

**NOT QUITE HUMAN:
AN EXPLORATION OF POWER
RESISTANCE AND DISABILITY**

VOLUME 2

Fran Branfield
Sociology Department
University of York

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David

I lost my sight in 1978, had accident at chemical works, caustic soda. Spent three months in hospital, but that was more through burns than burns to my eyes. Because they thought that burns to my body were more important than burns to my eyes. That's the reason they got so bad. Then I went to eye hospital after burns unit, and, well, first of all it was in Longcaster Gate hospital and I got bandages round my eyes, and the nurse says, I say: "What's the matter with my eyes?" She says: "Oh they're alright." And then when they took bandages off I couldn't see nothing at all. And the nurse just turned round and told me: "Oh you should be alright, you can have an operation." Then I was taken to another hospital which weren't too bad because it was a nice little place. When they came to give me supper one evening they asked me what I wanted. I told them and they said: "What would you like for afters?" I says: "A banana". So they come give me the banana I picked up the knife, I mean the spoon, and tried to get into the banana. I thought it was frozen. Never thought that they'd left skin on. You know just ... And I said: "Aye up! What's wrong with this banana? Have you frozen it?" And everybody burst out laughing because they had left skin on. And that's when I thought you just have to take everything as it comes, from there. Then when I did get out of hospital, mobility officer came up to me and said: "Would you like to go on the blind register?" And that's when it really did hit me. I says, " could I?" I could just see a bit out of one corner of one eye, I says: "I'm not blind! I can see." From then on me and me wife spoke about it and what things we could get, being on the blind register, and my eyes did get worse and worse and I went on

to the blind register and they could give me mobility. I did long cane training in it. Which I absolutely hated. But... I hated it because ...well... I used to go out and I was never one for concentrating, I used to always dawdle about and, as you know, like today, [he got on a training walk] I live in a dream world. I just go the wrong way completely...and I could never find our house. I just walked past it and land up at end of street, and that meant coming back and many a time I've gone out and gone down to the chemist, which is next village, a mile and a half a way, come from the chemist...You only turn a corner, it's just one road but I'd miss the corner, go straight cross, and the next minute there is a car behind me. And I know very well there should be no car behind me, they should be on my right hand side, so I'd gone wrong some where. So somebody would help me, got half way home and I'd find a car behind me! I'm walking over the bridge instead of the causeway. So - that's it. Once I got in the house I didn't go out for nearly five days, I just totally lost my confidence. Then they asked me if I wanted to go on rehabilitation course, for engineering. And that meant going down to Torquay, for nine weeks. And I went down there and did engineering, did mobility once again and that's when I come across guide dogs down there. They said: "Anybody interested in looking and having a practice with a guide dog?" So they brought them one day and, Oh that was it! It was...walking that speed, where I had been dithering about and you know it's just impossible to explain. It were just absolutely fantastic. Being free again and you could waltz off, no bother with anybody. And I applied for my guide dog - it took me two years to get. But I got that in 1981. My first guide dog, I went to Bolton for him. Once I had got my guide dog, that was it. I would never...I have been out once or twice with a white

cane when the dogs been poorly but - no way - once you have had a dog, and been out with a dog I'm afraid it's "How's your father?" You just don't want anything else.

How do you feel, as a blind person? Are you made to feel that you are different?

Oh definitely. I must admit you are. Because I can always remember one thing that really irritated me. Once I went down in to club, I went to bar for a pint, and my father-in-law comes round and he says: "Oh I'm just going down to other end of bar." So I says: "O.K." One of me mates come across and I were talking to him, next minute father-in-law comes across and he says: "Who are you talking to?" And I were talking to my mate but he had just left and not even said he were leaving and I were talking away to him. Talk about embarrassing! You just don't know where to put your face because people must have been watching me, thinking you know, well who's he talking to? You know if the people come up to you and say like Oh just a minute I'm going to see so and so - but they don't, they just walk away as if you're not there. It is very embarrassing. Particularly on buses. You know I mean... you'll get on a bus, especially with guide dog it's worse, because a lot of buses you get on, the back of the buses the dog won't go under the seats because there's little boxes under the seat - you've got to really be at front, near enough. And so I'll say: "Excuse me, is there a seat?" "Yeah, there's one over there". I mean where is "over there" to a blind person? You know it could be down bottom end of bus station! Over there! They don't seem to realise...it's the same when you're wanting to cross the road. They always frog

march you across the road. You know they say: "Do you want any help?" "Oh yes please", so they'll grab hold of your arm and lift you literally, you know you're on your tip toes going across road. But I find with...especially with a dog, I mean you don't seem to have that trouble, you just... I think it could be a lot of blind people you know, when they say can I help you across road you should turn round and say: "Oh yes please, would you mind if I hold your arm?" Instead of them...you know I expect it could be our fault as well as theirs. It's ignorance on both sides really. When you work it out.

Do you feel that, being blind, causes embarrassment for other people?

Yes, I had one person, well she always used to speak to me, I mean she were only across the road, she used to speak to me, and what irritated me even more was she was on the blind committee at Rotherham. But after my accident she would never speak to me unless she was forced put to. She was one of these...well they have a committee and there's...they meet every so often to decide if there's any blind people who want any help, if they can help them anyhow, you know with money or whatever. Holiday grants, and then they have a trip, they have a concert, and, well fortunately, because it used to be run just by sighted people but fortunately now they are starting to get one or two blind people on the committee. And starting to ask what they would like. It always used to be what they wanted, "Oh I think they would like to go to so and so". They would never ask the people what they wanted to do, if they wanted to go to so and so. It was just a case of "Ooh we'll all go to Scarborough" Or somewhere like that you know, but

they never asked the blind people. The same when I got involved with talking newspaper, and that were in 1982, I mean I first started packing cassettes in to wallets, and they had fast copying machines, tape recording machines, which, us blind people couldn't use. "Oh no you can't use those!" But now, eventually, we even do recording, go out doing copying, we do most of the stuff now, but for...when it started it was: "You sit there and pack the ..." and that's it. That's your limitation. When I first lost my sight I were watching a programme on television, I think I had only been out of hospital a week, and a chap come on, one afternoon, and he were a blind person, and they asked what he did and he were basket weaving. You know it just suddenly went through my head - is that all I can do? Basket weaving? You know. I just absolutely broke down, I mean there were just no way. I thought well I'm not going to do basket weaving. Eventually you find out there are different things. I mean just cos you have lost your sight...the majority of things you can do what sighted people do and half of the time better.

Do you think how you see your self has changed?

I think I am more confident than I used to be when I was sighted. I think it, in a way, is because I can't see people's reactions. I can't see people's faces, so I'm more confident in speaking. I do speak for guide dogs. Which I think if I could see the people there, I mean I went to one just before I came down here which were a hundred and twenty people I were talking to. There was no way one time of day, the thought of even getting up to speak to people like that...but because

I can't see them and don't...you know I just get lost in my own little world and I imagine no one there and I can just wobble along like nothing and it's...it's totally different. And plus, I don't know, but I think you...some people take the mickey. I mean the same when you used to go in to a pub and I'd say something like "I'll see you". And it would go dead quiet just cos I had used "see" you! People think I mean they'll come up to you and say: "I saw...you were down the road the other day!" In stead of saying I saw you down the road. They just automatically just stop there. It makes no difference to me and...it's the general public that...which have problems.

Before my accident, really, I were just a working chap, married, two children, a third on the way, and it were just like a routine. Morning and, you know running about going to work every morning, getting up and paying bills and things like this...but then after I had my accident I thought well I'll never groan again about going to work. Cos eventually my eyes got that bad, one ruptured when I was doing the engineering course, so eventually, to cut a long story short, they said that I might as well take early retirement and not work at all. I'm not allowed to bend, lift...anything like that so that really got me depressed, but I've done things which I would never have done when I was sighted. I mean I had those weeks down at Torquay, the rehabilitation. I mean there is no way I could afford nine weeks down at Torquay if I was sighted. I've had a month engineering course in London, I've done a demonstration in gardening around Harrogate. Just things I would never have done. What always amazed me, I mean I've always done my gardening, I mean I did my gardening from being a little lad, with my grandad,

all my life, and the problem is when I first started gardening after I'd lost my sight, I thought right, I'll get my onion patch done, I used to grow a lot of vegetables, so I started digging that up, and then it suddenly dawned on me, I thought well, which way am I? It was only what, twenty yard by twenty yard, but I didn't even know where I were in my garden. So I did have a plastic green house at the time so I started throwing little pebbles trying to find green house. Cos once I knew where green house was I knew the path were next to it. So then I thought this is no good, I can't keep going on like this, and I got involved with the Gardens for the blind Society. They give me tapes every quarter, they have a manual for blind gardeners, which tell you about all the equipment you can get, right angles and things like that, and I mean even vegetables and things like that have never been as straight in my garden when I was sighted! You know because you just start with a straight line and you've got right angles and you put that one down, and you've got marks at every foot, three inches, six inches, whatever you want, and, Oh they are nice straight lines! Everything looks absolutely beautiful. And year before last I won a gardening competition and television came down, and they were asking me questions about you know, why do you do it? I mean, I just do it because I like it. You know, some of the questions they were asking....just because I am blind. If it had been a sighted person that won that competition nought would have been done. But because I was blind, I mean everybody come. Papers, I mean first thing I knew about it was when the wife rang me up. I was down at the newspaper, she said that all the papers had rung me up, and she was saying television ought to ring up, and the next minute television rang to come down. God! Talk about nervous! I mean if I'd have been

sighted I'd have never got on television and things like that. I think it is a different world, I must admit. I find a lot of times going out, especially down the pub where...a bit of a bore. Unless people come to you and talk to you it's a bit difficult because I mean I used to go down with my father-in-law, which was alright. His mates would come over, and if someone were talking to him somebody else would perhaps come over...you know it were alright. But, I mean, I know a mate of mine, well for years he'd been a mate of mine, and he's been in pub and the only time I knew he were in pub was when somebody told me "So and so's over there." He never comes to see me, and he's even been stood next to me and somebody were talking to me and says: "Oh Pete is here". I says: "What's up? Aren't you talking to me?" "Are you alright Dave?" You know and yet he spoke to me nearly all my life. But yet as soon as I lost my sight, that were it. He wouldn't even dare speak to me. To this day I don't know why, cos I'd give him a great rousing about it. But it makes no difference. But now they do shout when they are going by but one of the biggest problems I found is people never say their name. And it's really irritating. I mean, alright, people should ask you how you are and all, but you can be chatting away a couple of minutes and you think now, who is it? And really it's my fault as I should say excuse me...but after we have been talking it's a bit embarrassing to ask who they are. And it gets a bit difficult from then on. Then you go home and say: "I've been talking to someone on bus, and he's been saying so and so and ..." "Oh aye", my wife would say, "that must be so and so". Then you know who you were talking to but...very difficult.

Have you found that embarrassment, yours and other people's is a feeling that

you have had to deal with quite a lot?

Oh aye. My first guide dog, if we can say crudely was my youngest daughter. She was about five, and she used to take me all over place. And she used to play hell with people. "What you looking at?" 'Cos they all used to look at me and it never made no difference, I even had people walk into me on purpose. She'd say "Dad he's just walked straight into you". Must be to test me, if I could see or not see. People do that. I must admit it, my daughter couldn't understand why people were doing it, you know walking in to me, and why people stared at me, and she would lead me all over, take me up to post office. Half the time I never knew where we were, I had more confidence if I had someone at the side of me. But I think, looking back now, I got my first guide dog, Toby, I came home with him, and really my youngest daughter never really took to him. It never dawned on me for ages. Then it suddenly hit me the reason why she didn't take on, because that dog it took over her job. It was her job to take me out. It took me a bit to realise it. It is difficult, it's the same when with family life. I mean we have more rows than we ever used to. And they are only petty rows about things. Like if I get a letter and somebody wants me to write back, you know, I get agitated because I say "Oh are you going to write that letter." "Oh, I'm doing the ironing" or something. It really is a stupid thing if you sit down and think, it is just that you know you can't do it and you want someone to get it done because you are liable to forget about it. And once you forget about it...it's the same if you put anything down...you know you don't remember where you put it. Even the wife and kids say "It's over there!" And same when you want owt doing like, they say I'm watching so and so,

or I'm doing so and so. I mean that's really is how most of the rows start in family I think. But one thing I did seem to come round, when we were down in Torquay, all the men, all the married men, the wife seemed to stop with them, whereas alot of women who came down there, the men, they either divorced them or...it was surprising how many women were divorced through them loosing their sight. You know the men just couldn't cope. I mean one lady I know, which to me is absolutely disgusting, she used to go with her husband and her husband used to take the girlfriend. You just couldn't believe it, I mean she was sat there not even knowing the girlfriend was there. How it was, somebody got that embarrassed that they just told her. That is really the lowest of the low! That is something I have noticed - there seem to be more women divorced through blindness, I mean a lot of women will stop with men but not the other way round. You know this is just what I've come across I don't know how..you do get odd men that look after their wives and things like that but it always seems the other way round. It put a big strain on our marriage, because I mean really you know wife couldn't even change a plug! Or bulb or anything. If owt needed doing I used to do it and that were it. I mean wall papering and things like that. I mean I didn't do it just because I was a man, it's something I always enjoyed doing. But once we got our own house, I love wall papering and things like that. Now my wife has got to do it. And I mean it frustrates me because I know that I can't go in and help 'cos I'll be in the way. I did try painting but she told me to get out, 'cos I were getting more paint on floor...you know it's just a case of wanting to help. And she's doing all the work and you get a bit embarrassed. and feel as if you should be doing something, but you can't. There is just no way you can. I have papered a bedroom, kids bedroom,

just wood chip paper but it took me that long I think well...she just does it now. It's just a case of I either go up in the loft to listen to my music, or go out with the dog, just to get out of the way when she is doing anything. Go down to the green house and work in the garden. I think on a practical level it did have a big effect on my life, I think it did, and now, I mean, we have worked at it. It's not been easy I don't think for Susan or me, but I mean we've had to work at it, but I think we've just about cracked it.

Do you think your hopes, dreams or whatever for the future are different now than they were before the accident?

Well, I don't know if I had dreams or anything else before the accident. It was just a routine of going to work and I ...well I think I have achieved more since I've lost my sight because I've been able to achieve it. I mean one time of day it were just going to work, getting in as many hours as possible, bringing money home, buying new furniture, clothes and things like that. Now it's just different. I mean I have got time to do things, I do a lot with the talking newspaper. I mean I go out and do interviews, which I mean to me, I'm not much good at it, you know, a good interview, but I enjoy doing it. I go out and do outside recordings of wildlife, I've only managed one bird at the moment! But the biggest problem I found out with that is that it is alright recording the bird but you've got to know what the bird is! I mean I can't see it, it flies off somewhere else...Eventually we.. the RSPB have offered to take me out and do recordings, you know and things like that. And same with committees, I mean I'm chairman of the branch of

Guide Dos Association. I started that voluntarily, five years ago. The woman who was in charge had to go for a new guide dog and so I did the talks for her. At first I said there was no way I would, but eventually I thought well it's only a one off thing and well Oh! Talk about sweating trying to remember everything, getting a bit of a story, putting it together about guide dogs....thought I'd forget everything...but once the first one was over...well now they are better because we show videos so people can see it, and ask questions and I just answer them.

Do you think that doing all these things that you said you would have never done means that you think of yourself as different from before?

Oh I think it's totally different from how I were before. I mean same as going out recording, I used to go recording when I was young, just messing about with mates, bit of Juke Box Jury kind of thing you know, but that's as far as it went. This is more serious...but what I think it comes down to is that now I've just got more time. You know to dedicate to these things. If I'd been working I just wouldn't have had time. Before it were working, my garden, my house, my family, well family first but down that road, but I mean that were it. There were nothing else, but now I can near enough do what I want. I mean if the government gave me six thousand quid I'd be able to do a lot more!

I've always been dependent on my mother and I've had two sisters and then I married and my wife's made all the home things, I mean I can do my own meals and things like that, but I mean my wife looks after me and I think it would be

difficult more, as a women who's lost her sight than as a man. But when we were talking about more women who lost their sight were divorced that could be the reason. You know the men have nobody to look after them so they go and find someone else to look after them, that could have been one of the big reasons. I must admit that men could find it easier. One thing I mean though I were fortunate with wife, I mean she didn't sit there, well she did for the first week or two, change all my bandages and things like that, but I mean after a bit she didn't sit there and molly coddle me and say like oh love just sit there and I'll make you a cup of tea and things like that. I mean I used to get up and make my cup of tea and her one and she would say nought. But I never did get in to making meals and things like that, even though I did have training down in Torquay to do it, and ironing! I mean I have never done ironing in my life! And someone said I could practice now that I've lost my sight, but well, ironing is something that has never appealed to me. I could do it if I've got to do it, but I mean when you've had your mother and sisters and then you get married and your wife does all the ironing, I mean it's just a thing you never even think of it! Just sit there and say: "Are you alright love? Want a cup of tea?" And that's it!

Can we talk more of when you first lost your sight? What are...

Well, they took me to hospital and the only thing that really got me so mad was that they wanted to give me X-rays and what and they ripped my clothes off. Well they tore them, and they started cutting my T-shirt off and my underpants and the only think I could think about was I'd just bought them the other day! It really

upset me - I'd just bought them! And they were just cutting them off me and then they gave me some morphine which took all pain away and it were alright. I were laid in hospital and wife came to see me that night and well after she said my face were all swelled up with all the burns and that, and my face looked like a spaceman's hat it were that big. I was going in and out dreaming and that. And I remember a nurse coming and saying: "Who's in there?" "Oh it's Mr. Nixon he's been badly burnt I don't think he'll last the night". I says "You what?" You know in my mind. Cos to me I was all there and what do you call it. Three days later I was still there, and the nurse came in and I said: "Excuse me, is anyone going to give me anything to eat?" I'd been stuck there three days - I know I couldn't eat much, cos all my lips were burnt and that, but they started feeding me, and that's when I asked: "Well what's the matter with my eyes?" And the nurse said: "Oh you're quite alright you can have operations to get your sight back." When she said that "get your sight back" you know I just couldn't say no more, I just broke down and cried. "Oh , don't be so silly, you'll get your sight back!" I then went to burns unit, and they told me the same, went to another hospital and they told me I might as well go on blind register. I had a little bit of sight in my left eye then, and he said he could give me some drops to enlarge my pupil, to look over the top of my eye, cos it was all burnt at the front. And I could sort of see things at the top of my eye, and I walked down street, well one of the kids was with me, and I thought it were great. I could see again it was fantastic! It lasted three days then it suddenly went. Later on I found out it were cataracts, which covered it. So my left eye ruptured later on so I had to have a patch put over that and then in Torquay I were total then, I couldn't even see light or dark or

whatever. Came back and he says: "I can do a cataract operation, which will not give you any more sight, but it will let the light back in". So they give me that, which nurse and doctors well they weren't too bad. I mean I got out of bed one night and I didn't know, I must have got lost, and you know how you wave your arms about, and all of a sudden I could hear: "You hoo! You Hoo!" I said: "What's up?" She said: "I thought you were waving at me". I said: "No. I'm trying to find bloody the loo". You know I'm busting to go and things like that. But I think they are getting more and more into it now because blind people go there so the nurses can demonstrate how to cope with blind people, you know, how to lead blind people and ...After operation they took me, some students wanted to see me, so they took me over to the big hospital, and I get excited because I could see a red line going down. They took me in a wheelchair and the porter just said "Oh aye can you?" You felt right rejected, he could have said "Oh good, that's nice", or something, "you can see a little bit", not just "Oh can you?" It really deflated me that, I thought well is this all they are going to say. I never seemed to get any encouragement or ought from the doctors. They never explained to me what was going on, never, it was nothing to do with me. I mean that's what really got me frustrated, I mean for instance, not so long back, eventually I had a corniagraph on my right eye, which got me a bit more sight than usual, but in bright light, because my pupils enlarge, it's like a white sheet coming down in front of me. I can see shadows and things like that which sometimes I think is worse than when I was total. Start jumping back and things whereas before I was oblivious to everything. But I do find it a lot better I must admit, I sometimes can walk about, no problem. I can't cope with crowds, just no way but if I'm walking

along a straight road and there is nobody there I can manage on my own. Trip up a few curbs but that's beside the point. Anyway I was there one time, and I have ingrowing eye lashes and they rub my eyes, and on my left eye I have a soft contact lenses to stop lashes rubbing. Well they were rubbing that bad, and I thought I were losing what sight I had, so went to see him and he says: "Um yes...er...um..." I says: "What's the matter? Is it going?" He says: "Yes, I think it's rejecting, I'll put a bandage lense on to stop the pain." Well in fact since they did that my sight has improved, because I don't have that rubbing and it is not rejecting. But he said it were rejecting, and as soon as they said that it, well it just deflates you. They don't tell you much, I mean, they never sit you down and explain what and why they are doing things. So it's all worry, and sometimes there is no reason.

Once you have accepted it you know, that you are blind, then the whole world is open to you. Nothing you can't do. I think a lot of it is...when you are sighted I mean you perhaps do a job and if you make a mess of it then it's your fault. But if you go blind and you go to do owt and you make a mess of it then everyone says: "Oh it's alright we know you can't see very well." So I think you have more confidence in yourself, you know if you do make a mess you can blame your blindness. Which if you're sighted there is nobody to blame. It's a bit embarrassing but...I mean it's like when I won that gardening competition. Headlines in paper: "Blind man wins gardening competition"! I mean I have always been interested in gardening so well, I could never understand why they made such a fuss, what was so fabulous about doing it. Just because you're blind,

it's not bothered me one iota. I mean same as fishing. I used to love fishing, I used to go all over fishing when I was sighted. Well I went with a mate to the Trent. He sat me there and tackled me all up and everything, I thought it was great. So I'm sat there and a couple of hours later I feel the water coming into my wellies! Well we forgot about Trent backing up so it was coming higher and higher and I says "Hey", he says "What?" I says: "Got water coming into my wellies, what's happening?" "Bloody hell!" he says "I forgot, Trent's backing up!" Well my maggots were floating down river and everything! I just went to top of bank and that was it for fishing! Perhaps if I went lake fishing and things like that but... I just didn't bother ...It's just a case of, well you're that independent when you are sighted, I mean you do these things. You go out on your own, where you want, when you want, but when you lose your sight you can't. I mean alright now I've got a guide dog I can go down to the shop and near enough anywhere I want, but there are certain places, like going fishing or going recording wild life round reservoirs and things like that where I need sighted help. And I have never been one to ask people to help me. I don't know if it degrades me, it just embarrasses me, but I mean even when I were at work we had chaps that live in our village and I'd never ask them for a lift. If they offered I'd take it but I'd never ask them. I'd rather go on bus than ask for a lift. It's the same now and when I lost my sight I just don't like asking. I mean brother-in-law will do what I want. But if I can do it without asking him I'd rather do that. He plays hell when he comes over "You should have asked me" But if I'd been sighted I wouldn't have had to ask him in the first place. I mean when you are visually handicapped you can't go with a bag of potatoes on bus, lugging that and holding your dog and all - you'd be knocking

everyone all over the place.

One thing that does embarrass me, if I want to buy a card for wife's birthday or something I can go down to card shop to buy a card but they say: "Do you want me to read it to you?" "Yes please" They read it out loud and you can hear all the shop listening, and you start glowing and after the second bit you say: "That'll do". One thing I really miss is, that me and Susan when we were courting, I mean she were at school when I first started courting her, and twenty three when we got married, and one thing we always used to do was go shopping on a Monday afternoon. I used to work shifts and she worked in a shop and had Monday afternoon off. So we went shopping. And that is one thing I really do miss, browsing, and looking at things. If I go shopping now it's a case of well I want so and so and this and that and that's it. You go to the three shops, you know what you want and there is no browsing. You can't go round town browsing. I go to the hospital every six weeks and then me and my wife go shopping afterwards, but you can't...I mean you go in a record shop you can't browse, you've got to know what you want. You happen to hear something on the radio and then you find out it's been out for the past three months but you have no way of knowing that. You have to rely on other things all the time, you can't browse round shops and that really irritates me. You know you can't go down the market and see nice cheap things.

When you went to the rehabilitation centre, what did you think of it?

Hated every minute of it. I mean I had just been blind a year and a half, then...perhaps if I had this bit of sight which I have now I might have enjoyed it a bit more. But I was told they like it better if you go down on your own to show you are more independent. I mean that were from Sheffield to Torquay on train. So I went. I sat there all the way down to Torquay mumbling to myself, nobody talked to me, things like that. You could hear people talking and you thought if I say anything will they notice I'm talking to them? Or will they totally ignore me? Or will I embarrass them? So I never spoke a word all the way down. Nobody asked me if I wanted a cup of tea or nowt, and I were gasping. Well I got there, they picked me up in van, got to Torquay rehabilitation place, and they said they were a bit late came in for tea. So I went into the dining area, sat down, had tea, and he says: "Right I'll show you your bedrooms." So off we go - this is a big manor house, went upstairs he points out the room and says he'll see me in the morning. I'm sat in bed and thought Christ! What the hell do I do? Fortunately one of the others came round and asked if I fancy going down pub. So I said: "Why not". I remember one of the lads from Rotherham being there and he could see a bit and he came up to me, so we all go down to the pub. So we are sat there and the next minute someone comes up and says: "Are you from Manor?" "Yes" "Well you've got to be in for ten O'clock". I says: "You What?" And the doors were locked at half past ten! I thought this was ridiculous. So I grabs hold of him like and he gets to the door and says: "Oh my God it's dark!" Well he got retinitis pigmentosis, and he couldn't see a thing in the dark, so these two lasses said: "Grab hold of us and we'll take you up there." So we get up there come's down for breakfast next morning, big flight of stairs, after knocking about

three tables over I find mine, there were one table I knocked over every time in the whole nine weeks. The chap sat next to me was deaf as well as blind, and I couldn't understand a word of what he said. He still phones me up once a month! And they had a place where you could have a chat with the others and a cup of tea, well it took me three weeks to find that room! Once I'd found it I were alright it was just getting courage up to explore. Well to me down there but if you get a bit of sight and could help yourself they liked you and they helped them more than the totals. It were terrible for the first few weeks, I'd walk into people and things. I'd get that mad and hide in the toilet crying. I felt really insecure down there. I was relying on other people all the time, and a year and a half after I'd lost my sight I wasn't capable of looking after myself. I thought I would be able to but...I just gritted my teeth and got through it. Yet saying that when I'd done everything down there I applied to go to London for engineering and I enjoyed that so much. But that was the works, I were working on the lathes, drilling machines, braille micrometers, and that was the sort of thing I'd been used to, working, and it were great. Used to get up in morning, plus what made it different was we were in separate rooms. In Torquay I were in a room with, I think it were six, to this day I'm still not certain how many were in my room, and I think that having no privacy was terrible. Plus, I could just make a bit of light out, even then I used to switch a light on, it made me feel secure. But there were a lad there who always turned lights off. It used to irritate me something chronic! But in London I enjoyed that great. But even there, there was a place where you could mix with sighted people, supposedly. I went in one day and stood at bar: "Oh you're alright love, go and sit over there I'll bring your beer to you," says the

bar maid. I says:"You what". She says: "I'll bring your beer to you". "But I want to stand at bar". "Oh sorry dear,"she says "but everyone always sits in that corner, that's the place for the blind". I'd have none of it and would stand at bar, and chat to people. I think it must have been first time a blind person was chatting to the others. And I think I'd been there a fortnight and this chap comes over and asks if I'd join the committee, and tell them what it is that blind people want. We even went to a strip show one night! There were four blind men, it were a laugh a minute! Then we went to a disco, it were sighted people that took us, really enjoyed it. It's alright being with blind people, you can joke about it and all, but if you get a crowd of sighted and blind I think you enjoy yourself a lot better. Blind people used to go there one time of day, sit there, never go out at weekends, nobody used to bother with them at all. I don't know if it's attitude of the blind people...they want to be left on their own but...I mean it is nice to talk about your own experiences and things with other blind people, but it's nice to be with sighted people as well. I mean I prefer to be with either people, but the problem comes, if you are with all blind people, if say you all want to go out to a pub, you have to rely on sighted help every so often. I mean if there is a gang of sighted and a gang of blind people it's great you can all mix together, have fun. A lot of the problems with a lot of sighted people is that they don't like to slip up and say wrong things to you. But once they get to know you and things like that, you can have great fun with them.

