No, it was not the paralysis which troubled me, I soon came to terms with that, I soon learned to use whatever was still useable - in my case chiefly my tongue - but I fought desperately to be a LITTLE GIRL. I wasn't a little boy and so I felt in some strange subconscious childish way not exactly sexless, I was too young to realise the significance of that, but a non-person.

There was a little incident which occurred when I was about seven or eight years old which I didn't fully understand at the time but which made a deep impression on me. I was taken regularly to Mr Emst, a portly elderly German, who made my steel calipers and steel corset. Because I was growing we had to visit him about three times a year. We had to leave them with him to extend and alter and go every day for a fitting. I liked and respected him. His 'supports' made me much less helpless and equally important he treated me with respect as though I were grown up. One winter my mother was afraid I might feel the cold without my steel corset and so she bought me a little pink corselet trimmed with lace to wear while the other was being altered. When Mr Emst saw my mother taking the little pink corselet off he blushed and apologised and left the room, saying he'd come back when I was ready. I, of course, couldn't understand what had happened, but I realised that Mr Emst had acted in a strange manner. When we got home my mother recounted the incident to my father and they both laughed a lot about it, that although Mr Emst could deal with me naked at times and never bat an eyelid, the sight of feminine pink under-clothes embarrassed him. I still didn't understand all this strange grown-up talk and hilarity, but I determined to wear pink underclothes with lace as soon as I was grown up and could buy my own clothes.

When I did grow up I began to realise the disadvantages of being a woman, if one was disabled. I won't elaborate upon the difficulties of menstruation if one is paralysed, because I am sure other contributors will have done this. Also how much easier it is for a man to spend a penny - using a bottle instead of a bed pan. My problem became lack of privacy. Now I know at once others will say but the disabled man is subjected to the same lack of privacy, but is it the same for a man? There is an inherited and built-in secrecy about women's private parts. I have known more than one woman who has delayed going to a doctor until it is too late because she was embarrassed at the very thought of being examined by a man. How often if one enquires what is the matter with a friend or acquaintance, one is told with an air of great secrecy, '1 think it is a woman's disease.' Has one ever heard of a 'man's disease?' But they do have them. How many women know that feeling when going into hospital, 'I'm no longer one of the secret society of women, I'm just a thing.' Your case is unpacked by a nurse: very kind of her because you can't do it yourself. But nothing you have is intimate and private, and your body - well, that's just an object of detached interest, it's no longer mysterious to those males' eyes examining it, and more important still it is not desirable, and a good job too in the circumstances; but will it ever be desirable, will any man ever again react to it as mysterious and desirable?

Women of my generation were fortunate in one thing compared to young women today. After the First World War there were two million surplus women. There were constant references in the 1920s to THE UNEMPLOYED and THE TWO MILLION SURPLUS WOMEN. No one knew what to do with them, they were both surplus and they wouldn't go away. I was one of the surplus women, but of my half-dozen close friends in adolescence and young womanhood only one married - there just weren't enough men to go round - and therefore I felt no stigma that I hadn't married. It never occurred to me that being an old maid had anything to do with being disabled. Many disabled girls now marry , but many don't: it is still easier for a disabled man to marry than a disabled woman. In many able-bodied women a disabled husband fulfils a dual purpose, a husband and someone who is dependent, which women like. But for an able-bodied man, a wife is, apart from a beloved object, a status symbol, an added demonstration of his masculinity. There are of course exceptions, many exceptions, but in this life it is better to face facts, and the sooner one does so the more constructive one's life can be.