The week before my accident, I used to live down in Rotherham, and I had never been down there since I left when I was seventeen. Just before the accident, when

I was thirty odd, the week before, I decided to go for a walk around where I used to live. I went and had a look at the infant school, I went to look at where I used to live, but the houses were all flattened, and I went to railway where I used to knock about as a young lad. Went down the woods to have a look at the tree where I used to play touch wood...you know and all round where we had Tarzan swing and things like that. To this day I don't know why I went round there because I had never bothered before and things like that. Then a week after that accident happened. I mean even that day accident happened...I were on afternoons and we had just come from town and it is the first time wife has ever told me not to bother going in to work. But there were so many bills in and that...you know, I had to go to work to get bills paid. But it was the first time she had ever said "Oh don't bother going in today." And it was the first time I didn't agree with her! And then going to work and me singing "Oh what a wonderful world", you know and things like that. And the same when I got there. It were blocked up and everything and I had to clear it eventually. I decided I was going to chop some sticks for this chap from next bay, but I thought "No, I'll leave that till later, and go and clear this lot out." And just as I got there it exploded. And if I had gone to chop sticks it wouldn't have happened so ...if you can fathom all that out...was it destiny, was it my thing to be...was it going to happen to me, and saying that, like when they say things happen in three, week after my accident a lad got blown up in a wagon, and blow all his chest in, he was stood behind it, a car wagon, and then a fortnight after that one of lads in oven, they have, like a railway that they shove up ovens, and something happened and they shoved it all in to cab. He lived three days. And out of them three there is only me that

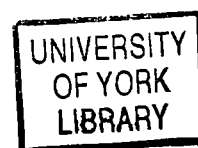
managed to survive. That happened in threes.

You were saying about your social life...

Yes, I don't know if it has changed dramatically. It might have changed as years have gone on. But before my accident I used to go down to the pub, and knock about with my mates. We used to chat about work and things like that. I used to have a stack of mates, then saying that...that slowly dwindled off once I lost my sight. I mean I'm married I got three children, it might have dwindled off anyway. Once you are married it does dwindle down...but a lot of the difficulties I did find, perhaps some of them not even talking to me, and I mean, my father-in-law would say: "Your mates over there, sat with John talking." But he never said a word to me. I mean one of the worst things they ever did to me, well, they might have not done it knowingly, was he were talking to me and then I were talking to him and then father-in-law come over and ask who I was talking to. They just walked away without even saying they were going. Same with people when you meet them in the road, they never say who they are. Instead of saying who they are. But I think a lot of people are too embarrassed to say their own name half the time. You don't bother to ask their names cos you just get a bit fed up, and people expect you to know them anyway. The worst are those who say "Do you know who it is?" And you have to guess! I suppose my social life has changed - it's in a different direction I should think. Instead of going down the pub now I go and talk for Guide dogs. To schools, institutes, working mens clubs and now with being chairman of the branch I have to go and receive cheques at clubs and

things like that. My social life has changed that direction. I really enjoy it. I didn't think I would when I first joined the branch, I just went there to help raise money for guide dogs. Then the lady that run it says you are going to talks and things like that. I said: "You what?" You know I just wouldn't do talks or owt like that. But when she come away for a new guide dog she just had one talk what she wanted me to do so I did it. I was petrified and just warbled on and warbled on. Eventually they had to stop me talking! I think we've finished now! We've got one for schools now and a lot of, well we show a short video and they love it. It shows the puppies and the dogs working and it shows what a blind person can see...a totally blind person, and a person who can see bits. I think children grasp it quite well. But that side of my social life has changed for the better I think. I don't think I even knew one blind person before my accident. I mean the first time I ever came across a blind person was on a bus. And I must admit I've been the same as sighted people treat me now. Because he come and nearly sat on my knee and I just hunched up, pushing myself further back, not even saying a word to him. I mean now I can get on buses and say "Is there any seats?" And, as I say they say "Over there"! So it's on the other foot now. That chap who nearly sat on me I do know him now. I do find it easier socialising with people who know I am visually handicapped, and know how to handle visually handicapped people, by saying things like - I'm just going to bar now - or whatever. Rather than just leaving you talking to yourself. But I mean people that know me it's alright. At the branch there are five visually handicapped people, no six, and four with dogs and I socialise with them, we have a good chat...the work we do is involved with helping visually handicapped in our area, by giving them a day out, having a

concert...you know them sort of things. I'm involved in that. And when I go round at christmas taking their cards or whatever, but it always takes three or four hours because the elderly people I visit always invite you in house...they are just lonely people. And it's because they can't see. If they go out people avoid them, where as if they could see they catch other people's eyes and you get chatting, even if it's only to pass time of day. That's one of the problems for the visually handicapped - it's eye contact. It's one of the most...well it's the same as when you are at a party or owt like that. I mean if you can see somebody across room I mean you see them, they look at you, and you can start talking, you're across there. When you are visually handicapped there is no way you can...well people have got to come to you and a lot of people are embarrassed, unless they know you. If nobody knows who you are, not even slightly, they won't come across to you, unless you are with someone else they know. But that is one thing I have found with guide dog, more people will talk to me than ever did when I had a cane. I mean when you had a cane it were boring walking, but now I can walk along with dog and everyone talks and chats, so it does make life a lot more interesting.



The only thing that really changed, is that I am not working now so I can spend time doing what I like. Before I used to go to work, get up, get kids ready for school, do my garden, off to work, coming home, perhaps go down for a drink, bed, you know it was just one routine, looking after the family and everything like that. But now it's a bit more varied because well, with my injured eyes I can't work now, and I've started doing voluntary work, and once you start doing that

you meet more and more people. I mean even just walking round town you meet lots of people, chatting to them. I must admit it's totally changed from like the routine and now I can go out when I want, I can go out whenever I want, do talks, things like that. I socialise more than I ever used to. The only freedom I feel that I miss is, even though a lot of men don't enjoy it, is going shopping.

Do you think you have changed?

No, and a lot of people think I must be bitter, but I am not bitter, it was an accident, it happened, it was just one of those things. I'm fortunate, some people have been blind all their life, at least I've had thirty odd years being able to see. I miss it like hell, you know there is no doubt about it. If I could see tomorrow, you know I would be quite happy. I expect most visually handicapped people would. You know to be able to see again! One of the main disadvantages with being disabled, I mean one thing you really need is money. And that is one thing you don't get. For me, for instance, I go out and I buy my gardening magazines, I've either got to have someone to read them to me or send them away to be taped so that means I have to buy magazine, I've got to buy a load of tapes and I've got to send them all off to be taped, then a month later I get them back and I have to listen to them all. I mean that is all expense which the government won't help you with and a lot of people think I get blindness allowance. People are always saying well, you can get it on so and so, blindness allowance, same as disabled people get disabled allowance, which we don't get now. Main problem is money. Because everything is a lot more expensive.

Colin.

It started about eight year ago, in hospital actually. I was in for my diabetes and they changed my insulin around and I got what I thought was insulin blindness. You know when they give you too much insulin of a different type. Anyway they said it was nothing to worry about, and that once the insulin had settled down I would be perfectly alright. It was about a year later, when I still wasn't reading at all, that they eventually got us to see an eye specialist. He said it was deterioration, and they tried the usual things, laser treatment, which worked quite good for a while. Then about four year ago I went to get more laser treatment, particularly for the left eye and the machine went hay-wire and knocked out seventy per cent of my vision in my eye. And that was when they stopped doing the laser treatment. About two months after that they registered me blind.

Did they give you any counselling then?

I think that was a dirty word, counselling. It was rather strange, when you get diabetes you need a truck to get all the information they give you home. They've got, really got, sort of services who'll teach you how to do your injection, your diet, they'll give you booklets and leaflets and information if you ask for it on anything. But the eye department seems as though once they have registered you as blind then there is nothing more they can do so bye-bye. End of story. I tried to just adjust to it. Got a bit bitter. I smashed up the house a couple of times. You know, you take it out on people who don't deserve to have it taken out on

them. It was the usual line; why me? I have sort of had trouble for twenty five year with the diabetes, in that your body lets you down quite often, but your mind...my mind always stayed clear, really clear. Doesn't matter how much pain I was in I was always joking about it. And when I first realised that my sight was getting a little bit dim you always had that hope that this time next week something was going to get done. For the first time, and I'm nearly thirty eight, I actually gave up. This sight thing is not...is not like anything else. It's as much psychological as physical. It's a really scary business. Got to be honest, I was terrified. Nobody to talk to, you can talk to family, but nobody understands until it happens to them. You get the usual lines from people. My social workers, and I mean I'm not grouchy by any means, they had the usual lines about people being worse off, which does nobody any good. I got fairly angry. It was the first time I ever gave up. Didn't try any...well I did try to sort of finish it all, but I didn't make a very good attempt. Ended up in this hospital an old Victorian place. Had the psychiatrist come along, who was happily crazier than what I was at the time! Really just worked it myself from there. I don't think you can ever really make sense of it, to be honest, most of the problems are minor ones. Little stupid things, like nothing massively big happened to me. I didn't fall down stairs particularly more than I had anyway. It was silly little things like pouring a cup of tea. But when it happens day after day after day after day where you are missing the cup or plenty of stupid things - you forget to shut the door right back against the wall or have it shut completely so you walk in to the edge of this door. And it might hurt a little bit but it wasn't a massive pain, but when it happened time after time after time you...I was rather vain about the way I dress, and

having to ask my wife: "Does this shirt match this suit?" "Have I got the tie and handkerchief set, the one I wanted on?" Did I have the red and blue striped tie with whatever colour handkerchief because it didn't match. And my socks - they were, in other peoples attitudes...The worse thing was friends, you know me and my wife would be walking down the street they would stop and chat for a while and then they would ask Rita "How's Col?" and I'm standing right there. The first couple of times it didn't really bug but after a while it got me highly annoyed. I mean I'm not Einstein but cos my eyes don't work doesn't mean to say that my brain doesn't. I think this attitude, well I'm not picking on any special group but people - the older generation never seem to realise how that actually does hurt. Lots of people seem to do it, in shops it's annoying. I think I'm invisible because they will serve the person who has come in after me. Specially if your eyes aren't really that...I mean mine aren't particularly horribly bad. so if you're standing there with something you want to purchase and they see you standing there, particularly if you have a white cane, somebody walks up behind you they will turn to them first. The mere fact that you have a disability means that you have got all the time in the world, it doesn't really matter if you need serving, if you're in a hurry. But again, the opposite when people are ultra helpful, that can be annoying as well. A lot of people just don't know how to approach you. I mean I don't know how many times I've been grabbed by the arm and taken across a road I didn't want to cross anyway. So it's a queer balance.

You were married before you lost your sight. Did it effect your relationship with your wife?

Not really, I think Rita had to be a lot stronger and...I mean I have had medical problems long before we got married. Rita had already sort of come to terms with those. And when he said about my eyes she was actually a lot stronger than me. Like I say Rita has always said it wasn't her throat so she was actually very supportive and...but I'm not sure whether that is more Rita's character more than anything else.

Has your social life changed?

I've made friends in what you might call the visually impaired world. To be honest I wouldn't have picked them as friends by choice, because we come from like different backgrounds, got some quite good friends in the visually impaired world who I probably wouldn't have met if I hadn't have lost my sight but most of my social friends who I had before I lost my sight are still fairly close. One or two seem very embarrassed. It's a bit awkward when you want to go out in a group and you got to sort of plan the event. A lot of my friends would go out to the cinema or places that are visually attractive so you find that you tend to get not invited if it is a thing like that. Sort of dances, we used to go to dances quite a lot, but they seem to think that because you can't see you can't enjoy yourself dancing. Which is a bit strange but most of them are coming to terms with the fact that my name is Colin Edwards not Colin the blind guy. The blind bit is just a side effect. I belong to a consumer group for the visually impaired, that's why I know other visually impaired people. It was initially started by social services, but left to us. As I say most of the people in the group are newly losing their sight. Got one or

two who have been blind from birth or who have had sight problems for ten or twenty years. In a lot of cases the new ones have come to terms with it better than those who have had it for years and years and years. Mostly I think because social attitudes have changed. Twenty or thirty year ago, from what I can gather, there was this thing that social workers and welfare groups that they knew best they knew what we need, what you want. A lot of these groups were run by people who had the best hearts in the world but they think because you have one disability you have nothing between your ears. It is the same now. They don't ask...I mean I don't really need to sit and play dominos twenty four hours every day. I really don't need to be taken out on trips, I'm just as interested in the things now that I was interested in before. I don't need to be molly coddled by a bunch of people who think they know best. What I want most is what I want.

Did you have any form of rehabilitation?

No, none whatsoever. Apart from long cane training. I think the consumer group works like that in some ways. It's quite hard when you have a minor problem, like with pouring cups of coffee and that, to tell someone else. But with other blind people they might give you a tip that you don't know about. But it is a catch twenty two situation. Because on the one hand it is good to talk with people with the same disability and share ideas and tips and problems but on the other you put twenty people with a disability together in a room it becomes us against the rest of the world. Whether you are blind, deaf, dumb or crippled you have to live in the world. It can't be an us and them situation. It would be a damn sight better

if the so called normal world was educated by people who've got a visual impairment or whatever. Talking to them about it you know. Because we really don't need an us and them situation. But I'm not sure where we start. Unless you start with the schools. But what are you going to do about the situation where the blind or the mentally handicapped are put in one little group - only with the blind, the deaf and the mentally handicapped - we'd be in there screaming we have rights like everybody else. In fact in certain cases we should have more rights than other people, not more rights but there are quite a few different disabilities and a lot of the outside world doesn't care for them. There are quite a few who are wronged in this country and every where else. One in five people have some type of disability, so things should be designed to take them into account, rather than for people who are walking around perfectly alright.

Do you work?

No. I actually lost the last job I had because I couldn't see. I mean the firm were very generous about it but um...if you need your sight for a particular job and you haven't got it then...

Do you think it has effected the way you see yourself in any way?

No, well it didn't particularly effect me. I'm fairly confident anyway. It knocked my ego a little bit. It was sort of nice being the guy who brought the wages in type of thing. But then...I think I accepted that better than the mere fact that I

couldn't do exactly what I wanted. But losing the job didn't bother me that much. I lost my sight quite slowly and then you tend to adjust. The only really massive trauma I had after I got the eye burned - you know I went from sort of being this guy who couldn't see particularly well, but who could still get around, watch T.V., go to the cinema, to suddenly being this guy who couldn't see his hand if he put it up in front of him. That was terrifying. I never left the house for four months. But again it was...well I sat back in the chair and said that I'm not going out at all. It was only four months later that I started thinking well why should I be stuck in here. I got very angry...well I should say a bit stronger than angry...that was the first time I actually blew my top. That was when a clever social worker told me that there was a million people worse off. He came very close to getting the long cane shoved down his throat. I mean they're supposed to be the people who are there to help you with your problems. Nobody seemed to understand. People told me to pull myself together but I mean how do you do that? I still haven't figured how you do that. The dog is making a difference now. I never owned a dog before it is totally new to me but for the first time...on the first walk we did together where there was no one around telling you to go left or right, I just had to trust the dog, and I had a death grip on the handle for the first two hundred yards. But then the dog seemed to know what it was doing. So you have got to trust something...The long cane...well you have to concentrate one hundred per cent of the time, and it only catches the obstacles where the cane is so anything above the cane you can hit...with the long cane you lose rhythm, say if some one is talking besides you so you end up smacking your head...the long cane is too easy to get it knocked out of your hand... people like dogs they don't

like long canes. I've found people on the street...well people don't approach you with a long cane, they now come up and pat the dog. I'm not sure why people don't like the long cane. I remember when I was sort of fully sighted this, well I only saw long canes a couple of times, and they look so different and nobody likes thinking that they are so different. People find it hard to approach somebody who has got say a bad facial scar, you know, a dog people know. It's a guide dog but it is a dog, so they come up. I mean the long cane it looks strange, people are used to seeing guide dogs, everyone knows what a guide dog is, but they are not used to seeing long canes. Long canes are horrendous in shops, they catch people's legs and all...the dog is much better.

Do you think the way you think of your body has changed?

I find that I relate most things now to my eye sight. Where as before with diabetes you have no obvious defect, apart from the fact that you have to stick needles in yourself, this thing made me feel a little bit more, well a lot more self conscious. I could wander in to a room full of people and unless you did something really stupid you know like having a syringe full of insulin sticking out of your arm, nobody would know you were a diabetic. With an eyesight problem you...well it tends to be fairly obvious when you walk into somebody right in front of you holding a glass in their hand. I became very self conscious. The eye sight stopped me...the one thing that me and me wife really and my friends really like was going out for a meal. And I found that I was, well I still am embarrassed. I do not like eating in public. Even where we are now I find it embarrassing,

because you never know if you have got anything on your fork, or you think you have cut up a piece of food fairly small, until you put it in your mouth and you find out it is three times as large as what you thought. That I actually hate that. It's a fear of making a fool of yourself. It is highly embarrassing. Especially when...unless you have got ...I think it wouldn't be too bad if you had it printed on your head "I am blind", because most people who are blind look like the rest of the general public, and when you do something silly like reach for a glass and knock everything over, I don't think people on the other tables think 'Oh look at that person, he is blind that could happen to anybody'. They just think 'Oh look at that clumsy fool'. I mean maybe they don't think that, but I am always conscious of it. I still hate going out for a meal. Start ordering things that you know aren't going to make a mess.

I think the biggest change that losing my sight has had is that me and me wife, well I can't do things confidently. We have got ourselves two kids and we always shared the responsibility for looking after them. And now, whereas before we didn't have a particular role at home, whoever got in first from working would put the tea on, who ever got in first would Hoover up if necessary, whoever got in first would do whatever needed to be done, even with the kids, if I were with the kid and its nappy needed changing I would do it. That's changed. It's changed to the point that I don't always know where certain things are, particularly kids clothes etc. etc. And it's not always easy to tell if a jumper is inside out or...like before I would do the washing up or the Hoovering depending how busy Rita was, it was as much my job as hers. Now I find that I can Hoover up and do a great job and

then Rita comes in and does it again. The same with the washing up. And that used to make me really flip out. I've got a really bad temper! But it's not so bad now, I accept that certain things, to do properly you need sight. So I probably do a damn sight less than I used to do. I think I'm starting to accept that. Occasionally I blow my top, you know when you think what you used to be able to do, yourself, before. It is actually very expensive if you can't see. It can be an expensive game. For anything. If you've got a partner it might not be too bad but otherwise...if you live by yourself what you did before you now have to pay for it or talk friends into doing it for you. And in a lot of cases you are left with no choice. If you have lost enough sight, I can't even go and shop for clothes. I have to have somebody with me and ask them "Do you think this will suit me?" Whereas before I used to love going out to buy nice clothes. And presents for somebody else. I know for a fact I don't do as much decision making as I used to. I mean before if my wife and I went out shopping, for furniture or whatever it was a decision made by both of us. If you can't see what a carpet looks like you may as well not bother. Those decisions are taken off you. And it's the same with wall paper, colour of paint. Even going for clothes, you might know what you want in your mind's eye, but how many shades of blue are there? Shop assistants are actually useless at describing the stuff they are selling. All your choices are cut anyway. I mean I think I am more fashion conscious than the average guy...I mean major decisions are still discussed by me and my wife but I have to trust her judgement far more.

We were talking earlier about the doctors attitudes towards you. Were you able

to talk to them freely?

They just registered me blind and I didn't know that I had a choice about it. I'd just been to see the guy and it was one of those situations where you would go in, they would check your eye sight, which was always a waste of time, and then you would wait for a while, then go and see the guy, and he would do the usual battery of looking in your eye, and on this particular day they raced me through like the queen mother. Went straight in, no waiting, and he said "I've registered you blind, I don't need to see you any more, bye-bye." It was...I mean I knew it was coming but it was still a kick, I mean I was actually in total shock until I got home. I didn't find out till twelve months later I actually had a choice about it, but nobody explained that. I haven't seen an eye specialist for three...four years now. But their attitude changed as well. I mean I have had diabetes for a long long time. And although I don't know the technical terms I certainly know the condition as well as any doctor. I found the doctor who talked to me as a human being, who had diabetes but who know a bit about it, but I went in as the blind guy who wanted everything explained to him. But they seemed to think that as I had lost my eyes I had lost my brain. I found out that it wasn't that much different. I could still be stropky, I could still be the comedian, I could ask questions. But they had a problem, they never asked me how I felt, how I was, what I wanted. I didn't like that. I didn't know anything about my condition and to be honest their attitude was "don't let it concern you. We are here to treat you". I didn't like that at all. You don't need to know exactly why it's not working but it would be nice if someone sat down and explained why they were giving you

certain treatment, why they were stopping certain treatment. Nobody ever thought about doing that. The one who was the most concerned with my eyes was me, and yet they ignored me. I mean they all come round and clutter round the bottom of the bed and you catch four or five words out of a hundred, and I used to say "If you're going to talk about me, would you mind doing it as if I am present. But if you want to talk as if I'm not here get completely away from me, where I can't hear bits, and have my own versions, and please talk in english and not in jargon."

Are you the same person as you were when you could see?

I think I am. I'm not sure if other people think I am. A lot of the problems seem to be their problems, I mean I don't really get any bad prejudice against me - get the odd person who thinks that you are totally different - but most people are quite good. I've never had any real adverse problems about it. I think I am the same person, yeah. But, as I say, I'm not sure everybody else thinks so. I find I'm much more cutting than I used to be and I was bad enough then.

Why do you think that is?

I think I stand for much less nonsense than I used to. If someone insulted me before I would just get up and walk away from them, but now my attitude seems to be well, I don't really care, I mean people quite often come out with stupid remarks about blindness etc. etc. and they really should think before they open their mouths. And a lot of people say stupid things like: 'Oh I wear glasses so I

know what it's like!' Well most blind or partially sighted people would love to wear glasses, watch the t.v. or read a book. And until somebody has actually got that situation they are never going to know what it is like. But again it's education.

Debbie.

I've had a bad back for a while and then I had arthritis, and it gradually got worse over a period of years. For three years I were house bound because nobody had said: "Oh well you know you're entitled to a wheelchair to get out", or anything. And because I was house bound I was trapped really so I got to the stage where I didn't want to go out and I became agoraphobic. Then U changed my doctor because we'd moved, and he suggested that I should have a wheelchair. I thought I'd have to pay for one, he said: "Oh, no, no, no you can have one." Anyway they got me a wheelchair and over the past three years and eventually, I've got to the stage now where I can go out on my own, I can't go into a shop that's crowded otherwise the panic attacks come back again. But, you know, I can manage. But the difference it's made is...er... you get a different out look on life definitely, because there are things you can't do, that you want to do, and you'll soon try 'em, no matter how much you know you can't do 'em but you'll still have a go. And the thing I found is if me and my husband go out people talk to him, over the top of me, as if I'm not there, and I'm, one of these people, I say what I think. And I say to them: "I am down here, you can talk to me, you don't have to talk over me, about me as if I'm not here", you know like you're ga-ga or something. A lot of people do treat you like that actually, even younger children look at you and think 'oh disabled - she's crackers like' - you know. It's amazing, it really is.

When you were under that first doctor did he explain to you what was happening?

No he didn't. No, all I knew was that I was diagnosed as having arthritis. I had it in my hands and my feet to start with, and in my spine. And it's gradually crept to the whole of my body now. But it was confusing at first. I was very active before, nothing would stop me, I walked for miles, and I kept thinking well, why can't I do these things. Nobody had explained to me what the arthritis was, and what limitations it was going to have. So it was just a process of finding out for myself really. It was gradual. The past two years have been the worst. I can't walk very far without the wheelchair, maybe four or five steps then I'm really tired. I've just had my home all adapted for me, the reason I moved into this house, cos the last house I was in wasn't able to be adapted. So I'm in here now.

Are you able to talk to your new doctor?

Oh he's great. He's like a, well he's more like a family friend, I can go to him any time . He's not one of these that you go in, and he's rushing you out. He's got time to sit down, ask you questions, how you're doing and everything. You know so you feel like you can talk.

How did your family react to you being unable to walk?

Well, up until a year ago I was managing to walk very short distances, and having to use the wheelchair to go out in. As I say the past two years its got worse and this past year I've been in the wheelchair more or less permanently. My husbands accepted it, I think, although he has found it very difficult because he's having to

do things he didn't have to do before. My children I'm not so sure about. I think the little lad, he's only ten at the moment, I think he is accepting it but he still wonders why. Like things if he wants to go to the park and things like that - before I couldn't manage to take him and he couldn't stand that. And I don't think it's so much being in the wheelchair, it was the agoraphobia which they couldn't understand. I just couldn't go outside. The oldest lass is fifteen, she isn't too bad actually. I think she has accepted it, although there is occasions when she'll say "But I keep wondering why Mummy, why are you in a wheelchair, and why you can't do these things." I mean I've tried to explain it to her, but it's...sometimes you think it's sinking in, and other times you think it isn't. You know, she is finding it difficult, and the fact that she is in her last year at school and there is a lot of things going on at school where the parents are involved and I can't go. I can't get in to the school. So she gets very disappointed about that. "But why can't you come?" "Because I can't get into the school building." You know there is only certain parts of it where I can get in and it's not where they are having the meeting. "Well other mothers come." I can't make her understand that you know. That is hard. Hard for me to say to them: "Well I can't do it." When I know other mothers do it.

Do you think it has changed your relationship with your husband?

Definitely. Oh yes definitely. I mean he has always been a big help in the house, but bow he's having to do more or less everything. He is very good, but before he used to be a very placid day to day sort of person, and now he's a worrier. You

know you can see that things get on top of him quicker than they did before. Plus the fact that he's got a bad back as well, so lifting me in and out of bed on a morning is absolutely...you know. And maybe...It's a feeling I get, I asked him about it and he said: "Don't be silly", but I get the feeling that I'm a nuisance to them. I mean that's me personally not them. cos they've said to me: "Oh no you're not a nuisance Mum, don't think like that". And I do get upset you know, more often than not. And I think it's I don't...I can't explain it, it's not like I feel as if I'm a nuisance so much, it's just so frustrating, I can't do it myself. That's the whole thing. And then I find myself snapping and things because I feel so frustrated. It causes more arguments...it really does. You know, I used to storm off into another room, or sit there and I get so upset that, well I do I self inflict myself. I do, I admit that. I wouldn't at first but I, just lately I've been going for counselling and they've sort of said well you've got to admit that you are doing it. So I'm getting over that as well. I used to cut myself and scratch, and bite myself and things, purely because of frustration, because I couldn't do things.

Do you think that your sense of yourself as a women has altered?

Oh yes, it's bound to isn't it? I mean I think it's because women are brought up to certain standard where they are told - you are the carer, you do the washing, you look after the children - and when you end up in a wheelchair all that goes out of the window, and you've no self esteem or anything. You've got to get undressed in front of other people, you've got to have other people take you to the toilet, like in my case, if my husbands not in, a friend comes in and does it,

and although she's another woman it still feels... it's embarrassing. It all goes out the window and you've just got to accept it. At first I couldn't. I'd sit and wet myself rather than say I need to go to the loo. But I'm getting over that, but it's been a long process for me. But I'm getting there! I never spent any time in hospital, they wanted me to go in, not because of my agoraphobia it wasn't going to do me any good in any case. I had a scan on my back and they found out I had a prolapsed disc and I had to go in and have an epidural done. Lots of drugs pumped in to my spine. I was only in there two days. I wouldn't eat, I couldn't sleep, I was in such a state that they ended up sending me home, with the epidural attached. I was supposed to be in for a week, but I just couldn't settle at all. I wanted to be back home. I like to be in my own familiar surroundings. You know when I first started coming here [the day centre] I was alright while I was here, but as soon as I got home I was physically sick, really sick, I had to go to bed I was that bad. But I'm coming to terms with it and getting over that now. But that is hard.

I just don't think of the future to be honest. I just think things are going to get worse and worse. I dread the time that's going to come when I am completely bedridden and I can't get up at all. I really do. I know in myself that I was so active before I just can't...I don't think I could cope with that. My illness was so gradual. At first I wouldn't accept that I was...I used to think no, I can keep going you know. I'm a really strong minded person, or I was, I'm not now. But I used to ...it was hard for me to accept. I wouldn't admit to things I couldn't do. I used to get frustrated with the kids, with my husband and everybody else, rather than

saying well I can't do it. All your independence goes. It's like...it's hard to explain...it's like you're a dummy sat in a chair. You know you've got to ask for everything, it's so hard it really is. I think if it hadn't have been for the panic attacks and the agoraphobia, and with being house bound for so long I would look back and see it differently, but it was a gradual sort of thing. Sometimes I think I can't remember that far back to before I was ill. But I think I can, I just don't want to remember. The most hardest thing is with my children. Because I can't do things with them that other parents do. That is really hard. When I have to say: "Sorry but Mummy can't do it." And a lot of those things I could do...like the pictures - we've got a big multi screen cinema near us. They will only take two wheelchairs - so if you don't get booked in there is no chance of getting in there. And then if you do get it you have to sit right at the back of the cinema and I prefer to sit to be in the middle, otherwise I feel ill, physically ill. And they have no facilities for anything like that. So there is no chance of me taking my kids to the pictures. Where as I used to do all that before. We used to go for walks, we used to go to the park, take them rambling, all sorts of things. I can't do any of them now. And that is hard. As I say when my husband became a full time carer, having to look after me and the children, he doesn't get time to take them either and I think that is the most hardest thing for the children to accept, not the fact that I'm ill, but the fact I can't do things with them, that we used to do.

Was any counselling ever offered to you before now?

No. I think it should be available to people as soon as they can't do what they

used to. Like as soon as I was in a wheelchair. Cos there is days where you get so depressed that you think you are never going to come out of it. I mean, I know I do, and I'm sure others do. Well I've talked to others here, and they do.

Why do you come here?

Well basically it was to get me out of the house to start with, you know to get me back out in to the community. Because I wouldn't go anywhere, and it has helped. Oh it's been great - it really has. Up until two weeks ago I had a wheelchair that had to be pushed, I couldn't push myself. That was depressing, because I had to ask all the time: "can you push me here, take me there?" But now I can get about, it's like a new lease of life. I can go where I want to go, I don't have to sit and be miserable, if I want to move I can and that has made a difference. I get companionship from coming here. I've made quite a few friends and you can come and talk to people who are in the same situation as you are so you know that they understand. When you're talking to able bodied people they look at you a bit ga-ga you know, she doesn't know what she's talking about sort of thing. Well I get that feeling although they do ...I mean even my own doctor to a certain extent, I mean he's marvellous, I think though it is sinking in with him? Does he think I'm crackers? And then I start to think well am I crackers? Am I imagining all these things? And then when I come here and discuss it with people who are in the same situation as me, you know, it clicks with you and you think well I'm not, because they feel the same. You know there is a difference between "them out there" and "us in here."

How do you feel about the general public's attitude towards you in a wheelchair??

Well I can't go in to a full shop. At the moment, what I do I call it a training programme, it's what me and my husband have decided to call it, I've had no help with this. I could have had but I felt so strongly that I wanted to help myself rather than having someone coming round and saying "You've got to do this, this and this". I wanted to do it gradually by myself. We got to the stage now where I can go into a small shop if there's not a lot of people in, and I can go shopping. I can't wait at the till, I've got to, well my husband pays for it. It causes a bit of confusion when you go into the shop, because the women at the till looks at you a bit stupid, and you know they're thinking "What's she doing?" But my husband says: "I'm just taking her out now I'll be back in to give you the money". Some of them are pretty good. But to go in to a super market when it's packed I just can't cope with that. I can't at all. I'll sit near the till and watch everybody coming past me, but I can not go round the shop. Oh no. I really feel ill, as if I want to pass out. It's a terrible feeling, I feel as if I'm dying. It's awful. But that's agoraphobia not my wheelchair. Other people with disabilities tend to look and treat you as an equal but able bodied people don't. Like I said just because you are in a wheelchair they think you are mentally defected or something. And you're not. You are able to have a conversation with other people, but they do, they tend to treat you like you're not there, you're invisible. Some people won't even look at you eye to eye contact, you know, they are sort of looking away all the time like they don't want to acknowledge you in a wheelchair. I don't know if it's embarrassment or if it's just that they don't understand. I think that there is like

this label stuck on someone in a wheelchair, that says they are mentally defective or something. You know I think more able bodied people need to understand that we are like the rest, we can be spoken normally to. Normal like in able bodied. But I do think there should be more outside information to tell people that you know, these people in wheelchairs are not mentally defective, they are not crazy, you know, they are just as clever in mind as what you are. You know. It's like the two go hand in hand - wheelchair and stupidity. I admit that when I was able bodied I was a bit like that myself. Although I would talk to someone in a wheelchair, so I understand...to a certain extent I sort of think back and well yes I was like that myself, so I can't really condone any one else and another thing is that they tend to treat you like you're a five year old. "Oh right dear?" You know - that kind of thing. You know you talk to me as if Oh God I'm a grown woman not a child. Maybe because people have to physically talk down to you in a chair makes people talk down to you mentally.

How do you feel about your body?

Well as I say I get frustrated with myself. I think my body is useless. Sometimes when I can't do something I think: "Oh Damn it! If only I could walk!" My mind says well you can do it and my body's saying well you've had it - it's a total loss. It is hard. think...the whole thing of being in a wheelchair is the fact that you can't do things, especially if you've been able bodied before, can't do things that you used to be able to do, and it is really frustrating. I mean it gets to the stage sometimes. that I know in myself that I get so depressed that I'm like that for

days on end. And I never think I'm going to come out of it. I've even got to where I've phoned my doctor and he's come out to talk to me and said "Look you are going to be alright." It's not so bad if it happens on a week end , because I come here on a Monday and that cheers me up no end, because I can see others who are worse than me. And I think what the hell am I moaning about you know, so it does give you a better out look coming here. I mean before I came here I felt I was the only one. I kept thinking why me? Why is it only me? ^There isn't a lot of disabled people around where I live, and when I came here it opened my eyes, it really did. I didn't think there was that many. I was amazed. I remember going home and saying to my husband: "There's loads there, you ought to see some of the people there." I was absolutely amazed. I really was.

Can you make sense of what has happened to you in anyway?

Not really, no. It's like you're fighting yourself all the time. I think sometimes you can, you tend to sort of...it's like you have to sit back, like you're looking at another person, and say well make the best of what you've got, and you tend to accept it. Then there are other days where things just go beyond, and you can't reason with yourself at all.

Do you mind me asking about your relationship with your husband again? Do you still have an active sex life?

Sometimes, it's difficult. We do have a sex life, oh yeah. I don't think our

relationship would last actually if we didn't. Although as I say he is very good. He is very placid is my husband. He's, how can I put this? It's not what he says so much as the way he reacts when you ask him to do something. It's like...but then again that could be me. I get the feeling that I'm too much trouble you know. And often I will say to him: "Oh don't look at me like that. If you do the wrong thing I'll do it my bloody self." You know, and I get angry with him. And he'll say: "What's up with you? I never looked at you like anything." And I think it is a mental thing with me, you think that everybody is against you because you are in a wheelchair. I think it plays more on your relationship with your family and your husband, because before when you've been so close as a couple, like we used to go everywhere together, and do everything together, and there is a gap between us. It's like a wall between us now, because he's having to do mostly everything that we used to share. So definitely there is frustration there. As far as other family goes... well, I don't speak to my parents because my brother raped my daughter so they've just cut me off dead, so I don't speak to them. And I don't speak to my sister or any of my family. They have all cut me off dead. So that's been hard as well and that's all happened over the last four years. So, you know, we've had a lot of family problems, as well as becoming disabled. So on top of me being disabled we've had a lot of contributory things that happened to every one as well. We had that and then the eldest lad was taking drugs and what have you. It ended up with having to throw him out because I just couldn't cope with it. We used to find him zonked out and he would just laugh at you. Then he got to the stage where he was hitting me, he beat me up and that was it. My husband said: "Out! We've had enough". We tried to help him all we could. I mean he was

injecting himself, so we had all that to cope with, and it was a lot. I felt as if my whole world was crushing, I really did. It was all coming down on top of me. I thought I was trying to cope with being disabled and not being able to do things, and I had all this and all and I couldn't...the lad used to be the one I could talk to. Before he started taking drugs and everything. He was like somebody I could go to and discuss things with. Because he was very grown up. So it got to the stage where I had nobody to talk to and I felt that my daughter wasn't old enough to accept what was happening, all these terrible problems. It wasn't right for her really. Because she was having a difficult time over the rape and everything, she was going to rape crisis and it was all getting too much for me. On top of that and all her being raped brought back the fact that I was raped when I was her age. And Although I was trying to console her it was upsetting me as well. You know. I had all that to cope with and I think my husband was just bewildered by it all. He's not very good at dealing with things like that. He tends to forget about them, put them out of his head. "I don't want to know", sort of thing. He lives for tomorrow, never mind today. But I think he was finding it very difficult. That was causing a very big strain on our relationship, it really was, at one time. But we got through it. I mean you have to. I mean in that respect it has brought us closer now. At one time I used to be the one who would deal with all the paper work, all the bills, if the kids had any problems they would come to mother, but now they're beginning to go to Dad. And he's seeing the other side, and he's dealing with the paper work, the bills and everything. Although I still do some of it. I can't manage to do all of it. So he's finding the other side now, and he's beginning to talk more freely so we're talking to each other which is a thing

we never did before. It was sort of "mother does this and I do that" sort of thing. But now we're beginning to sort of, although we don't do things together now it's brought other things into perspective. Which is not a bad thing really. But I still feel I can't go to my husband and talk to him like I would to an outsider. There are things that I want to say to him that I can't say to him. Not because I don't want to, it's because, well there's a fear that I don't want to push him away. I'm afraid, I'm really frightened of being left on my own and not being able to cope. That really frightens me. That worries me to death, you know: Am I driving my kids away? Am I driving my husband away? That really does frighten me. I don't think I could cope half as well if I was on my own. I know I wouldn't. Because they are very supportive. Even though the oldest lass has gone through all that she's been supportive towards me. One thing I do find about being disabled you are that concerned and that wrapped up in your own illnesses and your own feelings that you don't give a second thought to other people. I find that hard. It's wrong, I know it is. The kids will come to me and say: "I've cut my finger!" And I'll say: "Go get a plaster, don't come telling me! I've got enough to concern myself with." And they look at me blank as to say I was only asking you to have a look. And I feel awful afterwards and I think it would have only taken two seconds to have a look. But you do...I don't know if other people do, but I know I do. I'm terrible, I'm that wrapped up in my own feelings, my own...I haven't got time for the rest.

I'm thirty five and it's six years ago since it first started. But as I say the last two years have been the worst but mainly because of other problems. People don't

seem to think you have other problems if you are in a wheelchair. But you do, life goes on. Just because you can't walk and everything doesn't mean to say that your mind has stopped. You still have worries the same as everybody else. And that's the whole thing where people tend to think 'oh poor dear' and treat you like a child. That is really frustrating, that really aggravates me. You get days where you're depressed but mostly you think I've got to carry on. My thing I always think about is the kids. I think well the little one is only ten, he can't very well go out into the world and find a place of his own or whatever. The girls fifteen, so she'll be leaving school soon so she'll most probably be able to manage. And then I think of my husband, well what would happen to him if something happened to me? It worries me. And it's that which keeps me going. My family. If I didn't have my family I don't know if I'd want to keep going. I mean I have tried to commit suicide. I've taken an over-dose. I'm going back, what...three years now. Because I just got to the stage where I felt as if nobody cared you know. I was stuck in the house all day, all night, nothing to do. It was purely boredom more than anything. Sometimes I do think about it and then I think: "No, my family need me". Cos I've always been the king pin in the family. I've always been the one that they've all come to. You know: "Mum I've got a problem..." Even my eldest lad's come to me. They don't go to their dad. He gets embarrassed anyway. It doesn't bother me. It was only the other week one of the lads is in army like, he's on leave, and he came in and said "Oh Mum I've got a lump". I said "Where?" He said "I can't tell you that!" I said "Let's have a look, I changed your nappy before". Things like that but they won't go to their Dad. Anyway he had only strained himself that were all so... that was alright. And I need that. I need my family to come to me,

then I feel as if I am useful not useless. I think being in a wheelchair you definitely are made to feel useless. There are so many things that you can't do. I think the thing...I'm finding that I'm getting to the stage that I'm trying to find things that I can do, and be positive about it. Not things that I can't do. By coming in here I've seen other people manage and I think if they can do that then so can I. It gives you encouragement, it really does. Without these places I think there'd be quite a few people who'd just give up the ghost. Oh it's marvellous coming here, I really enjoy it. I enjoy the company, I enjoy the staff. You come here get your dinner or whatever, you can do whatever you like. There are plenty of activities...I come Monday and Thursdays all day, but on a Tuesday I just come for the china painting on the morning, and I enjoy that. And the thing is you feel as if you are achieving things because you can, well I do a lot of pottery here and you make them. It becomes worthwhile. Before I came here I had no sense of worth but since I've been coming...well I do have odd days like that but...when I come here I love it. I really do. The company, I like the fact that you can do things, whatever you want to do, you can be yourself, without people looking at you and thinking you are crackers and ga-ga. I love it. I don't know what I would do if I couldn't come here any more.

Did you work before you became ill?

No, I've always been a housewife. I've got four kids.

Does your husband work?

He always did work up until two years ago, when my doctor said: "Well you know it's come to the stage where you've got to give up your job and you're going to have to look after your wife full time." And he gave him a letter, but we are still having a lot of problems with that because em...trying to get through all the bureaucratic nonsense is ridiculous. That's difficult, that's another side of being disabled, oh God! I mean trying to get attendance allowance and mobility is...well I've been fighting for attendance allowance for five years and I'm still fighting. And the whole thing is , another thing that has contributed to it is, and I think is causing a rift between me and my husband is the fact that he can't go out to work so he's finding it difficult anyway, and I feel as if I'm being a nuisance and the social security, indirectly are contributing to it as well because they are saying that if I don't get attendance allowance by the end of this year, my husband is going to have to go out to work. Because you have to get attendance allowance for him to be out of work. And if I don't get it at the end of this year that is it. He has got to go out to work - there is no option. And they have also said....but there isn't any jobs for him to have...that doesn't make any difference to us we can send him on a course and he will working away from home and be home at the weekends. I said "What am I supposed to do?" That is worrying me to death. The letter from the doctor makes no difference to them, my doctor, specialist, social services, from here...it's beyond a joke. It's like fighting a losing battle. I mean I've seen people here that get both those and to be quite honest with you I don't think they should be getting it, but on the other hand I've seen people who are really really ill, worse than me, and they don't get it and they should. I don't know how they work them out I really don't. Well up until March this year I was getting

mobility and I had to have a re-medical and I've been refused. So I've had to appeal. That is terrible because you rely on that extra money for things like taxis. We have a car now, but we used to rely on that for taxis. And cars cost a bit just to keep it on the road, and we're getting to the stage where we hardly use it because we can't afford to keep it running. It is certainly more expensive being disabled. You wouldn't think so but like well your clothes for a start off. I mean I'm going through more trousers than...because the backsides go through cos you're in the chair all the time. Your jumpers the same. You use quite a lot of underwear where you wouldn't normally. And that makes a big difference. Shopping and things...you have to be careful what you eat because if you get overweight, well it's just not good for you. I think you have got to watch what you eat. Then you've got dietary problems as well... Well in my particular case I had to have an orthopaedic bed, so that cost over three hundred pound. We had to save, really hard saving for two years to buy that. Special equipment for cooking with, cos I like cooking...and we had to have the house redone, all low level tops and then you feel selfish and think well I'm doing this for me what about them. All sorts of different things. It is expensive, definitely expensive. Social security, government bodies, you can't make them understand that. And as I say this attendance allowance is a big thing for us, cos five years we've been waiting for it. It's getting on top of me it really is. It upsets me because it's like denying the fact that I am disabled. That makes me more depressed than anything else going on in my life. I keep saying to my husband: "But they're saying there's nothing wrong with me. If there's nothing wrong with me I can get out of my wheelchair?" And he says: "Don't you be so bloody stupid!" And I get really upset over it. But

they refused me on really stupid things like I didn't need my husband to take me to the toilet was the first one, and then it was...one of them even told me it was my age. I thought what the bloody hell has my age got to do with it? I was told I was too happy at one of them! Too happy to be disabled! They are really stupid excuses - I just feel like I've been fobbed off. You get to the stage where you think why should I bother? Where's my life going? Nobody wants to help. It's a terrible feeling. I mean having a family at home we have to get a taxi sometimes especially now as we can't afford to run the car. They will back date the attendance allowance but they can only back date it so long. Which in my eyes is wrong I mean if I'm entitled to five years of it they should pay me. The red tape is all so frustrating. There is a lot of things we can't afford and more so when you've got a family because you know you need extra so you feel as if you are taking of them. That is frustrating. The fact that you can't do things that you used to be able to. The most frustrating thing for me about being disabled is people tend to talk down to me like I am crazy. Like I am not there. And that other people tend to think that there is nothing wrong with her, especially higher bodies, doctors and things like that you know. But most of that comes from these medical tribunals. You just feel as if what's the point of living? You are not getting anywhere, you are not gaining anything. Then the plus side of it is coming here, I find that I can do things that I have never been able to do before. I've quite amazed myself actually, you know...so...and my family has become a lot closer, me and my husband are a lot closer. My own immediate family anyway. And we are working through our problems - we are getting there. I suppose these things are sent to try us. But you do manage, it's a case of having to, in my case

it is. I always think of my kids - I've got to go on. I never think I want to, I always think I've got to.

Eddy

In 1983 I went to Sheffield, just for short term. I went as, what is known as a lay paster. And we knew it was only for a short time before they got another minister. Just before I went to Sheffield I felt unwell for a while but the doctor didn't seem to think it was anything apart from a virus, or something like that. It was in Sheffield that I first started with M.S. They admitted me to a hospital and I knew then there was something not quite right. They didn't tell me then, I was in for ten days and they put me on injections, twice a day. After ten days I was a bit sore in a certain area! But they didn't say anything apart from that I had sever inflammation of the spinal cord. Which to me didn't mean anything. I'm not sure it means anything now. That was the beginning of the new year. Wasn't until the February, when I went back to the hospital to see one of the specialists and he actually said that it started with M.S. He said that I was at the right age, and every thing about my case is typical. It's when a person is most likely to start with M.S. in their thirty's, under pressure, and he said I must get some help. And it was all wrong because I had gone there to be the help, there was no way that some one else could come and help. By this time I was about half way through candidating, it's...well candidating sounds a bit vague and a bit important really...it's a selection period and it takes a year and nothing was said about my M.S. at all. I thought that having started with it they wouldn't accept me for training, but they did, knowing full well what might happen. I mean it might never crop up again and I might go for fifty years with out the M.S. being any problem. So they accepted me, and I was trained at Manchester university for two years

then I was posted to York and I worked for seven months before the M.S. cropped up again. And it cropped up quite badly.

My initial symptoms were my eyes. My eye sight that was very bad, my walking was effected. My speech wasn't too effected, just my eyes and walking and my hands. I'd drop things...couldn't walk very well. Then it cleared up. The doctors didn't explain it, they said that if it did clear up it would be remission, the only thing it means to me now is that for a while it goes away. Not sure if that is what remission means. That's what seems to happen. After the first time that's it for some people. They never think of M.S. again, but for other people they do get this second attack, not too long afterwards, two years...that's what happened to me. I think the second attack was worse, looking back. Both physically and to handle emotionally. Certainly the walking was as bad, and my sight was as bad as the first time, and I was clumsy again. I'm clumsy anyhow, so didn't notice that as much! But my eyes and my legs they were the worst thing. And always at the back of my mind is am I going to manage. I mean I have been sent to York, it's a five year station and that was after seven months. There is something not right about it all. You know is this the end. That's how I was thinking. I was supported very well, the chairman of the district, who's like the big wig as it were in the Methodist church, he said: "We'll see what your doctors have got to say and then we will think about the future. We won't cross that bridge until we have to". And the only thing that I think could have happened was that the hospital sent a bad report to the chairman. The next time he came to see me he said: "The only thing we can do with you, for your good is to supernumerate you." That's another

wonderful term! It means retired. I was thirty five I was. Retired thirty years too soon. Or thirty years too early for me. He said it was for my own good, to try and be a minister, to do all the things that minister have to do wouldn't be for my good. So they said they would supernumerate me, which they said meant I could stay in York. So that was good news, the bad news was having to retire. I was very disappointed at first, thirty years too soon. I wasn't angry just disappointed. In fact the chairman said to me: "You must feel, the question at the back of your mind must be Why Me?" And it had never occurred to me that because the reverse of the question is Why not me? I'd not done anything that would prevent it from happening to me. So I couldn't ask the question Why me? Why not me?

Do you feel that you could have done something to prevent it?

I don't think so, no. I mean I suppose by asking why not me? you kind of start to make sense of it all. It enables me to cope with it, but since coming here, to the day centre it has made more sense. As a station minister I wouldn't have time to even visit places like this, or the younger disabled unit at the hospital, but now I can. And so it makes sense. I come here as a minister or what I think a minister is.

Were you offered any form of counselling?

No, may be it would have helped. I can think of one person who came to see me, the new chairman, a super guy really - he's quite young - and he was very

supportive. He came as chairman, the first of September is the start of the new year for methodists, and he actually came to see me on the first of September. And of all the things that he must have had to do on the first of September, he made time to see me. That was my first day of retirement as it were. He came to see me. And since then he has been very supportive. He's come regular, he's never come with any answers, he was the first to admit that he's got no answers. I'm not sure that I've got any questions. I'm sure there must be.

How did your family and friends react when you first found out about your M.S.?

Well, Thelma, my wife, was very supportive, all along. She never asked awkward questions, of the doctors or me. She was just content to be supportive, and caring, which she has always been. I've got two children they were seven and twelve, well we felt we had to tell the children and the well, another minister with M.S. had not told the children and that developed all sorts of problems, so we thought we must tell our children. All we said was that Daddy was ill and that he won't get better. He might not get worse but he won't get better. And they were content with that, and have been since.

Do you think it has changed your relationship with your wife?

I think it must have done. But looking back I'm not sure in what way. Thelma has always been very loving and caring and that has continued even with the illness. If it has changed it has changed for the better. The only family I know are

Thelma's family and my family don't have anything to do with me. Nothing to do with M.S. it started before. So Thelma's family is my family. My mother in law is a very talkative person, and that can be very tiring, but she is the only mother I know and I accept her for that. We see her quite regularly, Thelma is her world, she is a very nice person and very supportive, especially to Thelma. To me she always has to show the latest photographs and things which I don't find particularly helpful. When I first had M.S. she was worried. I think she was worried for Thelma, but worried for my benefit as well. She came across and stayed a while with us to help us over that initial period. For a few weeks it was quite difficult. It has always been open for talking about. I think one of the reasons is that Thelma and I have always been open about it, we have always been willing to talk about it and people have always been, therefore willing to listen. Especially a handful of friends, we have always been open. And even now we talk about it to them as if they are fully aware. Which I am sure they are. That's been supportive, and very helpful. I can think of two or three people especially who are very helpful, and it is always an open subject with them. I've got one friend and he has been helpful in a practical sense to get little jobs done, that I'd have always done before. The garage door came loose, well before I would have thought nothing to do it myself. Now I've got to have help. I am hopeless at things like that. I just can't do it any more. I'm clumsy. It does frustrate me and it makes me angry. Angry with myself. That I can't do little jobs, it is so frustrating. You know my sight has got so poor that I can't read the post - not that it is ever worth reading. But I have talking book machine, and sometimes a book comes through the post and it's always in the back of my mind,

the thought that, you know, you are not ordinary. I'm not sure if I connect it with being a man, it's just one of those things. I mean there are lots of people I know who are men in the full sense, but can't read books so I don't think it had effected me as far as my own feelings about being a man go. But I can understand why it might effect some people.

You say you are not ordinary. Do you think that other people perceive you as different or does it...

I think my mother in law knows I'm not well and she actually came out with a stock sentence a while ago. We live in a bungalow now, no stairs to climb, but before I had to go upstairs for something and I wasn't doing to well at it and she came behind me and she said: " This is like a crippled outing." I thought thank you. She obviously sees me as different. It would have been better if she had said nothing but she has this wonderful gift of coming out with the worst thing. I thought yes, I understand what you are saying, I can't get up stairs very well now. To her I must be a cripple. I don't feel that I'm any different, not at all. I am in remission at the moment, for the past six months. I got well during the christmas time and since then I've been fine. Six months remission. It was a wonderful Christmas present. But before that I was in a wheelchair. And then the problems come from other people, I mean once you have legs which are no use for walking and you've got to use a wheelchair it is something that you have to come to terms with. But out and about it is other people that have the problem. They will always talk to the other person who is pushing the wheelchair. They never talk to me, it

was always to Thelma. And I felt that was strange, it was me with the illness, it was me who had to be in the wheelchair, so why talk to Thelma, why not talk to me, that was strange. And it was other people who had the problem with the wheelchair, not me. Strange. I think it is because they are embarrassed, they just don't know what to do, what to say. May be if they turned it round and put themselves in the wheelchair and they'd know how they'd feel...I don't know a wheelchair makes you look different perhaps but it doesn't make you any different. It doesn't mean you can't talk.

M.S. is about three quarters way through my life, you know if you think of it as a line. I can look back now to when I was a child and I can see M.S. starting, even then. I had a very bad time with measles and I've heard since that measles, well some research team reckoned that measles could be the start and looking back I think well yes, I did have a bad time with measles. I was never very fit, I used to get very tired, very easily, and looking back it was not normal for a child. I'd get tired after playing football for ten minutes. And looking back that could be M.S. just starting. And looking back now it makes sense. It helps me, I'm not sure if it would make sense to a doctor. Looking back it makes sense, or I feel it makes sense and it makes sense, more especially now because well...nine years ago I started with M.S. it was two years before I had to retire. And I had three churches then, but now I thought from very early on, in fact, this is going to sound silly this but if you turn the clock back to when it first started and I was in hospital...and I noticed there were a lot of wheelchairs on the ward and I noticed that a lot of people were in wheelchairs and it was always in the back of my

mind, why, what's the matter with them, why do they need a wheelchair. Having an over active mind I thought I might be in a wheelchair before long. Not knowing what it was at all, not knowing then that it was M.S. but it was a thought that was always there that I might end up in a wheelchair. And what then. And the only thing I could think of was, not having to retire but I could be a minister in a wheelchair. It might be different but a whole lot of normal ministers couldn't be in a wheelchair and they wouldn't know how to approach some body in a wheelchair. But I would know how they feel and the strangest thing...this was a wonderful experience that's been in the back of my mind for a while...the winter of '83 was really very bad and the snow was...well had to dig out of the house every morning it was really very bad. So I was in hospital in this bad winter, but while I was thinking of being in a wheelchair and still being a minister and still being used by God in a special way, it was snowing out side, but there was still a sunset. It was just a very special moment. I'll never forget that.

Does your belief help you come to terms with M.S.?

I think it does, yes. I don't think it is an explanation but at least it's a reason. While it was snowing and there was this sunset I remember reading one of the gospels and it said at evening, at sunset, they brought sick people to Jesus and he healed them. And I thought well, he might not heal me because a lot of people he didn't heal, he healed some, the ones we get to hear about, but there must of been thousands and thousands of others who he didn't heal. So not to be healed made me one of the crowd as it were. Not special. Now I can work here, and it

gives me a better understanding. There are two things always at the back of my mind. I can think of one lady who comes here, she has had M.S. for twenty-five years and no remission. She has had no remission, and I've had remission. I had M.S. for nine years, and now for the past six months I've had remission which I hope will go on for years. But if it doesn't that will make me better equipped to share faith with some people, my sight's not very good at all, and I can go and sit with people now and know something of how they are feeling, how they are able to cope. So I learn from them as well as, I hope, they learn something from me. It makes sense, I wouldn't change it. It sounds a silly thing to say with any illness but I don't think I would change it now. Well, I wouldn't go back to being a normal minister, I don't want to go back to being a normal minister. For one thing there is too much paper work! And I was never very good at that. But now being what they call a sector minister which just means a minister in a different sector, and it still means an awful lot to me. So I wouldn't want to change it. I would change my M.S. in some ways, I wish it would go away, but I realise how silly that statement is. because it will not go away and I must cope with it. To learn to cope with it, and learn to use what I have got. I can think of the young Disabled Unit especially. The first time I had been there...I have been in a few times but the first time, I went down the corridor and the nurse pointed to all the names on the doors and the doors were open and I could see the people we were talking about, and the Staff said: "This is Bill, he's got M.S." Bill did not look very well at all. I thought am I going to end up like that, and this unfortunate nurse took me down the corridor and every person she introduced me to had M.S. and it wasn't a good thing to do really, looking back. I think she just wanted to

introduce me to the people, it was nothing to do with M.S. she didn't intend to show me what M.S. could be like in ten twenty years time. But the first time I remember especially because I went knowing I was a minister, that it was something I wouldn't give up and knowing I would arrange my day being a minister. I could visit each person, even if I only spent two minutes with them...looking back I have had some very special times. I can think of one person, Eric, he's died now, very keen on cricket and I am. So it was always nice to visit Eric and talk about the cricket among other things. It was sad when Eric died. But he didn't have M.S. he had motor neuron disease and that is something different to M.S. But there was a young women there who was right next to the nurses station and I could see that she wasn't well and they needed to keep an eye on her. And when I was introduced to her, Mary, she didn't talk or anything. One of the staff nurses said: "Go and sit next to her, she won't be able to talk to you, but you talk to her." So that was my pastoral visit to Mary. And it was very difficult because Mary she really was quite beautiful, really was, only a couple of years older than me, and I used to go and sit by Mary and one day, one of the staff nurses waved me across to Mary and she said: "You know Mary can't talk to you ". And I said: "I know", and she said: "Watch her eyes". So I asked Mary if she had been to South Africa, and her eyes went up. It was up for yes and down for no. So I could talk to Mary. Not very long after that she took ill, and the two staff nurses stood at the door and one of them said that we needed to send for a minister and the other nurse said that there wasn't time. The other one said we don't need to send for one we've got one here. To know that they thought that in some small way useful when a person was near dying meant an awful lot to me.

It is something that I will never forget. I think of Eric and Mary especially.

My own experience of being in hospital was that no one really ever explained anything to me. But I don't think the doctors know very much about M.S. damage to the spinal cord, but beyond that I don't think they know. That might be me being a cynic but I'm not sure. I don't think I would want to know what is going to happen to me if it were bad it wouldn't be nice, the time I've got so I don't want to know. If it's going to get better that's worth knowing. But I don't want to know. I make the best of each day. That's how both Thelma and I cope with it, take each day as it comes and try to make the best of it.

Do you think it has changed you at all?

Yes I think it has. In some ways. I am now more aware of illness, more aware of how people feel through illness, which I wasn't aware of before. And now I can meet people here who will become angry for no reason. But now I know that that is part of the illness, part of chronic illness. People just loose their temper for no reason. If they want to loose their temper with me that's fine, because now I know, I understand just a little. Yes I am different. I am not bitter...I think there is a little bit of anger, anger at the illness. But having said that I can find a sense of peace about it. I am certainly more peaceful now than I was ten years ago. More at peace with myself as it were. Illness makes you look inward which is not an all bad thing.

You say that looking back you can see a continuity in your life, but when you first were ill how did you feel?

I did not feel as if my life were the same at all. It is only now, ten years on that I can look back and think, yes, it ...well the first time it is so unexpected, there is no reason for it at all. I think it took me about three years before I could sort of make sense of it and see it was part of me, and that my life continues.

Eddy (second interview)

I think since the last time we met, I'm now officially, I think that is the wrong word to use, registered as partially sighted. But I consider myself one of the lucky ones because the bit of sight I have retained is the central vision, I have lost all the peripheral vision, that doesn't seem important to me. I can't see Paula [sitting on his right] although I know she is there. But if I look directly at her I can see her. The thing I love the most is art of any description and with central vision I can still do that so ...I don't feel I've lost much. The way it came up was I was just wandering around where I live and I was crossing roads and I was being beeped at constantly and someone was always shouting something that I didn't understand, I think it was Hebrew or something! It didn't sound very polite and...until I went to the hospital and saw somebody whose name I forget, however, it wasn't till then that I realised what I was doing. I wasn't looking for the car I'd look once and it would be fine and my central vision was on crossing the road not on the cars. It was a bit frightening really you know...and this wheelchair is quite a recent thing. I got a relapse six weeks ago, but up till then then I'd had a wonderful six months. I used to walk to York have a cup of coffee took half an hour and then walk back. About two miles...They have a wonderful word for it excaserbation, why they don't say relapse I mean it amounts to the same thing. The first thing the doctor said, he said, well, bed for a week. It's alright if you have lots to read lots to paint...although you get in to trouble for spilling paint on the bed! Or coffee and then it's a course for six weeks of injections. I have lost count of how many times it has happened now, must be well

over six, and every time the injections have worked so there is always that hope at the end. Can't think of any other great changes...

Do you feel any different now that you are in a wheelchair?

I feel sad and angry. But I consider myself above both those two things. I am fortunate. I can think of somebody at the YDU who is actually in there, not permanent but for a long spell and she has never had a remission in twenty four years. For me it works out every six months so I am very very fortunate.

So you don't feel that being in a wheelchair is a permanent state of affairs?

No, and I think that helps me accept it. It is the one good thing about it I gain for the local chapel, and somebody there took me to the hospital to visit someone and she was in a wheelchair and the first thing this lady in the wheelchair said is: "It's nice to have a visitor who is on the same level as me". I just had a vicar come, she said, come to see me and he must have been seven foot six tall. A bit of exaggeration there but the point she was making was he just stood at the side of the bed and its I'm up here and you are down there, and that's not right at all. So in the wheelchair I can go to someone in hospital or anywhere in a wheelchair, I don't need to build bridges, there is one already there.

When I last spoke to you you were working as a sector minister, are you still working as...?

Yes, one wonderful experience I have had, this is within the last twelve months. I have not taken a service for about eight years and at the time I was having a good spell and it was communion and the minister who was conducting it was a young chap who I knew quite well, and on the spur of the moment, with no preparation for it, I didn't even have a tie on, I think I had a T-shirt on, I went in to the vestry and asked David if I could help with communion. He said of course I could. He told me to pick the bits I wanted and was able to do and he would do the rest. It was a wonderful experience it really was. First time in eight years. The most wonderful thing about it was people come to the alter rail and they normally kneel for the elements and they normally close their eyes. But not one person closed their eyes and it felt that they were up lifting me. It was almost tangible. I could certainly feel it, it was a wonderful experience. I thought, well, that's one step forward. The next step is to take a service and then this [the relapse] cropped up but er...I remember when I...gosh going back twenty years, no ten when I first started with M.S. The ward I was on in Sheffield a lot of people were in wheelchairs and it worried me at first thinking that this was going to happen to me, and I thought if it does what will change, as a minister, I thought I could be a minister in a wheelchair.

Do you think it has changed the course of your life ?

I have a feeling that I should say yes but well I can't drive anymore. But that is not a disappointment, strangely to say. There are so many lunatics on the road that there is no pleasure in driving anymore. So I can't say I miss that. One good

thing, although I shouldn't say this especially on tape! But when I am not so well it keeps visitors down and by visitors I mean relatives. Thelma's mum is well she is quite an incredible women and I am very fond of her, she is more of a mother to me than my own but she does not know when to shut up! In the course of a conversation, well it's not a conversation it is a monologue...you think to yourself you told me that ten minutes ago and she just goes round and round. It is tiring, but she is a nice lady.

How do you find people react to you when you are in a wheelchair?

They do react differently because of the wheelchair, they do tend to fear it. I have had quite a few occasions when people have actually walked in to me. It is strange it makes me a little bit angry that they can't be bothered to look and I am sure it means that well people don't know what a white stick means anymore especially children. It does annoy me. Sometimes I just don't stop and we meet in the middle and this chair is definitely harder than shins! I shouldn't have said that!

Do you think that 'normals' think you should act or behave in a certain way?

Oh yes. Very much so. If Thelma is pushing me and we see someone we know vaguely, not so much with friends, they will always talk to Thelma, never talk to me. That makes me very sad really. It makes me angry really as well, that they should think of me...I mean I think of myself as normalish...not a hundred per

cent normal but normalish, it's my legs that are no good, there is nothing wrong with my brain I hope, I mean I have just sat an O.U. exam.

How do you react to people who ignore you like that?

I end up pulling their coat or getting hold of their hand and answering the question that was addressed to Thelma. You have to assert yourself. It is a funny world.

Do you think of yourself as not normal, as disabled?

I am not over happy with the word disabled but I think that really sums it up. My legs are not normal and my arms are a bit weak but the rest of me is normalish, as normal as it has ever been!

Why do you think people react like this to wheelchairs?

I think it is lack of education. I am not impressed with our education system. I think one of it's main weaknesses is lack of communication about important things. As I said earlier a lot of children don't know what a white stick means, and I can imagine they want to know what this special harness on your dog is for. They should see the harness and think that's a guide dog. That's the teacher's fault. Disabled children and normals should be taught together, I mean there are some schools where they are mixed and it doesn't alter the disabled person but

it makes the other people aware and conscious. There is a lovely young lad who comes here, and he is spastic plus something else. His speech is quite bad but you get used to it and he's in a wheelchair and he can do very little normal things, but he comes to Priory Street and he paints with his mouth. He paints pictures and he is not content with being artistic he composes music. On our computer here, he can key words in with a stick and writes the music. So Richard is normal up to a point. Disabled up to a point. I never consider him as being disabled because of the things he does. I don't like to think of myself as being disabled. It is just one of those wonderful key words that society uses.

Do you think it is society that disables rather than your body?

Yes that says it exactly. Lack of access, I mean York is terrible for wheelchairs...I had a very frightening experience last Thursday. Thelma and I went out, and we crossed the road and got to the opposite kerb and this front wheel fell off and of course it tilted me out straight away and I was sat gracefully on the pavement. Thelma went in to a pub that was opposite from where I had had this tumble to get me something to sit on and I was scratching my head wondering what to do and this chap came out of the pub with a spanner and a stool and he helped me onto the stool and disappeared with the wheel and came back two minutes later fitted it, tightened it up with his spanner and tightened the other one up as well. And I was thinking coming home after that, he didn't do it because I was disabled he did it because it was a job that needed doing and he just got on with it.

Do you have anything to do with the M.S. society?

No. It's been a big disappointment. At first the first couple of visits well it's mainly older people and the last thing anyone wants to talk about is M.S. and I can understand that, but Thelma and I went along thinking we would discuss how it effected us and how other people coped, but they didn't. But there was another group which was just for under forties. So we thought this might be more like it, we met about four times, went to the hospital once, to see a physio, and we went to the university and two PhD students were doing research into M.S. but so tried to talk as simply as possible but it was difficult but I found that very helpful. But they do a lot of pub visits and that's not my scene as it were. And the group folded up I don't know why but that was a disappointment. Coming here is supportive.

Have you seen the M.S. Society adverts?

No I don't pay much attention to those sort of things. I do get their quarterly but...

Do you think that M.S. is generally understood?

No, I don't think they do at all. And the more you try to explain it, it just doesn't help. My G.P. explained it to me very early on. It's like a telephone wire and he drew this line and he said that's the nerve and he drew a covering round it and

he said that's the myelin sheath and he said that when you get an attack of M.S. it's like an inflammation of the myelin sheath and it can also damage the nerve. Now when the ATCH injections are given they can build up the myelin sheath, often permanent damage is done but it can be repaired up to a certain extent. But what he was saying was that it's like a telephone line, if it's damaged you don't get the message. I thought that was a good way of putting it, that's why he was clever enough to be a doctor I thought.

Would you have any advice to give someone who had just been diagnosed with M.S.?

It would have to depend on the person I think. Some people it would be easier, some people you would have to stay clear of it for quite a while. I recently met someone who has gone blind with M.S. and he is finding it very very difficult to cope and I have no answers. It is no good me saying what I do in my spare time. Although he is very good on computers so he has not lost everything.

Would you say that you had accepted it or would...?

I have to think about that...I am not sure if I would use the word acceptance. I am not sure if anyone can accept any chronic illness, you put up with it and you adjust to it to a certain extent. And now I am no longer conscious of it. At first I was very very conscious of it but now well it's different. There's coming to terms with it...I don't think I get angry I always think I could be a lot worse.

Did your children accept the wheelchair easily?

Yes, there was no problem with them. They were quite young and so it's become part of the furniture as I have been in and out of it. My relationship with my wife has changed. We used to love walking together. On good spells we still can, but when it's like this for six weeks it's the car everywhere.

Do you think you make less decisions and...

Yes. Thelma has always been far better with the finance and money and that side of the home than I have ever been. She is very good with figures, too good! It's not fair! So well saying that I am not sure if it has changed our relationship because it always been like that. I mean I don't go shopping that much or anything. I sometimes go to Sainsbury's but I sit in the car sketching which is better than going round shopping. But every week we make a day for going out. I learnt this from a minister friend of mine whose wife was teaching in Leeds, and he was stationed in York and they very rarely got to see each other and never went out. It wasn't too long after that that their marriage broke up and one thing I always remember him saying to me very early on was make sure you always get out together every week. Set one day every week that's for you together and stick to it. And we have done that...well it seems for ever...eight years.

It some ways it has made our marriage stronger, I think it has. I think it is one of those things which can go either way. It could have broken a marriage up quite

easily. But I am sure it has made it stronger.

Do you think your role as a man has changed?

Yes. Yes it has. I am not the head of our household, in I know that it's a stereotyped idea to start with, but going wider than Thelma and I, I think with in society within the country roles are changing so in a sense I am normal! It doesn't threaten me like that I don't think.

Have you seen any of the recent programmes on television on disability?

Yes. There were good and bad. I'm trying to think of them...oh yes the one about people in institutions got me quite angry. I didn't feel that people should be sent to homes like that. I am thinking of one person especially. A resident of one of the Sue Ryder homes, Reg was a methodist minister that went to Cambridge a real clever clogs an intellectual. I forget what illness he has got but he has lost almost everything. He has certainly lost his mind, he can come out with occasional words but he can't fed himself, toilet himself or anything. His wife feels that he is in the wrong place, and I am sure he is. She can't cope with him at home but...the trouble with these homes is that there is a mixture of psychiatric and geriatric and the twain do not go together. So Reg is certainly in the wrong place.

What do you feel about charities?

Well yes. I think there are a set class, I am very cynical I call them the do gooders. I sometimes ask myself whether they are doing it for themselves or for whom. The M.S. society is full of them. The honourable secretary, the honourable treasurer and none of them do anything for the people with the M.S. They are just do gooders. A lot of the people who need help just don't get it. I think they can actually do harm sometimes. I am sure they can. I think things like Children in Need are quite different. Every Christmas when it comes up I wonder if all the money goes to the right place ...but I knew this young girl and her mother thought she would benefit from a talking computer and I thought will she get one but she did. It was quite a thrill to see her with it. So I thought yes there is good happening. But at the same time the stereotype is made stronger. Television should show more realistic documentaries and well the stereotype idea that disabled means different, subnormal and that's not right. It's all John Major's fault! Well I'm sure he is doing his best but is his best good enough?!

When I come here [the day centre] I come as both minister and just another person attending the centre. Up until coffee time I was in the wood work room, having a great deal of pleasure, but then Paula who was here when you came in can be a real pain she is very hard work and I feel she is one of my flock. And there is quite a number of those. I always make a point of talking to certain people. Some of them have a bit of a psychiatric problems but a few of them have made some sort of Christian commitments, so that's another bridge. There are a number of people who I put on my pastoral list. Particularly Mondays. I am not employed by the church, I have trouble with the word employment. I always

correct Thelma when she says your job, because it is a vocation.

I mean being in a wheelchair does help, going back to Richard...Richard's arms are quite deformed, his hands certainly are, hence his painting with his mouth, and he needs help getting his coat on. Things like that. And I can do that sitting next to him in this and he is not conscious that I am putting his coat on for him and I am not conscious that I am helping. It's something I can do.

Are there any aspects of becoming disabled that we haven't touched on that you would like to?

Well not so much the fact of being disabled what has happened with having to be retired, I got no choice about it at all, I sort of think well, what can I do now? And years and years ago I always said to myself that when I retire I am going to take up oil painting. Now that retirement has come thirty years not too soon, thirty years too early, I thought well - oil painting so ...the strange thing about oil painting is the muckier I get the more pleasure I seem to get out of it! Probably made to clean up too much when I was a little 'un. It is a recent thing and I do get a lot of pleasure out of it. And I have been doing an O.U. course. This is perhaps the most important thing about my retirement. When I first candidated for the methodist college it was a college where you were unsure of what the future held for you and you wanted time to think about it and while I was there the four tutors, each of them said yes you must candidate because you are right. That was a wonderful compliment, looking back. And the English tutor said when

I go to ministerial college properly I'd get the chance to do a degree. This was a real thrill to me. I thought well it's possible, but because I was over thirty I only got two years at college so the degree I had to miss and this made me very angry. Other people who were younger than thirty were able to study and get lots of degrees but because I was over thirty...even in talking about it it makes me angry. Now I am catching up on things that I should have done ten years ago. I am no longer angry that I had to retire because it has opened new doors. Closed one door, for one thing I don't miss all the paper work. So it shut some doors and opened other doors.

Do you make plans for the future?

Yes, yes, in making these plans it is always in the back of my mind 'if' . I'm not sure if that's a bad thing or not. Assuming I get the O.U. degree that will not be the end, I am going to do two extra courses to make it an honours degree and then I hope to do a Ph.D.

Linda

I started with multiple sclerosis twenty six years plus ago. It was the actual birth of my son but I wasn't diagnosed straight away with it. It wasn't until he was four years old. After moving from the other house to this house. I went to the doctors after my son was born, with post natal depression and nerves. And of course they gave me tranquillisers and tranquillisers and it was not. They never referred me to anybody else and...well I wasn't getting any further, I wasn't getting any better. I was in fact getting worse. And my husband said to me that when we move house I was to change to his doctor, or seek a second opinion. Because he wasn't satisfied. So I said I'll change to your doctor. I did and he knew what it was straight away. He didn't say what it was, he sent me to a specialist up at the hospital. Even after then I didn't know exactly what it was that I had because he didn't tell me outright. He told me what was happening to me, what was wrong with me, but he never actually put it as multiple sclerosis. My symptoms were that I was walking out of my shoes, I was loosing my balance, I was walking two steps forward and one to the side. While the children were young I had the pram to hang on to, but later on it got a lot more difficult. But I struggled on my feet for as long as I could. And it's now, what, twenty years since I was confined to a wheelchair.

The first thing, the first reaction that everybody has is 'why me?' And there is no answer to 'why me', and some one once said to me "Why not you? Why are you any different from anybody else?" In that respect...you look at it in a different

light completely. Going out people looked at you as if you had a disease or something, they shied away from you, even a lot of my close friends did the same thing. But as Steve reassured everybody that it was not my brain that had gone, that my mind was still here, in fact he always used to say that I was cleverer than him! I didn't really lose friends, they were all married at the time and had their own families to bring up and I am in contact with the majority of them. They still come to see me, they treat me as if I am normal, they ask me to functions...they provide...well I went to a friend's daughter's wedding not so long ago, they had to carry me up the stairs and things like that, in the chair. You know, they had thought about things, laid things on for me specially. But...I don't want any special treatment, any preferential treatment, I don't want to go to the front of the queue...you know if you are in a queue for anything I don't want that. The worst experience I ever experienced was going in to cafes and people saying no you are not allowed in here with the chair. They say it is because there is not enough room, other people couldn't get by and things like that which is ridiculous. So we avoided those cafes, but for as many that refused us there was as many that opened their doors and made room just for us. Go in and they'd make you welcome.

I avoid going in to York, because it is one of the worse cities to get around, especially in the tourist season, and the pavements are not made for wheelchairs whatsoever. And if I do any shopping it's either to the super-market or on a day's outing or on a holiday. Being in a wheelchair has only curtailed sort of every day things since I lost my husband. That was the biggest blow, that was four years ago.

My daughter was getting married and things didn't work as we'd planned, he was just able to give her away. So things haven't been all that roses. It should have been the best year of our lives, it was our silver wedding, our daughter getting married, every thing should have been really well but...unfortunately he died just after he'd given away, after cancer treatment which didn't ...they said it was nowhere else in his body but it obviously was because he was really bad at the end. I was just devastated really. Picked up the pieces again...it's like going round the grand national course, I tell everybody...another hurdle, I'll jump it. I might fall next time round at beeches but I'll have a go. I'll go on as long as I can. I see my life as a challenge. The thing is that M.S. is a disease what you get. Nobody knows what it is, what causes it, how to cure it, how to treat it, nothing, it is all trial and error. But the thing is I at first never knew a thing about it, but with M.S. the thing is fight M.S. that's what it says on our tins, and fight it you have to, otherwise it will fight you and take over and you will loose. I mean I have seen a lot of people go in the time I have had it. A lot of my close friends and it isn't a nice sight to see people deteriorate through having this illness. But you can lead a perfectly normal life if you fight it. Try.

Is there any way in which you can make sense of it?

No I can not because I was an active gymnast, I played hockey and net ball for York, I was also a dancer and I had the best of health. And you know, it was...you know if any one was to have got it wouldn't have been me, sort of thing. But as I say it's one of those things. Other people get it, I mean people are referred to

me as young as sixteen with it. It's an awful age for a youngster to come and say what can be done? How can I cope with this? I just say go out and enjoy your life. When it comes to the time that you are confined to a chair and you are needing help financially, medically etc. then come back and join our society. If I didn't have M.S. I would go out, I would go in to town shopping, get myself what I wanted, not rely on other people, which is one of the things, asking for help is a very very hard thing to do. And I'm one that'll battle on and try and do it my way, but it is very hard to ask for help. When you have done every thing yourself for so many years, you know, it is very hard.

So you do voluntary work?

I'm on the phone twenty four hours, on help line for M.S. patients. If ever anybody gets stuck with anything, medically wise or wants equipment and things, doesn't know what equipment, or who to turn to, or anything like that, I am there more or less twenty four hours. If they can't get me, I'm not available, I'm on holiday or in hospital then they'll try again. But the majority of the time I am here.

I don't really have to see the doctors regularly now, but in the past my doctor was very good. Then he became ill and he gave up and it was passed on to a younger doctor. The younger doctor doesn't know a thing, still doesn't know a thing to this day about M.S. Because it was just passed at our annual general meeting last month, that I went to, his receptionist said to me, her husband is underneath the

doctor, and she said: "If it hadn't have been for you and Steve inviting me and my husband to your house to explain everything about M.S. I would not know....what things were available, how to go about it, and how to cope with it my husband would not be still at work today. He would have packed in and given up. But at the moment he is doing fine". I hope one day someone will take over from me. That knows a little bit more than what I do. But as I say at the moment we just do not know what causes it or anything else. I asked the doctor what M.S. was and he told me exactly what it was and what could happen to me. And I came out of that room and I thought well, I'm not going to go blind, I'm not going to loose my hearing or sense of taste or smell, I'm not going to be a cripple, have people feeding me and things like that. And I thought well I will fight this and see how much I can hold on to for as long as I can. And I have done. So far so good.

Did you find that your relationship with your husband changed?

No. He turned round and he said: "You are still the person I married, our relationship is still as good as ever and you are always going to be the same for me". And it was, right up till the day he died.

What about with your children?

My husband wouldn't let my children do anything for me. He thought it was his responsibility, as he married me, to do whatever I needed...and the children never got involved until they asked. My daughter said to me that she never wanted to

be a nurse but that she is ending up being one now. I said: "Well you are only putting me to bed". And she does one or two other bits and pieces, shopping and things. But I mean they are only young, I don't want to put on a young family. I mean she is just married, she's been married four years this year coming up and no way do I want to put the strain and struggle on her.

Being in a wheelchair, do you find it easy to meet new people and...

Every one around here knows I am here, they know where to come if they want to speak to me, they know how to get in and everything else and they always look out when I'm not here, look after my house and what have you, so I'm pretty well guarded.

The thing is I love dancing. Both on stage off stage, ball-room dancing, the lot. I'm missing out on a lot of that. Partying, a lot of partying we used to do, missing out on that. Going to the theatre and the cinema as often as I like, that's all out of the question, because I have to rely on some one to be here to put me to bed on a night time and to be here in the morning to get me up.

Do you or did you feel bitter at all?

No, I felt as if somebody had taken part of my life away. But to blame...there is nobody to blame, because we don't know what causes it. I can't blame anybody. It's like when my husband died, you know you ask the question why? Because he was so good to everybody. He was a church going man, he stuck to his religion

religiously, there was nothing that anybody could fault him on. He stuck by me and the children, we had a really happy life. And he even looked after his mother as well. And we lost her this last Christmas. He did everything that he could to make my life pleasant. He would say that I am going to do the shopping, so every fortnight we went to Asda in the car with my daughter and we just went round. And he would tell me to choose whatever I wanted. I run the house completely, I paid the bills and did all the financial side, the lot. I'm glad I did because I would be in dire straights if I hadn't have done. But it is one of those things...I wish somebody would take it off me now. The responsibility.

My life is worked to a schedule. I have to stick by it. If it wasn't I would just be...I don't know...all of a jumble. It keeps my brain going, that's one thing, I have an active mind, if my mind packs in I don't know where I'll be...it's just one of those things. In the future if I get too bad than I am going to have some one to live in and care for me. or, the other alternative is to go in to a home. I do not want to be with the geriatrics, not yet. One day I might end up being a geriatric, yes, but not just yet. But there isn't many places that you can go to stay for any long term for M.S. or any other illness. The nearest place is just outside of York. I do not look in to the future. I never bothered too much with the future, take one step at a time, one day at a time. Before I was diagnosed I wanted to get married and have a family. And after I had my son and I was ill, my husband said: "No more children." I have two children.

Do you think that your femininity has been taken away by being in a wheelchair?

No way. No, the worse thing was the catherisation, after I lost my husband because I couldn't get on and off the loo on my own. Didn't have the power in my arms...this has been a problem and still is a problem at the moment, I mean it is still in its early stages sort of thing. But if it comes to it they will most probably do a by-pass and sort it that way. I don't know, I just hope that it isn't too far in the distance that they can find something that can help and...well one never knows...I might meet another partner, I'm not looking for another. When you have had the best you can't expect another one! But it's absolutely, really really one of those things ...you just don't look too far ahead.

I don't get much support from social services, they are very back wards in coming forward. You have to wait a long time for things you want doing. But with all the cut backs things are only going to get worse. I do know that. With what they are providing, what's got to go on the doctors prescriptions, what the nurses used to provide. You just have to play it by ear to see what is available and what isn't available. The thing that bothers me is cleaning the house properly like I would like it cleaned. Doing it myself it was spotless and clean but when other people do it they don't always do it the same as you do. So you have to grip it all between your teeth and think well be thankful that it is being done. It is so hard to rely on other people all the time.

I have always put make-up on and I can put it on without a mirror. I mean I think if my eye sight went I would still be able to put it on. So I mean I only wear it when I am going out, I don't wear it in the house. I still wear modern clothes like

anybody else, things I like, the only thing is no tight skirts, no shorts, can't go swimming like I used to do, things like that are out of the question. But apart from that I enjoy what I can do and I accept everything as it comes along. I mean I have a catalogue which I have run for years, and I can see what are up to the minute fashions if I fancy it I'll have it, if I don't I won't. I mean I made two skirts last year, winter skirts, instead of wearing a blanket round your legs, like a lot of people do, I wear these skirts which are lovely and warm and feminine. You have still got your feet there and your stockings...and everything else. Coming to terms with it that is it. With M.S. you never comes to terms with it. Every body looks at it differently. But if you don't fight it it will fight you and it will win. I am not being funny or anything like that but it does.

How can you fight it?

You have got to know your limitations. I've got to know when I am tired and fatigued. I've got to stop and just rest. And renew my energy. I do Yoga I have done for a long time. That does help a lot. I just relax and watch television, keep my mind active watching game shows and taking part in quizzes and things. I don't do crosswords as such, I have attempts now and again. But it is awkward holding a pen and writing. Apart from that life goes on and you know I work to a schedule and that's it.

You say your husband was a church going man. Do you share his belief?

I was christened Church of England, so I am Church of England. My husband was Roman Catholic, so it was a mixed marriage. I have thought about it the Roman Catholic church more so than my own church. They know more about me than what the Church of England does. I don't often get a vicar to see me at all. My mother still goes to church. I can't. There is no way I can get up in time to get there for first service, unless it is a particular service that I want to go to. I used to love midnight mass every christmas I made a point of going to that. But since I've lost my husband I can't get to church on my own. I have nuns coming to see me from The Daughters of Charity. You see my husband was the care-taker of the catholic school, and the headmistress was a Daughter of Charity so they all know me. My husband wanted to live, he stood on his feet at quarter to six looking for his tablets and then at ten past seven it was all over, he was gone. He stood on his feet to the last. I see him up there even now, saying to me: "Huh, told you you wouldn't survive without me. You think you'll just jack it in cos I aren't there!" And I say: "I'll show you that I can carry on!"

Some people are embarrassed by the wheelchair, they, you know, step aside when they see you coming. You can see people that you've known years back, at school, and they don't want to know, they don't want to be bothered. They move to the other side of the road. Fair enough, if they don't want to see me, I don't want to see them. Works both ways. And you know the "Does he take sugar" syndrome. My husband used to say well ask her, she's got a tongue in her head. If I went in to shops and that and if the shopkeeper spoke to him, he would never answer them, he would let me answer. So that they knew it was me that wanted not him.

How old are you?

I'm fifty.

How do you feel about your body?

Well I didn't like my body when it put a lot of weight on through drugs, I tried to get it off. But I didn't realise how difficult it was, still being on drugs but I've managed to get it down to a reasonable weight now. My only problem really now is my stomach, but everyone in wheelchairs gets this problem and you can not get rid of it so well...I've got to stick with it. My husband always used to say: "You are you, you are still whole, you are still one person, the only thing is your legs don't work, your arms and hands don't work at times, but every other part of you does. You are still the same to me, you are still the person I married, you haven't changed a bit". So when you've got a husband who used to say things like that it makes you feel wonderful, and you can't blame your body, because you are your body and you can't blame yourself.

Do you think your attitude towards M.S. would be different if you had not had the support of your husband?

If I had had M.S. before I was married I would never have got married. I wouldn't have burdened anybody with it. Definitely. It is a burden. It is a heavy sack on your back, and it is there every day, By the end of the day it has got heavier and

heavier. But I was married and I have had every joy out of life that I could possibly have. Having two children born naturally, no complications, a wonderful marriage, a wonderful husband, supporting family, I couldn't have had it any better.

You have to have patience and tolerance. Patience and tolerance and the two main ingredients. You get there in the end.

Sarah

I do have muscular dystrophy and the doctors noticed it when I was twelve years old, but they couldn't find anything at the time, but I just started limping. Then I was O.K. from then on, I could do everything that every one else did at school and everything. Then when I was nineteen it started getting worse. So I knew I had it before but it only meant anything to me when it started getting worse when I was nineteen. It got worse and it got worse and then it...well sometimes it just stops and then it can just start again. Later on...a couple of years back it was really bad and within the last...well September last year I had to get the wheelchair because ...I mean I was finding it very difficult getting about on my own. And I never had a phone or anything to contact anybody so...I couldn't walk at all and so I saw the doctor and I was in hospital for three weeks and the doctors were quite surprised to see what's happened to me, they didn't expect anything from me, from the state I was in but now I'm actually walking. I can walk now. The doctors didn't really encourage me it's come from me. Because once I had seen the way I had been when I tried to walk and my leg was dragging and I didn't like what I was seeing cos I had determination in me at the time before I went in. It's all come from me. I have had support from doctors, I mean from a medical point of view they are very good. They have never really explained to me what they think will happen to me or anything like that, but when they came round one day, they just, well they didn't expect me to be walking at all. They didn't at all expect me to be doing anything, it's all come from me and I suppose they supported me through it. Now I can walk a bit, I use the wheelchair

when I am out but I always try and take my frame with me so that I can do some walking while I am here. As well as at home. I use the wheelchair when I am really tired, but with me being here I am not used to the walking frame so I bring both. That way I can use what I want to. When I go into town and things like that I'm in a chair. I'm not ready for that long walk yet. If I keep it up maybe I'll be able to.

When you are in town how do find people react to you?

Well, I've been watching people when I go in to town to see what their faces are like when I look at them. I mean a lot of them smile at me, a lot of others just look down at you and don't bother, I don't know what people think, maybe embarrassment. I mean a lot of people think that because you are in a wheelchair then your heads gone as well. But it's not. I mean I've got that from a lot of people...

How about family and friends?

Well at the moment...my brother and sister are O.K. but my Dad and step mother aren't. They just well...they just shove me to one side, don't seem to bother...you know. I don't know why...they never speak to me about it or anything it's just them...

How often do you come here to the day centre?

I come here twice a week. I get quite a lot from it. You get the support that you need, you make a lot of friends. I mean we are all the same. If other people have got disabilities it is...it is much easier. I mean they know what I'm going through, everybody knows what every body else is going through in here. Not only that but in here people know what other people can and cannot do. When I'm not here I have physiotherapy on the Monday and Friday, that's to help me with my walking and get me back on my feet. I've got a free day on a wednesday... I live alone and that's fine. I don't really know my neighbours...it's a new building, new flats so they just say hello to you when you're out side or something but they don't come and ask you if you're O.K. or anything. I mean everyone just keeps themselves to themselves. I've got a home help who does my shopping and things like that for me. But for shopping for clothes and things like that I've got friends who'll take me up town...so that's no problem.

There are things that you can't do. I mean sports and that. I used to play badminton a lot when I was at school and that. I loved that game...it's all the moving around that you have to do. There are things that I can do which there... well there are probably people out there who can't do them. There are lots of things that we can do and people are surprised at what we can do. I mean they think that you just can't do anything. Once you show them and start doing things...I mean people didn't think that I could drive or anything...I mean I am still learning, there was a time when I didn't think I would bit I'm getting there - it's brilliant!

I used to work as a sewing machinist since I was sixteen. I still sew. I think the main difference since I have had to use a wheelchair and since I can't walk well is...it's just getting out. Meeting other people, like here...People should know what we have and what we are going through. I mean what is going to happen to us.

What are your hopes for the future?

To get back on my feet. To get walking again, to get back to normal. I mean I can move around in a wheelchair but there's a lot of pushing...I mean you need really strong arms for that...I don't have that. I mean I don't like other people looking at me as if I'm some kind of weirdo just because I can't walk as well as them. I used to hate my wheelchair and then well...I knew I had to get in to it...and now, well I'm getting back to the walking again it just....I mean I never want to have to rely on anybody. I mean some people don't bother turning up when they say they will, and you are in the wheelchair and that...I mean you are just isolated at times. I am alone a lot. When I was walking and that before I was out quite a lot. If I could walk again...well I'd have my freedom! Yeah, freedom.

I don't have a relationship with a man at the moment. I don't know if that's because of me being in the wheelchair or what...I don't know. I would like to have a boyfriend. I do have...I mean there has been somebody I was close to, when he was working here. I was really close to him I mean I've never met anybody like him, he's been really good to me. He'd talk to me and be with me every week and that and it was really good...I enjoyed that. I like somebody who takes you the

way you are and not...I mean with being in a wheelchair it doesn't bother some people.

I've got brothers and sisters, and I haven't seen them for a while but my big brother who's in Scotland, I told him what I've been doing and that and he is really chuffed by what's happening.

Being in a wheelchair means you can't dance and move nicely all those sorts of things...but even so you can still join in. Last week it was the first time I went dancing with music down there. It was good. I was joining in even though I couldn't get up to make the movements, I was doing it in my wheelchair, it was pretty good. It's like the wheelchair becomes part of you.

I accepted it from the beginning, since I had it. It's just life - you've just got to carry on, whether you are in a wheelchair or not it doesn't matter, you've just got to carry on.

Can you make sense of it to yourself in any way?

Yeah. Yeah. I mean I was told before that I would end up in a wheelchair...but well permanently. So I am lucky I can get out of it...you just have to get on with it. I mean I never complain about my disability, just take it as part of life and just get on, do the best I can. For me my goal is to walk a bit better and not rely on my wheelchair. I don't know why that is so important...but it is. Once I have

passed my driving test that will give me a lot more freedom. Get out and that.

There's a lot of things that need to be done for people in wheelchairs though. I live in an area...well the shops there, there are loads of shops in York, especially up my end, I mean like the post office that have steps so high that you are on your knees trying to get in. I've never been in it. It's the same with other shops, they have stairs or they have big steps to get in. They just don't think. That is all I can say. They do not think about disabled people on their own. In the main part of town it is O.K. some of the shops haven't got stairs, it is quite easy to get in, but some of them are terrible. Others have, well it's good if you can get in them. But it is a big problem. They should make it easier for us, for disabled people. Instead of having to try and get somebody to take you. If you want to go yourself, I mean they should have something for disabled people to get in and out of shops on their own. So you can be independent regardless of the wheelchair. what really annoys me is the pavements. They are terrible, some of them. Well they are alright where I am. I mean we have the sloped bits at the edges to get up instead of the step. But there are some places, like up in Clifton, that's worse. I mean the wheelchair I had before this, the wheel was buckled about two or three times because of the pavements, because the pavements are all up. I mean if any one were to walk there they would fall over, I know I would. And some pavements are just pathetic. It's all these practical things that could make it so much easier.

I did have a social worker but now I don't. I'm managing without now! I never

really got any help with anything. I was always left to do it on my own. They are the one who need a right good kick up the...! She was just...well she said she would do something for me, write to this person or whatever. Then she'd come the next time and say she still hadn't written and it went on and on for something that could have been done long ago. Instead of having to wait and wait and wait.

My doctor I have now is brilliant. I don't always have to go to him, sometimes he'll come to me. I mean sometimes he just pops in if he is passing by, and just come and see me. It's really good. Not like the last doctor. I mean I never saw him, but this one I see quite a lot.

I've accepted everything that is wrong with me. What I've got. I am depressed a lot at times. I mean I don't show it in front of people. I mean it all comes out either at night, which is the worst time, or during the day if nobody else has been. I don't think I am bitter though. What really gets to me is when somebody says they'll come and they don't. That really gets to me. When somebody says they'll come, and take you out or something. And you wait in getting ready and nobody comes. Yeah that can really get to me. I get so mad at times, I mean they don't care, they are the ones that can walk about, go where they want and everything else. We are the ones who are stuck in all the time, having to wait for somebody to come.

I don't know what I want to do, I'll probably go back to work or something. I don't want to do that at the moment cos I've been having operations as well, and

I'm waiting for another one.

Do you feel yourself different from people who are not disabled?

Not different, I mean even though I am in the wheelchair compared with somebody walking about...I wouldn't say we were different...not especially...we are just the same as what every body else is. Since I've been in the wheelchair I wear different clothes, I wear dresses, skirts ...at one time I wouldn't wear any dresses or anything. I wear quite a lot now. I think I didn't at first because I was embarrassed of myself, what I had to wear...I wear splints on my legs and I didn't like showing them. I think it's because I thought other people would laugh at me or whatever but...it took a while for me to get used to it, but it took me to look at a younger girl. A younger girl that...about three or four, she had the same...well I thought if she could do it...well it changed me a lot...I've changed a lot lately. Just, I mean wearing different things. I mean I wear a lot of trousers and that but I always wore trousers and when I go out now I wear skirts or dresses and I just well I'm just changing myself...completely. The plastic splints come up the back of leg...they are just to help me pick my feet up when I'm walking.

The doctors never used to say anything they just used to look at me and they made me walk distances around the room and that was it. Come back in six months - that's all I got. But down here I have had so much done for me, an awful lot. I mean I've had, well I never even had physiotherapy before. There was nothing. I always wanted to know what I had wrong with me, and my work wanted

to know so they could put it in their records, so when I asked at the hospital and they told me. Well actually I got them to write it down for me and so I could take it in, Muscular Dystrophy, I mean there are all different kinds. I got it written down for me and I took it in...Knowing what I had...I mean I think that was what the problem was cos people would ask why I was limping and I didn't know what was wrong with me, so I didn't know what to say to people...but once you come to terms with it and that, then it's easy to talk about it with people.

I'd like people just to treat us as normal, as normal people. It's just the way they look at you. People look at you and just look down at you, and that is one thing that really annoys me, when you are in a wheelchair people talk down at you. "Oh do you want me to do this for you?" "Do you want me to do that for you?" I can do it myself. It is..if people just accepted us the way we are. I mean we are not from another planet or anything. I mean sometimes you would think we were. I mean I have had somebody tell me that I am not normal. I'm not normal! Because I had a disability I am not normal. I was upset at the time but when ..well I had an argument with her, I says: "I am normal. I'm just as normal as you". "No you are not, you've got a disability". "So what". That's why it is easier to be here, at the centre. I mean it is just people out there who won't treat us as normal. I mean I like mixing with different kinds of people, I mean people say that everybody has got a disability in their own way but...but since I've been here...it's really brought me out. Talking to people and that...when I first came here I wouldn't talk to anyone and then he came, the chap I told you about...and he just started talking and he got me talking. I've been talking quite a lot lately!

When people talk down to me I let them know. I talk back to them, not the way they are talking to me, but I'll talk back to them like I'm letting them know that it is annoying me the way that they are talking to me. I won't come out and say it directly but I let them know in my own way. I had to learn that. I mean they used to talk down at me on and on and the more they did it the more annoyed I got about. I mean somebody else would say: "Oh she talks down to us as well". I just find it worse for someone in a wheelchair to be talked down to. Even when I was in hospital and the nurses came: "Hello Sarah are you alright?" I'd think Oh go away, and the next minute they are talking normally with somebody else. I mean if you can't talk to me normally don't talk to me at all. I mean my brothers and sisters talk to me normally...just normal like I was anybody else, they never talk down to me.

I had a party and only two people from here turned up and I was annoyed about it, but somebody else is having one for me and...so..I have got really friendly now with quite a lot of the people here. This is central to ...to me I suppose. My social worker told me about it. Well at first I thought I didn't want to go, you see there are two centres...the one across is for mentally and this one is for physically disabled. But I only knew of the other one and it had me all...and then I found out there were two places and it's been pretty good. I mean the staff are good, everybody is good.

Hilary

Well there are two different theories on when it exactly started. I was first aware that something was happening in 1969, I was in a R.A.F. station, as I married someone in the forces, and I worked there. And I was having problems with my right eye. I was going blind in my right eye. I was also just starting to have a problem with my left leg, it was just pulling, just very slightly. And I went to the R.A.F. hospital there, and they kept me in for about six weeks doing various tests on me, then they discharged me and that was it. They didn't say exactly what it was or anything and I just came out and I was fine, my eye seemed to have sorted itself out and I got back to normality and it was perfectly alright. And then everything was fine up until ...I got married in 1973, and we were stationed out in Cyprus in 1977, I think it was and I had a hell of a relapse the second year we were there. And I finished off in hospital again and I had to be brought back because I was in a hell of a state. It kept just travelling and travelling and travelling. I finished up in Newcastle general hospital and funnily enough it turned out that the neurologist was the registrar that I came across in 1961 in Sunderland Royal. He believed that my M.S. did start then, cos I was a suspected meningitis in 1961 when I was eighteen. It wasn't meningitis and I was only in for a fortnight and I was discharged. But he reckons that definitely was the start of it. So I've had it since 1961. I didn't know about it then, I didn't know about it until 1977. In 1969 I was told it was something to do with the central nervous system and that was it, nothing was explained and that was it. But because I was fine, I mean I went back, I was working, and I was dancing and I just forgot about it. In 1977

when it was finally said that I had M.S. I thought Ha ha, I didn't know a great deal about it, I'd heard about it, and I knew it was to do with the central nervous system, and I thought could this relate back to ages ago, and ...but it didn't really bother me that much. I was fine, and again we were stationed out in Germany and I was fine. I had a physiotherapist who was the dental officers wife, who lived opposite me, and she came round every day and literally taught me everything I know. And within nine month of it all I was able to walk three quarters of a mile with one walking stick. When she came to me the first time I couldn't even get out of the flat. I was that bad with it. I was dropping things, my hands were affected. You name it and it was happening to me - I was in a hell of a state. And she just taught me so much, how to look for it, where to look for it, what the signs are, how to do this, how to do that, I'd have to go out for a walk every day to improve every day. And what you have always got to remember when you are going in one way you have to get back again, you know if you go twenty yards that way you have to go twenty yards back, so increase it by five yards back each way, and just work it up. And just gradually I got better. Until about eight years ago when I had a hell of a relapse again. That effected my balance. It's not vertigo. We were stationed still in Germany and I went to see the neurologist who said: "Well of course if this can happen, it's not vertigo it's a balance problem. It is quite rare to happen with M.S." He said: "There it is, and that's it." And it's just at certain angels I put my head, if I look up or look down it just feels as if my head is being flung backwards or forwards, and the pressure builds up in the temples and it's horrible. If I am standing I have to go down on my hands and knees and stay there for about thirty or forty seconds until it sorts it self out and

goes away. They did try physio treatment on me at York, when we came here, but ...just moving the head very very slowly and things like that. How do I feel about M.S.? I've accepted it. I've come to terms with it. There are some days better than others, some minutes better than others. I appreciate the fact that I am not too bad with it. I'm also a diabetic now I found out eighteen months ago. So now I've got two things, one from either side of the family. The M.S. apparently my uncle, my father's elder brother had multiple sclerosis. It is not supposed to be hereditary as such, but my aunt she reckoned that my great aunt, again on my fathers side, who I can only barely remember as a child, she reckons that M.S. is what she had. So whether it skipped a generation came down either way I don't know. But then I don't know exactly what happened with it. On the whole I...I think until you come to terms with what you have got wrong with you , you are fighting a losing battle. And you have got to take every day as it comes along, that's it. M.S. well... it bothers me...it doesn't frighten me. It bothers me some days, but it is not going to go away so why get uptight about it. I mean that doesn't help. It is just a case of getting on with life. My diabetes is playing up more at the moment, than my M.S. so... I even said to my doctor, "You know what they say, they say things happen in threes, knowing my luck the third thing will be cancer!" And he looked at me and he said: "No, hilary you must not say that." But then he looked at me again, and I said: "I'll look at it this way, if it is it is and there is nothing you can do about it, hope to damn that it isn't that but there is nothing you can do, and knowing my luck it will be something that way inclined, and anyway they say you've only got three score years and ten, and I've only got three year to go till I'm fifty..." I would dearly love them to find a

cure for the M.S. At least with the diabetes you can keep it under control. With M.S. we have no control of that whatsoever. Because it just goes hay-wire when it feels like it. And we haven't a clue what causes it. I mean it is just there and it has been around a hell of a long time, about one hundred and fifty years, I mean that's it. Creeping paralysis, disseminated sclerosis, multiple sclerosis, I mean what's the next thing? Cure? But I don't know it doesn't really...I mean I don't wake up and say every morning "Oh I've got M.S. what a horrible day I am going to have." I mean that's it, unless it plays me up particularly I just come to terms with it. I expect it to be part of me now. I don't love it, I don't hate it, it is just part of me. I am just an M.S. person.

I don't think it took me a long time to come to terms with. I was told actually, by my physio and by doctors actually, that I came to terms with it very quickly. As soon as I was told what it was that was that. I think I have had so much go wrong with me over the years, I mean I was in a near fatal car crash when I was twenty, and I have had a lot of gynie problems, I've never been right since I was seventeen so I just say I am a walking catastrophe. So it doesn't bother me, you know. I keep thinking what the hell else am I going to get. You know I am just one of these people. But I know with some people it takes a hell of a long time to come to terms with things, but until you do you are fighting as loosing battle and that makes you nasty with it as well. Until you come to terms with it, with what's wrong with you, you say well it's not that bad, I mean I can still use my hands, I can still walk a reasonable amount. I am getting less and less, I mean at one time it was half a mile, now it is down to about two hundred yards if I am

lucky, I get a lot of pain with my M.S. that's why I am going to the pain relief clinic tomorrow. They came up with a very interesting fact actually. The doctor said that he's found that people with M.S. who take Triptamine, antidepressants find it very helpful for the pain. The pain is still there, I'm aware of it, but I'll give them their due, it has helped. What he'll say tomorrow I don't know. Helps you sleep at night time as well! But my own doctor was quite interested in it, when I told him that. So whether he will use that to help people with M.S I don't know. Again pain doesn't affect all that many people with M.S. there is only a certain percentage of us that get pain. I think it is those that are reasonably quite active, that get the pain. The pain relief, they are all anaesthetists that run the pain relief clinic, cos I went to one in Reading as well, and he said, when you think about it, if you can still feel pain that can't be bad can it. I said I suppose so. This is probably why those that don't feel pain are the those in wheelchairs permanently and that. Those that can still feel certain areas...I don't know. I had a friend once, who cheered me up completely when I first found out I was M.S. How true this is I don't know, but I have heard it quite often, M.S. only affects intelligent people. She once said that to me: "It only comes to brainy people". She helped out at a M.S. place and told me this and said that it was true of me. I just thought well you carry on thinking it. "Well, I said, "if that's true I personally would rather be as thick as two planks than have M.S." So that's my way of looking on it. But if it is something that I have had right from the start with the suspected meningitis, I've had it almost thirty years. I'm still here, I can still get on with life, and I've just had to accept it. It is not the end of the world.

How did your family...

My father never accepted it. Well he is dead, he died four years ago. My father was not a great one for accepting anything to do with illness of any kind. We are not a close knot family, never have been. I've always been the one that's been away anyway. I have never been at home much. My mother accepts the fact that I have got M.S. but she never discusses it much. We only see each other about once or twice a year, we speak on the telephone and that sort of thing. But she never really discusses it in detail. My husband understands what it is, yes. we have a thing that I don't ask my husband to do anything unless I need him to do anything, because I feel that how ever am I going to get on in this life if I keep asking him to do things that I'm quite capable of doing myself. So he knows that if I ask him to do anything then I am really pushed, and he does it. But no, he doesn't do anything for me whatsoever. Unless I ask him. I've got a wheelchair and I've got a battery scooter and I use that purely, well when my legs won't work, I'll use them for a change. But I am determined to keep on my legs as long as I possibly can. I'll be perfectly honest the wheelchair frightens me sometimes. I hate going in it. I'd rather crawl than get in it. Because I know because I have got a progressive disease that I am going to finish up getting in it. Eventually. I do not like that idea. I want to be as independent as I possibly can. So I want to keep away from it as long as I can. So I don't know...but I'm a great believer in Use it or you loose it - I'm a great believer in that. And she was on television, she said it not long ago. And she's got M.S. and she does the same and I am a great believer in that. I've said for years that there are a lot of people with M.S. that

I feel are in wheelchairs that really don't need to be in wheelchairs because there's me, and people are weaker in wheelchairs. How many people are totally disabled? Or paralysed. There's not many. You've got to work at you. I mean you have to move your hands and I did exercises just moving the fingers and wiggling them around and doing that type of thing, bending the arm, wiggling the toes up and down for the muscle, things like that. swimming is the best thing you can do for it as well if you can get in once or twice a week. Just keep going as long as you possibly can and everything.

I hardly ever use my wheelchair. Only when we go on holiday. I mean it is easier to get in the car than to take my portable scooter. That's the only reason. But the first thing I do when we come back is to get out and I walk down the garden, and I do the same when I have been on my scooter. I hate the wheelchair because some one is pushing me. On the scooter I am in control. No one is helping me. I want to be as independent as I possibly can. And in a wheelchair I'm depending on someone else.. to push me, and I'm just sat there. I am not using my hands or anything, I'm not in control. On the scooter I am in control, I stop when I want to stop, I can get off when I want to get off. I do not feel disabled on the scooter. I do not want to look like a disabled person. I've just got this thing, ...I mean I don't mind other people thinking I am it's me...I just don't want other people to class me as a disabled person. I've got a walking stick, and I suppose people think...well I think it is bad enough having that. I do not want to be labelled. Some people have asked me why I use a walking stick. I was once told...it's visual. People are aware that there is something different. If someone was to come

towards me and we are both about to bump each other, I can't suddenly change direction. The message doesn't get down the way it should do. I trip over my own feet. With a walking stick it is visual and people tend to give you that space and go around you and that's why I like it. But

I don't mind the walking stick, but this wheelchair...I know eventually I may need it and I am just trying to do without it as long as I can. I am trying to say well right I don't want to use that wheelchair. I was told that I would be in a wheelchair before I was forty, well I'm forty eight in October and I don't want that bloody wheelchair before I am fifty. I don't want it before I am sixty if I can possibly help it. I just don't want it. I just personally want to keep going on my legs as long as I possibly can. because I just don't feel I am ready for a wheelchair. Physically and mentally. I just want to keep on going. I just don't want a wheelchair. I mean some people accept them, I hate mine, I stick it in the garage and that's it. Even the scooter I have to get off and make myself walk, because there may come a day when I can't leave them behind and I am just making the most of my legs while I've got you. If the day comes obviously I will have to accept it, The same way as I have to accept I have a progressive disease and like I have diabetes. I have had to accept them and I've only known for the last year and a half that I have diabetes. And I've had to accept that as well and at the moment I feel better not knowing about wheelchairs and things like that. If I have got to later on then I will have to.

The future doesn't frighten me at all. I just hope that...well I've got to the stage, I will be perfectly honest, I don't want to live until I am one hundred. I suppose

if I was fit and healthy, no not even that because I think the world has altered so much, the environments getting so bad, I mean I wouldn't go out on my own at night time...I wouldn't feel safe...I mean go back thirty years ago and you were. But I don't know...I'm quite content to die when I'm seventy. I've said it to my husband. And I've got this thing and I have said it with him, if my M.S. ever got that bad I wouldn't want to go on. I would take my own life. I would want to. I'm not saying that if I went in to a wheelchair or something like that but if I got to the stage whenthe main thing is not being able to go to the toilet on my own. Because I think that is...I think that is really...I got a friend, she's seventy odd and she's in a wheelchair, she can get around a bit and she's got a card, she's signed it, if somebody comes in and they find her - don't try and bring her back to life again. Don't even try. She used to be a nurse and she says she just doesn't want it. Something that she said was: "If I can't get to the toilet on my own..." We did have someone with M.S. in other branch and her husband gave his job up...and I mean the only way of communication between them was by the movement of her eyes. She used to wink with one eye for yes, and the other eye for no. That was the only form of communication they had, and she was only in her forties. She did die actually, not long after the last time I saw her. And she just went down hill so quickly with it. And I thought to myself I only hope...well I'm only grateful it hasn't effected my brain. Normally it doesn't go to the brain, it is very rare for it to effect the brain...but it had with her. I suppose it varies so much. From person to person. I mean I had a friend who is Danish again saying it doesn't tend to run in families, but she had it, and her elder sister died of it and her brother who is a farmer in Denmark also has it. Three in one family. The girl

I used to work with, years ago she's got it, her brother's got it also. And yet it is not passed on. It is supposed to be not hereditary. But they say once it's come out in the family it does tend to keep popping out again. But how true I don't know. But I suppose until you come to terms with anything you're fighting a losing battle. You have got to come to terms with it and fight it as far as you can.

I think I've just got a positive attitude on most things. I'm just that way inclined. I think because I have had other things happen to me before ...I mean because I tend to talk in medical terms. I've even had consultant doctors turn round to me and say: "Of course you are a nurse are you?" And they talk in a certain way. And I say: "No I'm not!" "But", they say "You do know this..." and I say I may do but I am also mistaken for a school teacher - I don't know why. I think it is because I am so bossy!

Do you think it has changed your relationship with your husband in any way?

Not really. None in the slightest. He was in the forces and well...he is not away as often as he was in the forces, but he is always busy doing something. No it hasn't changed in the slightest. I mean he occasionally washes up for me now, makes the occasional cup of coffee and that's it. But apart from that no not really. He mows the lawn and I've got a window cleaner now, cos my husband said he didn't particularly want to clean the windows and if it's only going to cost two pounds he said hire a window cleaner. And that was it. Up till about seven years ago I used to push the mower but that I had to give up. I can't manage that now.

But as regards...I haven't a home help, and I do everything else. I get a bit worn out with it, yes, and I think well I was in the garden yesterday and last night my two fingers on my right hand were playing up...but that's one area and my right eye and my darling water works. They are my three areas that tend to play up. So I have to think that's enough I am shattered. I know yesterday that I had done far too much, but I have got so much on this week that I wanted things....then the garden... I was absolutely shattered last night but well I'm still here. I don't think there are any differences really, apart from the fact that I don't go out to work now. And that I go to the toilet more often! But apart from that no. I have for donkeys years eaten the same diet, that didn't alter with my diabetes, and no I mean I haven't had to alter anything, not really. I mean we moved to York but it has always been my husbands job that has moved us. This is number sixteen since we have been married, but never mind! Ten of those were her majesty's forces fault. The Queen was at fault!

I'm not one of these like other people who think why me? You go through that...occasionally you think why me? Oh yes there are certain days, if every thing is playing up, again more my M.S. because that is the pain and I am limited in what I do. My diabetes doesn't effect me that way. I may take a blood glucose reading and it may be a little high and I think Oh God look at that that's not very good, my doctor will not be very happy with that when I see him next week. And things like that. But no, I think, no not really, it's just life and I think ...well at first you say why me? And then you say why not me? What's so special about me? Some times when I see some elderly people, like my mother who is eighty two,

she had an operation to sort out a hernia and she is fine. And I think why are there so many elderly people pottering around. I think of me at forty odd, and then you think of poor little children. A child of a few months...they have obviously come for a purpose to come back again, because I am a great believer that you come back again, several times to be made more perfect before you go to the kingdom of heaven. This type of thing. I don't know but it's a cruel world sometimes and life is not fair. I'm a great believer in that. But there is nothing you can do. You can only pray to God that you get through each day and that's it and certain things you say "Oh thanks for that." And if things do get you really bad, oh yes I have had a few tears but I'd far rather you have the tears and get it out of your system than hold it back and let it tear away at you inside. Because I think that is the worse thing that you can do. Get rid of it, tear it out, have a good cry, have a slanging match, have a screaming match, get it out of your system, but get rid of the frustration, cos it is terrible if it builds up in side of you. Have it out of your system, I mean there is nothing wrong in having a good cry about it. If you are feeling a bit sorry for your self, but why the hell feel sorry for your self because it is not going to go away. You just have to get on with life and do something. Accept it and think O.K. if the sun shines this month or whatever...

Why do you come to this day centre?

I started mainly for somewhere to go. I mean I came from the South of England and York does not have the same things as the south has, WRVS do things, Red Cross do things, for the younger disabled people things were done, even by Age

Concern. When I tried to find out what was going on in York for younger disabled people this day centre turned out to be the only place to come to. So what choice have you got? I think it is very important for disabled people to mix with other disabled people. It does depend on their attitude, I mean some of them do tend to feel a bit...I don't know...some of them don't talk a great deal about their disablement so you don't know what they are thinking in their head and tend to think O.K. yes they are here. I mean Jane and I can talk...she can talk about things but there is some of them cannot talk so freely and openly as she can. So we often have little discussions on things and then some of them think you are prying into their life. And the I was once told that they are not concerned here with what is wrong with us, and I thought well why...I mean are they ashamed with what is wrong with them? I mean I am not ashamed of having multiple sclerosis. I can't give it to anyone, it is not my fault so why should I tell anyone. I can't give it to any one so why keep away from me. It's nothing to be ashamed of is it? I mean it is that magic word disease. Disease of the central nervous system. Once I was talking to a women and I could see her gradually moving further and further away from me. All of a sudden I said: "Why are you moving away from me?" She said: "I'm not" I said: "You are, look...What I've got I can't give to soul." I said: "I know this word disease sounds horrible but well you know I'm married and we have been married, and we sleep in the same bed and we touch each other and what I've got I can't give to a soul." I would rather have people say to me: What is M.S.? I've got this thing and people say 'Oh yes' but they don't know what it is. Years ago it was a word that wasn't used but now...it doesn't bother me...until you come to terms with it. Again you see, when you

prattle on about it people tend to think you have been a nurse...but I suppose having the gift of the gab does help as well! I mean sometimes you have to make other people feel easy. But it depends on the person, there are some people you have to work very hard with, and other people, no. I find the magic thing is, I think I've just done it to you, is this magical touch. Again you have to be very careful where you touch people, haven't you. I mean when I have my M.S. stickers you have to be careful where you stick it. But it's this magic thing this magic touch. But again so many people when they are talking, no eye contact. And eye contact, the expression, intonation of what you are saying, the tone of your voice which is so important. I mean some people just never look at each other when they are talking and unless you have that you can't relax with people, I think it is so easy, but a lot of people haven't got that. I don't know where it came from I think it is just there. I was painfully shy as a child...until I was about thirteen, fourteen and then it all came back again. But there are lots and lots of people who are. They just don't relax, and until you get that feeling where you can reach out and touch a person and talk to them...but some people back away from that. People don't back away from me very often, I'll be honest. It is I suppose how you approach a person, it's what you say to them initially that puts the guide lines down. Some people have such a big wall around them, it's like you have to take every single brick down to talk to them.

I like to be among, not all disabled people, I like a cross section because we are not all disabled in this world. And I don't like being just with all disabled people. I like a cross section because it's a cross section world. There are some, well I'll

be perfectly blunt the reason I come here is because I am stuck at home, my husband is out at work, and I'm stuck at home looking at four walls all day. I go to the hydro pool on a Thursday here and I love swimming. It's how you are introduced to water that matters you know...and your breathing is very important. I'm going to write a book one of these days, although I have been saying that for years but there is always something else happening so ...

Can you make sense of what has happened to you in anyway?

It just happened and that's it. That's life. And that's all there is to know about it. I mean there is no way of sitting down and working it out, it's not that you can sit down and solve some great problem, or some great logarithm or something. It is just a fact that that is life. I have just been blessed with the fact that I had certain things go wrong with me and I mean, I was born with a veil over my face and that's supposed to be lucky, I don't know whether this is lucky I don't know. I've been blessed with plenty of love in my life so maybe I've been fortunate there. The only thing that I've been lacking is health. Everything else I've been lucky with. I've never been really poor, I've never been really short of cash particularly, and never ever, my parents weren't, we're not - my husband and I aren't. The only thing really that I have lacked in health. Everything else I've been not looking for. And I'm always saying if you've got your health you've got everything, that is one of the worst things you can be short on. Because, I mean if you have got your health you can go and do all sorts of things. Life in general - well it's just that some people get more things than others and I'm just

unfortunate that my health is not so very good. But there again compared with some people mine is not too bad. I just view it that I'm just on the middle of the tract I'm not up and I'm not down, I'm just along the middle. I've got good days, I've got bad days - but I'm here. I can still walk around a bit, I can still see, I can still use my hands, I can still cook and that. I still do most of my house work, well I do all my house work, my husband doesn't do anything. My main problem is the fact that I can't walk as far as I used to be able to walk, and this balance problem. So I tend to do things in slow motion and things like that. But apart from that, and the pain. But when you live with the pain every day you just get used to it. And these tablets that the doctor gave me help, but I'm aware there is still pain, but it has toned it down a bit.

My life is just one line, just one thing going through it. A continuation. It's just that you get good points and you get bad points, that's it, It is just that you ...it's all just one life, it's just a different chapter isn't it. Slotted in to the book and you come out at the end of it and it is just something else to write up about. Some people go through life and they have nothing to write about, they just take their health and things for granted. But you tend to think because you see people jogging around and they look alright and they say they are alright, they may have a million problems at home. I mean their marriage might not be good, they might not have any money, they might argue like cat and dog and well they might do many things. No it's just one continual...just one life. And that's it. It's just that I have had a few bad incidents come along and that's it. But on the whole it hasn't been too bad up till now. It's just how you come to terms with it. It effects every

single person differently, accept it and fight it as best you can. That's the only way you can do it. Come to terms with it and fight it as best you can. Don't give in to it, come to terms and say: "I accept you, yes", but that is not giving in to it. I accept the fact that I have got a disease there is no cure for yet. Stress the yet at the end there! I'll be careful, I'll not overstretch it, like I did yesterday, but no... life is just...it had good points and bad points and that's it. I don't hold too much against it. I've been much worse with my M.S. than I am now. But the thing is people didn't see me years ago, like I was. I couldn't even get out of the flat where we lived. So people tend to just judge me as I am now, but I have done so much for myself because...well you have to keep on going. Improve as much as you possibly can. Don't give in to it. And that is all I can say. M.S. is an individual thing, there is never ever two cases the same. We have all got something similar but I think if your attitude is good...but some people, bless them, they have...life's been good to me apart from my health. That is the only thing that has let me down. We can't really say that is too bad can we? If we only have one thing go wrong, health. Mind you that is a very important thing isn't it?

Hilary (second interview)

I'm diabetic now, I'm on insulin now, twice a day. We were on holiday in Tenerife when I went in to...I finished up in a clinic, cos as you know when you go anywhere now you have to take out private insurance to cover your expenses - lovely holiday! Five days in a clinic! And well I was taking tablets for my insulin and it was playing up my M.S. or visa versa - the M.S. does not play up the diabetes or so I've been told lately, I had to just go in there and it's like anything else. Coming to terms with it and with all this garbage they throw at you, on how you do, you know, your blood reading your blood glucose first, then your insulin, because I am on the pen. With my balance problem I couldn't go on the long one and it's like everything else you have to come to terms with it, and it's alright...you just inject you find the stomach is the best place to inject especially if you are female. I used to stick it in my thigh but my god it was dreadful, very painful and but no...in the stomach it is alright you occasionally bruise but as long as you keep moving around you're O.K.

My M.S. is playing up today because I have got a cold and that has effected my diabetes which is also high as well but apart from that...I am more concerned to be honest with my diabetes than I am with my M.S. I think basically because the M.S. I have had for a long time and that is not going to suddenly alter. I have a milder form of it. It's a slow progressive thing, it is progressing very very slowly but it doesn't...I am more concerned with my diabetes because that can alter and as they point out to you at the hospital you can not die of M.S. but you can die

of diabetes. So that is why you are more concerned. When I am at the hospital they couldn't give a fig about my M.S. But I see two different doctors in different hospitals for them both. But most neurologists ...because I am so slow in moving with my M.S. I don't go and see her and she says to me: "I'll see you in three months, six months, a year". I ring her secretary if I have a problem, and then she sees me in that week. But you know - diabetes three months check up. I just go down and they check what's happening, of course if you've any problems you just ring up the diabetic liaison sister and she'll pop up and see you. But it is just getting to grips with it.

Diabetes doesn't make me feel more disabled than M.S. though, not really. But again that varies I think it really boils down to the fact that when I feel more disabled it is when I am in the wheelchair and it still goes back to that. If I am on my scooter I'm not disabled. But if someone is pushing me in a wheelchair I am disabled. But the fact that I use a walking stick I think that I have had that for so long and that I have gone from the wheelchair to two walking sticks to one that's just me. It's just me. I think my main thing I find difficulty with M.S. is writing letters. Because I am having to look down and that is where my main area is looking up or looking down, if I turn suddenly to watch something then ...it's not vertigo it is damage done between the brain stem and the solar bowl and it's the pressure builds up in my head and if I'm ever standing up and you suddenly see me go down on my knees I am just down there for about two minutes then it passes and settles down a bit...that's my only problem. But it's like when it happened, that was my neurologist in Reading, I'm afraid he didn't have a very

good bedside manner, bless him! He just said "M.S." and I said what will happen will it get better and he said "No". He said that there is no cure and I said: "What will happen?" and he said: "We don't know". Question mark.

It has settled down again to what it was. I used to get relapses and remissions, on average on every five to seven years. And I think it still stays like that...but how it happened I was hanging my washing out, this was when we lived in Reading and I found this pressure in my head and I felt there was an electric current going down my legs...it's my lower legs that are worse and my two outside fingers are not too bright.... and of course the magic old water works and ...well obviously I thought that was my M.S. and they sent me to an urologist. So off I trotted and they did the X-rays and all sorts and they just put me on tablets but since I started on insulin I am no where near as bad as I was. I am still taking one for that but I found that since I started insulin I am virtually sorted out. So I think it was maybe ten percent M.S. and ninety per cent diabetes. Cos I think really the diabetes is for that I just don't go to the toilet anywhere near as often as before. I get up once in the night and that is it. It's like everything else...They are concerned with the eyes in the diabetic clinic, with blindness.

Do you have problems with your eyes through the M.S.?

Yes, my right eye. That's usually only if I am under pressure. I have never had double vision with it. It's just like a clouding over of the eye. I first came across it when I was watching T.V. and I said to my husband: "Is that the television?"

"No", he said, "it is alright". So I knew it must be my eye, and there is a pain in the back of the eye socket and that doesn't happen all that often. There is a connection between stress and M.S. Most people do get quite bad with stress, a lot of people get depression... I didn't really get depressed. I was lucky at the time, I was in Germany and the dental officers wife lived opposite us and she did physio and she was just marvellous and she was visiting me and we were sitting talking and she said something about me having M.S. and up till then I didn't know I had M.S. no one had ever told me. Question mark question mark. And off course it didn't upset me and I told her I had never been told. But I was on these injections which tend to make you hypo and you look at the world through rosy glasses and you think this is great you know. So that is probably why I never got upset with it. But it's a funny thing cos I suppose it takes away that thing I mean you have a name at the end of it. Because I knew something was wrong from 1969 cos I was in RAF Holton for five weeks, and my eyes were playing up very very slightly and I knew there was something vaguely happening in my legs, but off course it cleared up after a bit, but again I was on these injections and again this marvellous feeling, like being on the booze or something and feeling a bit light headed that sort of thing you know. And it's not too bad but I don't know it's that magic thing that's got a name at the end of it and you just don't know what the hell is wrong with you. But she thought I knew and I didn't. And I suppose people think well, she took it very well, but again it was because of the drugs. There is only one thing I don't get with my M.S. which is fatigue. I get tired like everyone by the end of the night but I have my friend , she used to have to lie down quite frequently for rest, and she could never understand it, you know,

and they reckon there is only about ten per cent....it is the same from the pain angle. I get pain from my M.S. and all the doctors view it as a good sign cos if you've got pain then your myelin sheath hasn't been killed off completely, and it keeps the paralysis level down. The pain relief doctor says the same thing. Again there is only supposed to be about ten per cent of people with M.S. who get pain with it. The antidepressant drug, Nortriptyline...now I am not depressed I said this to them and this is the only thing that works to kill pain in M.S. and because it is only so so mild a form that you are taking if it doesn't do anything on the mild form then it just won't do it. You either take very very small dose or it won't work. But a lot of people when you say you are on antidepressants tend to think 'Oh yeah and it's nothing to do with depression' but they just don't know why it works.

Do you get depressed?

No. I mean I get depressed when things don't go right for me! Like I've been a bit off this week because of this cold and mainly my diabetes has been very irregular but my M.S. not really. I'm one of these, I didn't bring this saying around but "Use it or you lose it" as I always say even the healthiest person if you stuck them in a wheelchair for a week and they stood up, they'd have problems walking. So I reckon keep your muscles as strong and as mobile as possible. And that is what you have to think of. No it doesn't depress me, I have never been really depressed with M.S. or diabetes. Concerned but not depressed.

What about bitter?

No never. Cos I always think well, M.S. why me but you have to think why not me? What is so special about me and then you have to think of people a lot younger than yourself, some of them don't get to the age of five, or they are more disabled or they have already died before school age, so you have to think why not me. You have to view it on that kind of thing. But if it does get to that stage then you have got to get it out of your system. Either have a blazing row or have a damn good cry. Get it out of your system because the longer that stays in that can come back on you and that can make you...and that can make you worse. You have got to get rid of it and again some people just don't know how to cry, you have got to come to terms with it.

How would you advice someone to come to terms with it?

Sit and talk through it with someone else. I know we are all different with M.S. but ...there are supposedly never two of us the same with it. But well, you would join the multiple sclerosis society, and you belong hopefully to a branch near you, and you should have someone there, nine times out of ten they have someone there who has M.S. and talk it through. You can't have someone sitting there saying and you should do this you have just got to talk through and say well do you feel this do you feel that and do you feel that we, this magic we, that we could do this, and talk about it. You have got to talk about your M.S. it will not go away. It is there and you have to face it and say I have got you for the rest of

my life, unless they find a cure, God bless! But you have just got to say I have got this and it is not going to go away. Why get angry with it, accept it. Accepting is not giving in to it. Accepting is saying I will live with it yes, and if I push it and do too much, yes it is going to come back at me. And you also have to accept that you can not compare yourself with some one else with M.S. we are not the same. Don't listen to those who say "Oh I'm in a wheelchair", and don't look at people in wheelchairs, listen to someone like myself that has M.S. for years, but I am not in a wheelchair.

I hate the wheelchair. I would rather push the damn thing than sit in it. I've got a new scooter, my other one was starting to go a bit, not temperamental but I bought that one second hand...this one is second hand, from the Abled Living in York. They have just moved premises again, they were having difficulty with people parking outside now they have there own grounds so what ever you want you can have a drive around on... this one yes but you will find most people have the same thing about the scooter, not just people with M.S. but disabled people, with the scooter you are in control of it, so long as you can use your hand alright and you can press your buttons and things like that, and the top half of your body is O.K. and you can manage. I would advise anyone with a disability to look to scooters. Much better than wheelchairs. But you just have got to keep yourself as active as you possibly can. And just accept the fact that what you have got - just learn to live with it, it will not go away.

Wouldn't an electric wheelchair be as independent as the scooter?

I suppose there is just this thing about the wheelchair because I think what put me off was when we were in Hanover and the physio who was an oldish women she stuck me in this wheelchair, I had been in relapse and she took me upstairs and it was overlooking where all the lads were playing football and I thought she'd only be gone for about ten minutes, half an hour later...she never came back. And there's me sat in this wheelchair and I cried and I thought 'My God, I'm thirty-two years of age and I am sat in this wheelchair what have I got?' And I cried and I think that was what put this fear about the wheelchair and of course Stephanie was brilliant to me. I couldn't even get out of the flat, I was dropping things and she taught me so much and I was very fortunate to have her everyday, five days a week. I mean within six months, she said if you have a relapse you are going to go down for a few days and you have to look for the first signs of coming out of it, and build on it again. Everyday I had to walk and you must remember if you walk five yards one way you have to go five yards back the other way. But I had to build that up and within six seven months I was able to walk half a mile and back again. And that's what I think and I have never ever forgotten what she taught me. I was very fortunate because I wouldn't have got that sort of treatment on the national health. But I will never forget it she gave me so much even though she was the one to tell me I had M.S. But no I don't get uptight about it at all. I have my off days and have a good cry and a curse at it and then think O.K. get it out of your system and the forget about it. It will not go away.

Before you were ill did you know any disabled people?

No. Because my husband being in the forces you don't come across that sort of thing unless you go to one of their hospitals and you only do that if you are ill yourself so, no, never. And of course no one in the family ...my uncle had M.S. but it was never talked about it, I mean he died of it because I remember going to his funeral but it was never mentioned. It was my aunt coming to my parents golden wedding anniversary and she came in and we were home on leave and my walking stick was in the hall way and she said who's is the walking stick? Have you broke a leg? And I said: "No", I said "I've got multiple sclerosis". And she said: "Your uncle Jack had that". But it were never talked about. I have got to admit though that my father and his elder brother were not close. They didn't dislike each other, don't get me wrong, but they just were not close. My sister and I are the same. I think it is something that has run down all the way in my fathers family, but they did not talk to each other.

How is it for you to talk about M.S. with your family now?

Well my father died so there is only my mother and my sister. I don't see them unless I am up there. I talk to my mother on the phone, we go up about every two or three months, but er...my mother talks about it but my sister no. I don't think, well again my sister and I are not close. So we never see each other long enough to sort of talk about that kind of thing. I know if my father had been alive he would not have talked about it. Because I know he used to avoid anybody who was ill. He wouldn't go and visit people in hospital. I think people are frightened. For themselves of what is going to happen to them. I could be

wrong I don't know but...I am not embarrassed by it I sometimes say to my husband: "You don't like pushing me around in a wheelchair do you?" And he said he'd run with me but he didn't like walking pushing. But he hasn't got to do it very often and I sometimes say: "Am I an embarrassment to you?", but it happens so rarely, it is only if we go on holiday that we take the wheelchair with us, and in fact he has got a trailer now for the new car because the scooter will not go in the car, so bless him he got a trailer so if we go anywhere...he won't have to push me. But I don't think he is embarrassed I think it is because we have a thing where my husband will not do anything for me unless I ask him to. And we have always been like that because I have got to be as strong as I possibly can. I don't know how much worse I am going to get, how long it will be before they get a cure for it, how long he is going to live, I mean he could pop off tomorrow or I could pop off tomorrow. So I think it is just me, the way I am. I want to be as strong as I possibly can. That is just me.

I never saw disabled people as different. They were just disabled people. I always wanted to be a nurse anyway so there has never been that...my mother's the same but I am even more so, no I'm very caring nature so I wouldn't be awkward or anything. If anyone fell in the family it would probably be me who went to help them even if it meant I fell down myself when I went forward. That's just me.

Are you active in the M.S. society?

I wouldn't say that I was exactly active in it. I think on the outside the M.S....I

don't think the society does enough. I don't think they realise that a lot of people, when you're younger and just become disabled it's the branch, well that depends on who's heading it, it is all a bit mind boggling if you have just been diagnosed with a disease that is progressive and people go to the society and you see people who are much worse than yourself. It's frightening and I don't know...they all tend to be elderly people and I asked where the younger people were and I got told that after I had been there a few times that they do come but after they come and see all these old people in a bad state they tend to be put off. I do not want to see what I am going to be like in ten, fifteen years time. You find a lot of people do tend to keep away from going. It is off putting seeing people so far advanced with M.S. Also here they all meet in the evening and once these dark nights come in everyone says 'Oh I get sat in front of television and who wants to come out in this weather?'. I have got to admit that no, I don't tend to have as much with it in the darker months. Do have a nice Christmas do though! So that's a bonus! But on the whole that's not bad. They do have a welfare bit and if you can't get out to meet people there is always someone who will pop in to see you. The welfare secretary is good, she has M.S. herself and she is not too bad with it and she has had it a while and you can go forward and be positive about it when you are like that. You don't mind talking about your ups and downs. If you are one of the unfortunate ones and your M.S. is bad from start then you are not as easy to talk about it. There are one or two who go and they just are not at ease with it. It is because they haven't come to terms with it. And some of them never will. It's as simple as that. Because they have been quite bad with it. Everyone's marriage is effected by it. A lot of people get divorced I know two or three that

have. But those like myself who have had it a long time and who gradually get worse with it, unless its for some other reason, it is not M.S. which destroys our marriages. But for some, maybe those that have children, I don't have children, I couldn't have children, I mean maybe that's good. I mean there are other stresses like husbands, job, question mark, question mark! I mean there is a huge question mark hanging over his job now, they're amalgamating, one in York and one in London and a lot of jobs will go. So that is the main strain.

What do you think of the adverts for the M.S. society?

We had a section through on it and I mean I don't know. I think they have got to concentrate on the people who have got it. I think they could give a bit better side view of it, because again it is all this "and this could happen to you and that could happen to you". It's frightening to some people and I agree that they have to do it this way to get the public outside aware of....I mean years ago people didn't know what the hell M.S. was. I think they could give a positive and a negative side of M.S. this could happen, on the hand it could not. I think they must look at the positive and negative side and not just frighten people off and say this will happen because we are not all the same with M.S. and I think at the moment it can be a bit, you know, positive on what could happen, but it might not happen. It's a big fifty fifty. I mean the majority of people with M.S. do not finish up in wheelchairs. I was once told that within ten years I would know if I was going to be in a wheelchair or not. If you are not in wheelchair after ten years you have a milder form of it, so I think you have got to have a more balanced

approach to it. This could happen, on the other hand it might not. But I think if that is the only way to make the public aware I don't know. I think it is very important that they are made aware or otherwise how are we going to get the money. It is only a charity isn't it? I mean we have got to get the money in for research haven't we? It is not just this country M.S. is everywhere. North America, Canada. Australia. It has to be made aware of it and possibly that is the only way...but I think it should be a bit fifty-fifty. This could happen that could happen. It is very individual. But maybe that is the only way to do it I don't know.

Did you watch any of the programmes on television on disability recently?

I saw one of them actually, but to be honest I think they were on Channel 4 and I am not a great watcher of Channel 4. It depends what I am doing. But I did see one yes. I think people have got to be aware of what is happening and I don't know. With other charities people come and put things through other people's doorway and collect them later. They do not do this with M.S. They depend on M.S people themselves and people who deal with the M.S. branches and I sometimes wonder should they not go and put leaflets through like Oxfam do and people like that. On everyone. O.K. they can still have the flag days with people helping out. But I feel we could get a hell of a lot more money if we went to most peoples door. Because it is only if you are out shopping and places that you will see this person with M.S. sat there, and still a lot of people are confused. Because it is a disease. And alot of people are frightened. Then this happens as well, it happened to me on one flag day, this chap did give something and he came back

to me and he said "It's very good of you to sit there for two hours, to do your time like that, it must be awful for you sat in that wheelchair when you can actually walk around". I said "What do you mean I can walk around?" He said "You haven't got M.S. have you?" I said "Yes I have". He thought I was just sat there getting the money. He just thought that the M.S. branch just got normal healthy people sat in wheelchairs pretending to be disabled. I mean I am glad that I can get out of that wheelchair and walk, not a great distance, cos my distance is getting less and less with my M.S. I am lucky now if I can walk a hundred yards but that varies from day to day. I know at the back of me that I am not in there...it doesn't frighten me but I am glad to get out of it. And knowing I am doing my bit but that's it. I still hope in the back of me that it doesn't get to that stage. Maybe in ten years time but I don't know...I can't see a cure in ten years quite honestly. That's in to next century isn't it? I don't know. Again though this AIDS thing, I mean I shouldn't say this but that could lead indirectly towards a cure. I don't know.

Do you think that there is a specific role expected of you.

I think with M.S. people expect you to be more disabled than you are. because they have this picture that with M.S. you are very disabled, in a wheelchair, you can't walk, you could be blind, or you could be this and I think this positive negative approach has got to come out more. Not every one. Not everyone with M.S. gets that bad with it.

Do you think of yourself as a disabled person?

Oh I am disabled. But I am only mildly disabled. That's the way I view it anyway. I am not badly disabled. I am disabled otherwise I would not have a walking stick and I wouldn't have this balance problem and I wouldn't have diabetes. But sat here if you couldn't see my walking stick you wouldn't know I was disabled.

Do you like to be able to pass as not disabled?

It doesn't bother me one way or other to be honest. People will have their opinion of me whether I am standing on my head or sitting down or whatever, I think that is just something. Again if people saw me sat down here now they would just think it was me sitting talking but if people knew they would think Oh Hilary is disabled she has M.S. But I haven't got a great big sticker on me saying I am disabled I have M.S. I have diabetes. I don't know what really happens, it's how people view you. It's just this image you give across when people first meet you, I don't know. I am disabled. I accept the fact that I am disabled but that's not the end of the world. There is other things that go on as well. That's life and you just have to accept it.

So you don't think that you have become a different person since you have become disabled?

To some people it may feel that, it depends on how you view yourself inside. No

life still goes on, it is not the end of the world. I mean I can't dance now! And obviously, I would still be working and I don't know but apart from the things that I can't do physically, I mean mentally I am still the same but physically I am not as good as I was and that is the only difference. Mentally there is no difference. Nothing wrong with my brain. A lot of people tend to think that people with M.S. are slightly more intelligent than average. Whether that is true or not I don't know, but we are led to believe that that is true. So no it is what you think, apart from the fact that I can't walk as far and I can't stand on my head and I have this balance problem, I have to have a shower and I need a hand rail in the shower and a seat so I can sit down in the shower...I mean apart from that...that's it. It's just life, you accept it. Life just goes on. I'm not uptight about it, some people are, I'm not. Occasionally yes, but you have to get it out of your system.

Do you think there should be more positive images of disabled people on...?

Yes I think so. Well it can happen to anyone can't it? Children, adults...I mean like black people are now seen in soap operas, on television...true black people like the Bantu tribe, M.S. does not happen but I mean the fifty seven varieties yes it can happen to them. But there again you come in to this world neither black or white but one of the fifty seven shades in between, unless you are like Micheal Jackson and go whiter and whiter all the time! But the majority of time you are the colour you come in and you can't change it. It's like women live longer than men, are men going to get uptight about that as well! But life is life...it's not the colour of your skin or if you have a disability but what you are like underneath

that matters. I think people should be more aware and we should have equality as able bodied people. The fact that we can't move around and do things doesn't make us any worse does it? We should have the same chances in life.

Do you think it is society that disables people rather than bodies?

I think it is like that yes. I mean the media decide everything, don't need to go no further than what's happened in Maastricht lately. Oh yes it's the general public and the media. Of course you get labelled and that's been happening for years. But I mean you are what you are, it doesn't bother me. I don't mind being labelled disabled. I mean I am disabled. When I was a child an ex little boy friend of mine called me 'four eyes'! But that's it and I turned round and said: "All the better I can see four times as better than you!" Kids can be really nasty though. But, no, it doesn't bother me in the slightest. But I just think that, yes, people should be aware that yes there are disabled people and yes I just think that we should have better rights, that's all. But whether anything will come of that I don't know. The world is the world and that's it. There is a hell of a lot of people worse of than I am, disabled, or with plenty of money they can be worse of than me. But there you are, that's life. You just got to plod on with it.

Alex

I left school at sixteen, didn't bother with 'A'-levels and things, did a couple of 'O'-levels. I left school and went to be a gamekeeper for two years. I worked on the Earl of Araby's estate, Staffordshire. I looked after pheasants, 2,500 acre beat. I used to bring them up. I used to have several pheasants in a pen, collect their eggs, put them in incubators, hatch the things, and be mum and dad to them for about six weeks before I put them in the woods, then rear them up until they were mature and then shoot them , of course. I didn't get to do that very often at all 'cos the gaffers did that. I got a bit bored with that so I went and worked in a factory for about a year, a basic labouring job, then I got bored with that so I joined the Fire Service for two years, and I was incredibly bored with that after two years. You are always waiting for a disaster to happen. (Laughter.) Our job, if we were called if something had gone wrong, so all that happened is that you cleaned your wagon you polished bits and bobs and you just sat around waiting for someone to crash their car or set their house on fire. I didn't think it was a particularly positive thing to do, even though the results of the job were usually quite beneficial, I mean if we helped someone, but waiting to have to help someone isn't particularly good. You get morbid thoughts waiting for a smash on the motorways. I got bored with that so I thought what can I do, and my ambitions were very low, I was at the age when I wanted to get as many women as I possibly could and get drunk all over the place, so I thought why not join the navy. So I joined the mob and went ... I was lucky and achieved some minor ambitions to a greater or lesser extent. I got drunk a lot, yeah, much more than

I do now. I travelled the world which was a great privilege as I really enjoy travelling, learnt to sail. I was quite good at my job, you know. I got promotion pretty quickly, I had seven changes of rank in five years. I joined as a rating, passed out top of my course, er, got what they call a supersonic sailor. I was selected able seaman, which meant that I got six months accelerated promotion, and, er, went through to qualify for SSAB, you had to pass your first promotion exams within six months of joining the ship, which I had done, which was relatively painless, and I got promoted to leading seaman as a killer, as we used to call it in the navy, then, er, within two years to the day of joining, because of my meteoric dive up the ladder they thought I would possibly be good officer material. I was selected for officer training, passed my test and I, er, got a commission, However, if I had stayed where I was, not become an officer, I could have stayed in the navy until I retired and probably would have done, but because I became an officer and hadn't got 'A'-levels and obviously wasn't very clever they decided that, er, they have a basic rule that, er, if you don't have 'A'-levels you can't get on, this was - er, they cut me down from life to nine years, and I said well, if you don't guarantee to give me a job after nine years I'm going. So I handed my notice in there and just disappeared.

I messed around for about a year, alternating periods of unemployment to attempts at assortments of jobs, I did all sorts of things, selling insurance, self-employed builder, building contractor for a while, that was quite successful but lucrative but, er, didn't seem to satisfy something so I went to university. 'Cos I thought it was going to be easier than working, which it turned out to be, and

right towards the end of my, er, first year, I was coming up to my preliminary exams, I had the stroke which slowed me up a little bit. Through the summer term plus all the summer holiday I was basically in bed or in a wheelchair, towards the end of August, and I'd been walking for a few weeks and I thought right that's it, I'm going back to university, not sitting around here. So I really wasn't at all mobile, I could get from A to B, I could just about climb a set of stairs without falling down them. But I thought that nothing was going to induce me to get better faster than having to force myself to look after myself, despite uncertainty of parents and doctors saying do you think you really ought to do this, I just wanted to get straight back.

So you did it against ... ?

Oh, yeah, sod 'em. I wasn't going to sit around in bed. Basically it was getting silly, they were suggesting that perhaps I was being premature, but 'cos of the way the NHS was at the time they weren't prepared to take me in daily to do physiotherapy, and I needed daily, you know, actually daily supervision - that was the only way I was improving. A lot of the movements you do for the physiotherapy need two: somebody else to stretch your arm out ...

So when you had the stroke what happened to you ?

Well, if you draw a line down the middle of my body the left side went totally. All the muscle tone had gone in my face, it was all, you know, hanging down, and I

lost about fifty per cent of my eyesight in both my eyes, the optic nerve which affects that side of ... the vision's gone. I lost the use of my left arm and obviously my left leg, but since then I've learnt, I can walk reasonably well, but my left arm is still naff, it just doesn't work, there's nothing I can do with it, the only time I can control it even is to rest on paper to write with. So that was a bit of a struggle, I had to teach myself to read again, that took me eighteen months because the eyesight distortion meant that I'd read one line, read to the end, when I scanned back I'd miss the beginning of the next line and end up looking into space ...

How did you teach yourself this ?

It was just sitting down and trying it.

Did you get any help with it ?

There wasn't any help to begin with, not really, but I'm a bit self-contained actually and prefer to do these things by myself. I don't like admitting weaknesses to myself or anybody else. I tend to be pretty self reliant and still am.

What disablement have you got now as a result of the stroke ?

About 50% vision and, er, no left arm and very poor balance, I struggle on buses, I can't go on buses 'cos I can't stand up to stop them and things like that, at the

bus stop, so limited transport. I have to go about by taxi and things 'cos that's the only thing I can really control. And I can't walk as far as I'd like to. I was always pretty fit and active - I used to box for the Navy - I was pretty fit. I used to really enjoy physical things - hard work, weight training, digging holes, gardening. Quite a lot of that has gone and I've diverted that into - I think I've probably diverted that into academic energy rather than physical energy.

When you first had the stroke - presumably that was totally unexpected ...

Well, er, I mean the fact that it was a stroke was totally unexpected, yeah, but I didn't know what was going on. I'd had a headache for a fortnight and I'd never had a headache before in my life and my girlfriend kept saying 'Why don't you go to the Doctor's?' but I said they'd only give me bloody aspirin. Or taken me to the dentist ...

So eventually did you pass out or ...

Er, I can't really remember all that clearly, but I'm an early morning person, I was out at about seven o'clock - I was doing my washing in the launderette and I was just walking to take my washing out of the washer and put it in the drier when, er, I just felt I wanted to be sick. I had a cold sweat, you know, and I thought I didn't drink that much last night, you know, and I,er just had to sit down and in walked a mate and he asked if I were all right and I said 'Yeah, of course I am' and he obviously thought that I didn't look alright. He went to fetch the porter,

you know, who wandered in saying 'Are you alright son, what's up?'

Apparently whenever I stood up I was staggering all over the place, I just hadn't got any co-ordination at all. I didn't recognise these symptoms in myself and, er, the porter got the nurse and she was real sharp and stuck pins in me all over and understood immediately what was wrong. So that was it. Took me to Norwich where they also recognised what was wrong but they hadn't got the appropriate equipment to look after me so they stuck me in an ambulance and took me down to Addington. So that started an unusual phase in my life. Before I'd been very active and fit and totally self reliant, and I am more or less now still.

Did you have to learn to be that again?

I don't think I ever lost it, but it's just sheer determination, the way I've always been, but then my parents brought me up to be independent. The only loss of independence is the fact that I use the refectories to eat, you know, I always enjoyed cooking. I used to cook myself but trying to peel a potato with one hand takes an hour. I've got better things to do with my time, I'm not going to waste it cooking. That's the one very recognisable area of restriction. With other things you can just overcome with ingenuity.

So you don't see any break in your life - before you had the stroke and afterwards? You don't see it as a changing point ?

Well, obviously it has changed me in some ways but not in ways you'd expect. I

mean ...

Can you say in what ways it has changed you ?

I didn't know, all, well I think I became a lot more selfish. Yeah, straight away, much more selfish. I got to look after myself and all this sort of business.

Do you think that was as a result of having a fright ?

I don't think so, I think that it was just that, er, there are lots of things that I used to be able to do and now know that I couldn't and didn't want to embarrass myself by being seen to be trying and failing. You know, I just don't like failing. Em, I've just basically never failed anything I've done in my life and I don't intend to start now just because I was ill.

You actually curtail your activities.

I, er, I, er, restrict my activities to those which I am sure of success in, which is a bit unfortunate because one of my best personality traits was that I was always taking risks.

But you were saying that you discharged yourself from hospital and ...

No, I didn't discharge myself from hospital, I discharged myself from home. I'd

been sent home by then.

How did you find the reaction of parents and friends after you had had the stroke ?

On the whole very supportive. I was rather surprised how many people heard about it to start off. The number of people who bothered to travel to see me was quite surprising. But on the whole I'd say that they were pretty supportive in their understanding.

So you wouldn't say there was any difference between the way you relate to friends you've made since you had this stroke and ...

No real difference in the type of people, no.

So the break has come about through the things that you find you can't do?

Yeah. It's just that I no longer do ... I'm the sort of person who, well activities that I got involved in ... like being able to work during the holidays, that has stopped. So I suppose there's actually ... I suppose in some ways it's affected my confidence in certain ... ideas of self confidence about how employable I am for a start. I mean it gets a bit dodgy and that's basically the reason I bothered to carry on and do a Ph.D. It seems to me that a bloke who is now over thirty and, er, recently disabled, bad eyesight, can't drive, he hasn't got much chance of

getting a job. It seemed to me that the thing to do was to continue in my studies and prove that I'm still quite capable despite the fact that, you know, I've got a range of disabilities. I still wouldn't put it on my C.V. that I've had a stroke 'cos there's a lot of people that just wouldn't give you an interview, but if I get into a situation where I can be interviewed then I can make it quite clear.

Did it affect your speech at all ?

No, no, it's the wrong side of my brain fortunately. Otherwise I probably wouldn't have gone back at that stage to university.

You lost some vision, but you can still read the VDU ...

Oh, yeah, but it's not impaired clarity, it's my peripheral vision. Looking at you I can't see the bookcase, for example. I feel it's more dangerous, it's more distorted, if I were in a car with people coming out on the left, you know, I just wouldn't notice them, and even though it's not blurred sight, I've still got pretty crystal clear sight.

Things that you say have changed are particularly to do with confidence in employment and in your own physical ability.

Yeah

Does that in itself affect your confidence?

It does in some respect, it makes me feel more likely to feel nervous in pub situations and things like that. The most disconcerting thing about pub environments is the lack of balance and the fact that I don't have peripheral vision. 'Cos I can be standing there and walk forward and instantaneously someone is standing there in front of me, they just come in from the left hand side and it's difficult to sort of stop in time and correct. So I, er, feel intimidated by the fact that I don't notice what's going on around me so much. I mean, half of that is my own fault as I make a great effort not to show that I am disabled. I try to walk without a limp.

Why's that ?

Well, I want to be treated as a normal person.

Do you think that people treat you differently ...

Well, I that, er, that, er, very rarely in conversation, certainly in looks and appearance.

Is it noticeable to others that you have a naff hand?

Er ... no, because I keep it hidden very well ... but er ... I don't know ... there's

something about .., if you're obviously disabled and you're limping quite heavily or something like that then there's something about the way people look at you. Very different. Even people I've known for a few months in this university still don't know that my left arm doesn't work. But I think that since this happened I taught myself very well to mask various things about myself. I always used to like - to enjoy fighting, you know, go down the pubs and things, scraps all the time, and I used to pride myself that I wouldn't bully anybody, er, because I would pick on people who only wanted to fight me, so I, er, learnt to recognise the situation you had to learn to recognise people's body language very quickly. If you want to be a good fighter you have to fight someone who can't beat you, so you never lose. It's not that you're actually better than them, it's just that you pick your opponents better. So I've learnt body language from a very young age and I stick to that. So I'm, you know, using the old skills to push me along.

Can we return to when you first came out of hospital - how long were you in a wheelchair?

About three months.

And that's when you lived with your parents?

Certain friends of mine used to come and wheel me round the pubs - you know, a bit of a novelty for them.

But you always knew that you were not going to remain in ...

Oh, yeah,yeah. The thing was I never became depressed or even upset about having the stroke. I always knew in my brain that I was going to get better so there wasn't a problem. Why should I get depressed?

Do you know why you had a stroke?

They don,t know, no. It's just some congenital deformity with the blood vessels in the brain which chooses that particular moment to pop, you know. Perhaps they didn't like washing that morning.

You always felt then that you'd get back to normal?

Well, I ... I actually predicted for myself that I would be better than I am already. Er, perhaps youthful enthusiasm or something. But that was the biggest thing, I suppose, I always expected to smash myself up on a motor-bike but I'd never expected my body to let me down. When it did it was a bit of a confidence taker. I had absolute faith in my physical ability and I never expected that to change. I suppose I recognise now that I am, I don't know ... I don't know what word to choose ... it's not vulnerable but, er I'm not invincible and I'm sure I thought I was until I had the stroke.

How old were you when it happened?

Twenty-six.

And how old are you now?

Thirty-one.

How did your family react?

Well, parents were incredibly supportive. My brother and sister were in the limitations. Craig my brother-in-law drove down from Leeds when I was in Cambridge virtually every week just to come and see me. They weren't over protective at all, but Margaret is a nurse anyway so she's seen it all before, she knows how to balance things, and Craig was a copper at the time so he had a similar sort of training, so there was no sort of overbearing pressure. Actually the one person who I rebelled against, or whose attention I resented, was my girlfriend at the time. She was always around. I used to get really irritated by her. I don't know why that was. Don't know what it was, perhaps it was something to do with someone being close to me, seeing me so exposed like that. But, er, my mum and dad were pretty good, you know, they kept the balance as well.

Did your relationship with your girlfriend break up?

Yeah.

Was it long after or was it ...

Oh, well, I'd made my mind up actually to end it before I had the stroke so ... well, it was all a bit of a pity ... she was a student and didn't have any money and I didn't. She used to spend all this bloody money coming down to see me in Cambridge and I was ... I really didn't think that was on, I didn't ... not because of money 'cos I don't measure friendships in terms of money, but that she was taking time out to come and visit me. I just thought, you know, I wasn't giving her anything back. So there was a bit of guilt on my part. So when I did meet her back at university we just discussed it and I said, 'Look, I'm a liability to you, I can't expect you to start looking after me, making sure I don't trip up, banging my head or anything so I think we ought to leave it'. I don't think she was too happy by that decision but it had to be made I think.

I've become much less tolerant since I had the stroke

Less tolerant?

Oh, yeah, much less tolerant. Over all sorts of things. Particularly to do with disability.

Why do you think that is?

Oh, I don't know, I think it's a bit like, well, I can get over it so can you - don't moan at me about your bloody problems. The way things are I really ... I ... I

don't know if these are the right words to say it but I'm much less tolerant of people complaining, I don't like people, you know, 'Oh, I can't do this, I can't ...' any whinging really gets on my nerves.

Do you think that is a direct result of what you've been through?

I really don't know. I don't know. I think perhaps that's a bit of a tenuous thing, but it's something about myself that I know now, notice more about myself now. I know it wasn't there before. But I am much more helpful towards people in practical ways, practical work, you know, I go through peoples work if they ask me to, criticise it where I think it needs it, proof reading and things post-grads didn't do for me when I was an undergrad. So I'm less tolerant of disability but I'm much more prepared to help, whereas before I would have begrudged them the time. Could have been down the pub.

But if I see someone in a wheelchair, if I'm going to think of anything I think 'How's that poor sod going to get down that pavement without a ramp', rather than feeling sorry for them. 'Cos I tend to think any of the sympathy I got never did me any good. I don't think it did. Certainly, er, seeing people around me who were affected, my sister and that, it didn't do me any good. What's the good of somebody feeling sorry for you? I mean, it's nice being able to have a shoulder to cry on, but you don't want it every bloody corner you turn. You know, people should talk to you and find out what you want. That's the main difference, I think. I'm less of a workaholic than I was.

Your career plans haven't changed?

I really don't know. I mean, I basically made the decision to go on to post graduate to prove that I could still do it, you know. Despite the fact that I had been ill. But I think I would have probably wanted to stay on anyway, you know, it's easier than working isn't it? Three more years of it. I thought 'Oh, yeah, I could get some of that. I'm even thinking about doing post doc work already. Nine years of a good thing. I'm not sure if that'll work out yet though. Got to find a project I'm interested enough in doing. That I want to do. I'm not willing to compromise my enjoyment of life just simply to stick around these places.

Frank

I'm twenty-five, I had the accident about four years ago, which has left me paralysed from the stomach down. I'm in a wheelchair. I was on holiday in Scotland, on the Isle of Skye, and I was with a friend and we were driving along a road just enjoying ourselves and as it was a really nice sunny day we had the windows open and my friend threw a cigarette out of the window which flew straight back in on to the back seat, and on the back seat there was a duvet and the lit cigarette started burning on the duvet and my friend sort of let out a shriek and said: "The back of the car's burning", and unfortunately I did the wrong thing. I turned my head and in doing so I must have slightly jogged the wheel because the next thing I knew we were sliding down this ditch at high speed and Bang! That was four years ago, yeah.

What were you doing at the time?

Well, at the time - do you mean work-wise?

Yeah.

I was working on an archaeological site in Canterbury.

Doing what?

I was excavation assistant. That means I was out in the fields, digging up things and sort of recording and planning and things like that.

How long were you in the hospital for?

I was in hospital for about four months, this was all for medical treatment because I was pretty banged up because the car was pretty crumpled up and er...my legs were trapped underneath me. At least that's what I'm told, 'cos I lost consciousness. I had the accident and the next thing I knew I was in hospital. My legs were completely bandaged up. I didn't realise that I was paralysed. I thought my legs were broken, when you are paralysed you can't move your feet, but I didn't realise that straight off, because they were broken and in plaster anyway. I didn't realise that my spine was broken up until about two weeks afterwards. I didn't believe it when they told me. I always thought that it would get better, that it was a temporary thing, like one does in these cases.

Could you go back to the dig?

No, I don't know if you know anything about archaeological digs, but it tends to be temporary contracts, you get hired to, like, do one site and then if there is more work they might take you on for that and you're offered a new contract and so...like by the time I came out of hospital they had finished anyway. Which was quite convenient for the local trust because they didn't owe me anything.

What did you do next?

Well, I spent quite a lot of time in my parents house.

How did your parents accept it?

My parents reacted very badly, I mean, they er...sort of ...like started to do everything for me, especially my mother. I don't have a very good relationship with my mother, she tends to be quite neurotic and protective anyway so that just like, made it even worse.

How long did you spend with your parents?

I spent about a year with my parents in my parents house, getting more and more depressed and more and more angry and I felt completely ineffectual sort of,like, I had to learn to like cope with being in a wheelchair and not playing sports. Having to well... like every time I wanted to go out having people to take me out and er...like having to spend hours and hours explaining to my mum and dad that I'd be O.K. and that nothing would happen to me and er...wanting people to leave me alone and that I could actually sort of like... move my wheelchair and if anyone did leave me alone I could get back. I could zoom around in my chair.

Would you say that your parents pushed you into a role that you were not comfortable with?

Yeah. My Dad less so than my mother. I suppose my Dad tried to take charge in different ways.

What sort of ways?

Well, he encouraged me to do things and think about the future and think about what I would do, But in a sense he was very much trying to impose his view of what I should do on to me which...

Is that very different from how they related to you before?

No it's not very different from how they related to me before but I suppose before I wasn't confined to a wheelchair, I was always sort of...well, I could open the door and go out. I could leave them, I could disappear for however long I wanted. Whereas after...well, it's quite easy to stop a wheelchair, they could just hold me back.

So they physically stopped you?

Sometimes, yeah.

How about your friends at the time?

Well, er... I felt very let down by my friends because they...they felt very

embarrassed and they sort of...I don't think they ever actually got over the embarrassment of me being in a wheelchair and er...I don't have that much contact with most of them now. Because after about six months I sort of realised that the only way that I was going to escape and start afresh was by forcing myself to move away. Which...well...it wasn't an easy decision to make, because there is so much pressure within the family and within your friends to like convince you that you are an invalid and that you can't do things and obviously I had lots of my own doubts as well which...but the thing that helped a lot was going to day centres to get therapy and actually meeting other people in wheelchairs that...well even some of the therapists were in wheelchairs and seemed quite happy, they had cars and could flit around and go away for weekends and some people were talking about going to India and people had travelled and it, and well, I got quite interested in reading about disability, about people being in wheelchairs. There's a really good book...but er I can't remember the name of the author...but anyway it's about this guy who travelled all around the world in a wheelchair, and he's written a travel book about it, made millions and things like that...T.V. shows. Wogan. That was a lot of help because I mean if, well, the way I see it is if they could do it why shouldn't I be able to do it? Something about the day centre...I didn't really like going to the day centre in the beginning. Well I still don't really.

Why is that?

Well it's too much like...well, sort of...disabled people of the world unite and sort of a club where every one is patting each other on the back. I suppose you get an

element of "Oh, I'm lucky to be less disabled than that person down there", which I wasn't too keen on.

So you have very mixed feelings about the day centre?

Yeah, I mean it was a lot of help because it opened up possibilities, it made me realise that I could talk about my disability and find out about disability without embarrassment and without having other people impose their stereotypes on me, and without this feeling of pity that you get from a lot of people, which they try to hide...but once you are disabled you can pick up on other peoples embarrassment.

Do you find other people's embarrassment difficult to cope with?

Difficult to cope with and offensive. I've changed but the change has got nothing to do with the fact that...I don't know...I suppose it's like gender stereotyping, in a wheelchair people impose a whole set of values and attitudes on to me which I don't like.

You say you have changed. In what ways do you think you have changed?

It's as if I were a completely different person, like the person I was before the accident is dead really...died in the accident. A certain element of rebirth I suppose, of greater awareness and also there is a certain amount of optimism

really, I can say that now. I didn't feel that way like in the first two years that followed the accident but...I think I feel probably more at home with myself and more...I accept myself a lot more, I accept my disability and it has made me accept myself. Being disabled has narrowed my choice because it has given me more direction. Before, you know when I was digging in Canterbury, I wasn't sure whether I wanted to go to university or not, I wasn't sure if I wanted to continue digging, doing field archaeology for the next ten years, or whether I wanted to , you know go into academia, things like that. Where as now, obviously, I can't dig anymore because you can't take a wheelchair on site, it wouldn't be very practical, so in a sense that's restricted my possibilities to the sort of more intellectual pursuits, which ultimately is probably a lot better.

You're at university now ?

I'm at university now, yeah. I'm at Bradford studying a B.A. in archaeological sciences.

How have you found being in a wheelchair at university, have there been many problems?

Yes I've had problems. Not really on the social or personal level, main problems are things like access, lack of facilities for disabled people. Lots of stairs and steps and kerbs in the wrong places, no sort of ramps or anything for wheelchairs. Also some of the doors are quite small so it's hard to get through...

So how have you managed ?

Well, I've coped. One copes! The welfare officer and things like that. They try hard but the results aren't much - it's all down to economics. Most universities haven't been designed for coping with disabled people and government cutbacks and things like that means that nothing tends to be done. Sometimes I wake up and I feel down and just don't go to a seminar or a lecture because it's all too tiring. I have to rely quite a lot on friends, not really to get me places but to help me over certain bits, lifting up stairs.

How have you found being in a wheelchair from a social point of view ?

Well at university it's been great because people have never known me before, people have always known me as being in a wheelchair and they quite easily accept that. I think the problem before came because people had known me running about and sort of non disabled. Before I used to be quite a sporty person and my friends were as well, and we used to play a lot of sport together, quite a lot of badminton which contrary to popular misconceptions is quite a strenuous game.

Do you play any sports now ?

Yeah, since I've got to university I've started again. I mean I, sort of for a while, I was quite disparaging towards people who used to be in wheelchairs and go on

marathons and things like that but, well, I used to think that people who were in wheelchairs who did sport were only doing it because they had something to prove and that, you know, why don't they accept that they are in a wheelchair and they can't do sport ? But then I thought that that was a really stupid thing to think. If I wanted to do sport there was no reason why I shouldn't carry on doing sport just because I was in a wheelchair. I played badminton. Obviously if I'm not playing with other people in wheelchairs they have to tone their game down a bit. I've got fairly strong arms from pushing the chair around, I can really rush about. I've got a good social life now, I think what probably helps as well is that I've got a car which gives me a lot of freedom. I mean compared to most students I'm quite lucky to have a car, which means that we often go out on trips down to the Dales and the Moors and things like that. Also it means that as I don't drink very much any more it means that whenever we go out I take the car and can drive my friends back. Since I've become disabled, because I know the physical limitations and I realise that I won't be able to do anything physical, like excavation or something like that, so I'm very much restricted to working in an office or, you know, doing academia.

Can we talk some more about what you said about the person before the accident is dead? Is there no sense of continuation?

Yes and no. I mean there is continuation in that I still feel to a certain extent that I am the same person, but it's more on the level of things like awareness of my place in the world and other peoples place and the way I relate to people and all

that. I'm much more aware of that and, er, it probably made me a lot more tolerant and a lot more understanding, and that represents a fairly drastic change, 'cause like before I questioned things a lot less and now I question things a lot more. So in that sense yes, I have become a completely different person, because there's been this shock of discontinuity - it's been so severe and also the - well, I suppose I am, I have changed, I have become a different person, because the way other people relate to me is completely different, so in that sense yes, we are talking about two different people. Now, for example, if I come into a room I'll immediately be a person in a wheelchair and, yeah, there is a negative element in that. People impose stereotypical attitudes on people who are disabled. But on the other hand it does, well, as soon as I come into a room I am noticed, and people notice me, so I suppose it makes me a point of interest, the fact that I am a person who is disabled. I'm at university, I'm doing things, I've got a car, I'm independent, I've got my own house, I suppose to a certain extent people have a lot more immediate respect for me and for my achievements.

How do you feel people relate to you when you are, for example, in town ?

Well, unfortunately I think they very much see me as sort of like a poor disabled sort of person. They tend to be quite condescending and they are also sort of frightened of me, I mean sort of like going down the street quite happily and people will look at me and immediately look away, and sort of like, for example, you know, I'll be going in a shop and you'll have mother and child and the child will stare at me which is sort of like fine, look at me with interest and the mother

will sort of say don't look at that poor man like that. Which bothers me but I've come to accept it. I suppose being in a wheelchair has made me a lot more socially adept because the onus is on me to fight peoples preconceptions and people are frightened if somebody is different, whether they are blind or in a wheelchair or got any physical deformity. So I've had to, in a sense I've had to... I'm a much more confident person. The onus is on me to make people accept me and make people feel comfortable with me.

Did this take a long time to learn?

Well, it was something that going to the day centre taught me, you know, talking with other disabled people. Sort of like an exchange of information on how to put people at their ease with jokes and things like that. It's in a sense very artificial. The day centre is a little bit like a learning social skills school. I mean, if people feel frightened about me being in a wheelchair they can also sort of walk away or ignore it whereas I'm in a wheelchair, I can't. Physically I'd find it harder to walk away! So I have to tackle the problem head on.

Brad.

I had an accident in '74 in Australia. I was at university, so I finished off the degree I was doing and started working, I've been working for the same organization... I had three months or so in the hospital, which was a bit short, most people have about six months or more, but I wanted to get out as soon as I could. I wanted to return to university or else I would have missed a year.

So you didn't miss any of your course?

No, well it happened in the holidays and well...it was convenient in that way.

How did people react to you? If they had known you for the first year without the wheelchair...

well, it's funny,...most of the people I was in the university with, who I had known for one year and they weren't close friends at that stage but they were all well meaning. I learnt to do all the right things and be well, there were problems like getting around the building and things like that. I don't think people need much motivation to be kind, but they don't know what to do and what is appropriate to do, they don't understand, but I don't know, I didn't understand...it was a bit of a muddle at first there.

So you didn't have any rehabilitation?

No, that was one of the problems. Usually if you break your spine you get a month or two intensive medical care and then two months or so of stabilization. And then at least three months of rehabilitation. But if you've got direction, a goal, you don't really need it. If you're going back to a house, a family home or something, maybe you need it, but if you are independent it works O.K. I think your family suffers a lot more than the person who has the injury. You know they really are upset. It was a bit like a suicide or death in the family. I mean, it was always accepted that I was in a wheelchair but they over reacted, they didn't know how to react. They couldn't handle it at first.

How about your friends?

Well, one friend just couldn't handle it. I didn't see him for the best part of ten years, I think. The story was as I heard it through parents and things, that he couldn't stand the shock and the strain, he was frightened of his own reaction, what he would do. But everyone else seemed O.K. at the time.

How did you react?

That's a very hard one. You're supposed to have answers to this sort of question in every day conversation, but you don't really know, as it is such a gradual thing, it doesn't come and really hit you. It's gradual as one thing comes up and then another...I think you have to have a fatalistic attitude towards life in general.

As you carried on at university could you say it really changed the course of your life?

No it didn't actually. No, it didn't at all. I think it made me more resolute to carry on, but the direction remained the same. I may have had a change after the first year, done something else, but there were just too many things to do at that stage, up ahead after the accident, get back at the university, lots of adjustments to make, too many to make career changes...I could have been better off if I hadn't specialised but done a wider course - it would have been a better career move if I had done landscape architecture than going through a four year specialised course and then specialised later on.

What sort of reactions do you have in general?

Well you get used to them...people look. Well, I suppose you know what I mean - what with you having a guide dog...that's like...like having a wheelchair, a signal of being different. Do people notice the dog and not you?

Definitely.

I don't really react to it, I probably did initially, I guess that hurt. But I just don't worry about it any more. People are not offensive, most people are very helpful and that becomes a nuisance in itself, you know, people trying to help me cross the road and things like that. All you can do is understand what they are saying,

what their feelings are, and just be kind to them. But it really can get too much. You can be treated more like an invalid which is not what you want. I tend to just ignore it, I must admit. Probably rankles inside but I don't react to them, I don't tell people, you know, to leave me alone. It's only a short term thing you don't have to you know, half an hour and both of us will have forgotten about it so, you know, I can't be bothered by it. If people are persistent in talking down to you, well, they are the people you tend to avoid, I guess. But most people don't do that, most people tend to react like...well like it's an initial shock...you know...most of them see the wheelchair first and then the person. But you can appreciate that really, I suppose that's really true.

I realised the first week that I was in hospital that I wasn't going to walk again. I had a whack on the head as well so I was pretty out of it. I was floating a bit at that stage. I realised something was wrong and the doctors are fairly brutal about these sorts of things, so at least the patient knows where he stands - doesn't stand so to speak! At least the doctors I had were...It didn't really drive home, I don't think until I was home. You can't really understand, I don't think, because you think there will be a medical breakthrough in the next couple of years and it will be all sorted out...you don't really understand the mechanics of it at all. You don't understand it, that's all. You know that you are going to be in a wheelchair but you don't understand the ramifications of that. You have got to fight them one by one before you can realise. And all that is...it takes time.

Do you think it has changed you?

It has probably made me more independent I suppose. But I don't know about that anyway 'cos you never know about these things. People...I was only eighteen at the time. I was only an adolescent so you have got to do some growing up anyway. So I don't know if there's a difference or if it's part of my make up. I might have been independent. I like it to not stop me doing things, you know. I don't really want to go climbing Mount Everest but I do active sports like I have always and would have normally done. I've tried scuba diving and parachuting, that sort of thing. So I like to do what's possible but I don't have any burning ambition to prove anything. If I want to do something I try to find a way to do it. There are things that you can't do, it is a limitation, but if there is an opportunity and you want to do it then you try and you sort of work around it.

Do you drive?

Yeah, I'd be lost with out my car. You have got to rely on your own resources. You can't wait until you are given public transport for a wheelchair, you've got to drive. You have got to try and rely on your own resources.

How have you found attitudes and what have you in York?

Well the bureaucracy is pretty inefficient and useless. They just don't understand what is going on. They have half an idea but they try to do things but they don't really know, they are not tuned in to the real sort of problems. If you take them to them they are always friendly but they don't go out of their way or anything.

How do you get around on campus - it's hardly designed with wheelchairs in mind?

Kings Manor, in town is where I go every day. Its a really old building. It's terrible no joy at all. It's only through the help of my friends and colleagues that I am able to cope at all. I think the university could have done a lot of things if they had tried - but it was all a bit too hard for them. As I'm only here for a year I thought that I'd be banging my head against a brick wall to get things changed, but I mean, for example, this stove is on the top of a cupboard and is absolutely useless for someone who is disabled and very dangerous. If I put a hot pan on top and am stirring, not only is it practically out of reach, I can't see the top of the pot, it tumbles down on top of you and if you're that way inclined you'd sue them, the university for a fortune. And I don't think it's good enough. I brought this to their attention earlier on but the bureaucracy is so slack. Things just take forever to happen.

Being in a wheelchair has been no problem as far as socialising goes. People just get used to the fact. The real pain as far as being in a wheelchair at York is physical, just the logistics of getting around the place. I applied and was accepted for this course a year before - in the previous academic year, but there were so many problems to work out that it just didn't happen till this year, and so I came here knowing there were a lot of problems. I came here with the prospect of having a dictaphone in the lectures and listening to them outside. That's what it boiled down to. It seemed I'd have little contact with the tutors or faculty but I still thought it was worthwhile making the trip, but in fact I've done 99.9 per

cent of the stuff. That's the same as all the students on the course.

Is there any difference between how people act towards you in England and how they do in Australia.

That's a hard one. Probably not really, no. There's not such a high profile for the disabled in England as there is in Australia and America. I think there is much more awareness of people in wheelchairs wandering around the streets and things - there's a lot more ramps in public buildings and taxis with wide doors and all those sorts of things. So people are much more aware of it, I think, the ordinary person in the street knows more about it than the same sort of person in England. Human nature is the same, though, and people react just as easy to the problem here as they do there, I mean there's not the same two cultures anywhere but I think our two cultures are pretty close. Go to Japan and you're in trouble. They don't talk to you in Japan. I was travelling with a friend and whenever we were in a shop or something the person in the shop would always talk to the person I was travelling with, over my shoulder, and miss me out. They must have thought I was an imbecile or something of that sort.

Has that ever happened here?

No nothing like that.

What about relationships with women?

Lots of friends. There's been a few possibilities but I haven't been very interested in them. The two people have to be compatible themselves as well as sort of getting adjusted to wheelchairs and other sort of things. You've got to find the right person. I mean, you've got to find someone who'll accept the disability plus you have to find the right person for yourself. I think on adding up the numbers the odds are against you. I think my parents are waiting. But my father was driving the car at the time of the accident so he was culpable, so he has little problem. I think he had more problems in adjusting than I did. My mother got used to it but she was heavily affected.

Do you have brothers and sisters?

Yeah, a few of them - an older sister and a younger sister, a younger brother. We're quite a close family really. They've got used to it now. We always see each other and talk to each other. I'm the only unmarried one now. My brother got engaged at Christmas time, and a couple of years before that the other two went, so yeah the pressure's on. You get to feel the odd man out when you're sort of the third person in a group and you sort of think ... it's a difficulty, really, but you've just got to ... it makes things easy for you in some ways 'cos you can just turn up without a major song and dance ... you're not descending on someone en masse. But you really are the odd man out, the odd person out. In a lot of cases, especially when you get to my age or a bit younger ...

How old are you?

Thirty-three. Everyone's married and everyone's got a family, everyone's going through the divorce courts and getting a second family to start off and I'm still left over.

Paul

My wife and I were out in the Lake District, on holiday, walking. It was a February and we were half way through this particular walk, and for no reason at all my right leg started dragging. I had to make a conscious effort to make it stride forward. And then it went off and I thought it's just one of those things so you know ... then two or three weeks later it came back again and went off again. I didn't think any more about it but the third time that I experienced it I went to ...thought I'd better go to the doctors about this. I was with BUPA at the time so I could go immediately and I went straight to a specialist about this and he gave me this going over and all the treatment. I had to go to another hospital for my eyes etc. etc. all sorts of different tests. I didn't hear anything for three months and I had no recurrence of this leg trouble, and then I had a telephone call from this specialist - would I go and see him on the Monday morning in his private residence where he had his own surgery you see. So I went there, Rosemary went with me, and he said "I'm sorry, Mr Stevens, you've got multiple sclerosis". To me that was just a word. It didn't mean anything, sort of thing you know so I can remember now saying to him "Oh is it terminal?" And he sort of laughed. I says "Look Mr Bright, I'm paying you - don't you laugh at me because I'm asking you questions in my ignorance. Just tell me." "I don't mean to be rude, he says,"that's the first time I've been asked that". So then he explained to me what would happen. He said my right sides affected and he said there will arrive a period, couldn't tell how long it would be, when I've got to stop work, and when I have er am not able to walk without assistance. So I carried on work but then five

years ago I stopped work because my movement was getting poor and my offices were upstairs above Lloyds Bank and I couldn't get upstairs sort of thing so I just had to pack up. I did work from here for a little while, but it's not successful. So I stopped work and then since then I've had a life of Riley! I can't get about but having said I can't get about I've got an electric buggy that I keep outside. I've got my wheelchair here and I can get out to my buggy, out there, and I get on that and I'm gone, you know. So I er knock about with another lad that has M.S. and he has an electric buggy as well and so we we're great pals and the drawing together factor has been M.S. because his path and mine, although we both live here never crossed. I was a sales director and he was a lorry driver. But that doesn't mean anything. When you're disabled that means nothing. What you've got means nothing, as you well know, so we just have a good life together and enjoy ourselves. We go all over the place, we write for the local paper, and I think that's you know...Generally speaking we have a good rapport with the people in town, although yesterday morning I had a nasty experience. I was, sometimes on this electric machine of mine we ride on the footpath, and I was on the footpath and a youth, who is one of the town roughs, came diving out of the paper shop and ran into me. And I got a mouthful of abuse from him and I'm afraid I lost my temper with him and I said you just come close enough my friend, cos I always carry a walking stick on the car, on the machine, and I said I'll give you a bloody good hiding. But of course I've heard it all before and off he went sort of thing, but er the words he called me I'm not prepared to repeat - he called me a so and soing spastic you know, which hurt as you can well imagine but anyway I'm over that now so.

I've lived here twenty-four years. Generally speaking I've found that people initially had the feeling of, shall we say sorrow, that you were like you are. But having once got used to you the majority of them don't treat you any differently to what they are. But then I think, like all things in life, you get out of life what you are prepared to put in it. So that's my experience with people. And that experience I had yesterday morning was the only bad experience I have had with anybody. I'm still a member of golf club, I used to play there every week, in fact I used to play so much that at this time of the year my wife was a golf widow. But I still go on a Saturday morning, still meet the fellows I used to play with but now of course I can't play but we sit and have a pot of tea and a natter, but I've got a golf buggy and when the weathers anything like I go out with them. As I say, this is my experience that you get out of life what you are prepared to put into it. It's no good sitting back feeling sorry for yourself, you know because people just get out of your way. They say "Oh Christ mind here's the moaner again". That's been my experience.

For about eighteen months I was very very angry about it. You tend to think why me sort of thing, but eh, my wife helped me to pull myself together. In fact she is my right arm and right leg sort of thing. She is a wonderful women for whom no praise is too high sort of thing. And she told me she said: "You know love, you're going to have to pull yourself together you can't go through life like this." And all the anger was directed in here, there was a sort of a face on out there, but not in here. I was emotionally wrong in here. But then as I say, Rosemary pulled me together and from that day on, well, we do have a super relationship and...er.

Do you think that your relationship has changed?

I think perhaps it's made me a less selfish person. If that's what you would call being changed. Yes I would. Before I had M.S, properly I used to say we'll do this, we'll do that, without a great deal of consideration for her wishes, but now I stop and consider. We're still...I stopped driving, I don't drive because my reactions aren't anything as they should be for driving, so what we do, we go out as I say regularly, and I say to her what would you like to do now, or where would you like to go, is there anything you'd like to see, would you like to go to a theatre or wherever. But of course we've always got to take into account the facilities that are available. We have what we call an Access group here, it's a nation-wide thing whereby disabled people who are unable to gain access into certain buildings in town and I belong to the local access group and we are chipping away, like water dripping on a stone. It's not a process where everybody welcomes you with open arms sort of thing. Because generally speaking it means they are going to have to spend cash. So that's one of the things I do. I got involved about nine months ago. It was new to this district and I was on the ground floor. My pal who I knock about with, he's stood for the town elections the last time, and was voted as a town councillor so... a lady said to me the other day...it was his physiotherapist she was down...we go to the day centre every Wednesday and spend the day there, have lunch there, and do our own thing in the afternoon, sort of thing. But the lady physiotherapist was there and she said to me, she showed me a paper and it were a thing from the press at York about who won and she said: "Don't you think this is wonderful?" I said "No, not

particularly, why?" "Oh," she said, "I do I think it's really wonderful that he's made the effort and succeeded in becoming a town councillor". But to me this is just lip service by the Evening Press. But he has put himself out to do good for other people. She says: "Yes, yes I see what you mean now".

Has your social circle changed quite a lot?

No. No. I have a pal that lives across the road who is seventy years old, but he's as fit as a butchers dog and he goes out with us, wherever we go Albert walks with us. As to social circle, no. I still have pals at the golf club. Peter's social circle and my social circle cross occasionally but only on the parameter of socialness. He's pleasant to them and I'm pleasant to them but we don't mix, eh, and that's not from a snobbish point of view it's just from a, can I say we don't mix point of view. You know we've nothing in common, as it were.

I never had any counselling, and I don't think it would have helped. If that sounds rather pig headed, for want of a better word, er I don't mean it to, but I cannot see where anybody counselling me would help particularly cos I'm a very strong personality, and at the end of the day I would have still done what I wanted to. At the day centre we are the only two there who have M.S. on that particular day. We are perhaps the eldest two there on that particular day, because Wednesday is the day that younger people go and we find that with our experience of life we are able to help, and only verbally, and advice verbally, the younger parts, who are say, on our table or who come to us for advice. It's quite amazing the number of people who come to us for advice. From political problems, financial problems,

health problems and things like this. Now where we're not experts, and we never try to give them advice, we point them in the right direction, who to see, or what type of questions to ask sort of thing, but we don't try to give people advice from that point of view.

My life certainly did take a different course since I got M.S. As I say I had this eighteen month period where I was very very angry and very very bitter, just occasionally now one does get bitter about it, but of course it's so much easier now to say we've got a good life so why should we be like this. So er no I don't think there's anything particular in this . I mean before I had M.S. I was a great sportsman, I played soccer for England's schoolboys, I played Yorkshire League cricket, but golf was my abiding passion and I don't feel bitter about not being able to do any of those things. I'm still involved in those things but from a spectator point of view, because I've reached that age in life, now I'm fifty five now, so I've reached that age in life where the taking part, in golf certainly I could have kept on, but not to the standard. I played to a fairly competent standard sort of thing. But as you get older things go backward as you well understand. Certainly in the three games, soccer I couldn't participate in, but I refereed well, but then you're too old at forty seven, why that arbitrary age I don't know - I dare say I could have played cricket but I wanted to stop playing cricket when I started playing golf, which I did do. Golf you can play ad infinitum because the handicap system is such that you as a high handicapper can play with a low handicap. And the system works.

How do you view the future?

Well, no plans for the future. I don't make plans for the future anymore, simply because of having M.S. I take each day as it comes and we play each day by ear, as it happens, there are certain, shall we say factors of disability that, er if you can accept them you can get by. Now eventually I learnt to accept them, as did Peter, and Peter was just as angry as I used to be and then as I say we met up one day, his friend said to me, because I had an electric machine at the time, because financially we were fairly sound, em, and his pal met up with me, the group of local people, The Lions etc had bought Peter a machine and they said could he come out with me. I said, "By all means I would welcome his company." He said, "Oh good, you know where he lives?" "Yes I do," I said, "but he's got to make the initial effort himself to come out on his own, let people see him on an electric machine, out." And that was the most difficult thing I ever had to do was to go out myself on the electric machine. I remember when I left here at ten O'clock one morning to go to the bank, and the bank is, from here, half a mile, and I finally got there at twelve thirty. People stopping you and talking to you, asking you how you were, you know. Well it was a very very nice gesture on everybody's part, and this is what I said to John, I said: "Peter has got to make the initial effort himself," I said, "he will be surprised how he is welcomed back into the community." And he was. You can understand this then, in a wheelchair I feel disabled because I'm controlled by somebody else pushing it, but on the electric buggy I'm as free as a bird. I can go where I want, at whatever speed I want to go at, in the legal limit sort of thing, which is as fast as the machines will go, believe me they're flat out at eight mile an hour, so on that I don't feel disabled. Sat here I do feel disabled because I am, well, I moved my walking frame when

you came in, I didn't want you to crash into it, I can't get up without that, I'm non operational without that, it helps me get up to plonk myself in the chair and then I can get about the house. I've just had an extension built onto the house with a downstairs bathroom and a downstairs bedroom so we're now more or less on one level, whereas before we got a stair lift in and that enabled me to go upstairs and use the bathroom etc. but this will make things much easier for Rosemary when we are all on one level, when I want to go to bed I can get into the chair, open the door and I can go to bed. Without having to worry about her, sort of, well as I said to you she's my arms and legs. So now adays it's just that little bit better, makes life more easy for her. We have a lady cleaner that comes in on a Friday, she's been in this morning and she does all the cleaning in the house, does a good job and then Rosemary will go round...I also wear an alarm, you see if I fall, which I do occasionally, I can't get back up again, but I press this and they can hear me and they can hear me from where ever I am and they know I'm in trouble and they send the ambulance men round to pick me up and dust me down, and of course they stand at the door and say: "Bloody hell Paul you've been at the whisky again!" But that gives me a lot of confidence you see knowing that I'm not laid there because I did have the experience before I got this in that I laid there once for four hours upstairs, not frightened, unnerving as opposed to frightened. It was one Saturday morning, Rosemary had gone to York shopping and I'd been upstairs to the bathroom as I was coming down I went my length and that was it.

Did you get your electric machine shortly after you could no longer walk?

Yes. Yes I did and it was given to me by a very dear old gentleman who I used to play golf with. His wife had had a heart attack and she'd died and he had had this at home and he rang me up one day and he said: "I want you to have this." I said: "Well Sandy I'll pay you for it." "You will not" he says, "mention money and you won't get it." So the golf professional, who's a decent sort of a fellow and who I'm friendly with, him and his wife brought it through for me, and that was when I achieved my independence again. But since then I gave that one away to the Lions, who have passed it on to somebody, I don't know who, and I bought this one new, because this is the sort of super doopah model I've got now.

Do you go out in the wheelchair at all?

I don't go outside in it, no. Only like Sunday night we're going out for a meal and then I've got to use it. Obviously the electric machine is too big to take into a restaurant. I think that people who don't know me, just occasionally you can sense the pitying look, when you're in a wheelchair, but I think they're embarrassed because they are not quite sure how to approach you, instead of treating you as a normal person. Like the locals round here, I mean it's not big enough to get lost in, they all know us and treat us as we are, with the exception of, as I say that so and so yesterday morning, but you know that's a thing that happens whoever you are. No worries, no worries.

Do you feel that your body has let you down?

No. No. And I'll tell you why, because I've had a lot of pleasure out of my body from a sports point of view, a physical point of view, sex wise, er it never let me down when I worked and things like that. I was a company director for a London company sort of thing and people often say to me, "You know I can never understand you Paul". And I say, "Why"? "Why do you live in a place like this, one of a block of four, a terrace, instead of a big posh house up the mile?" "I like living here." I say that I can see all that goes around me, but if I lived up there there'd be nothing, So I said I suit it here, the only thing I will not tolerate from people when we're out on the electric machines, and Peters the same as me, it's quite amazing the number of people who stand in front of you and who say I've got this wrong with me, I've got that wrong with me. I say, don't tell me I don't want to know and I go away. I leave it you know. If that's rude well then it's rude. But you see for the last, not last year but for twelve years previously we'd been to California on holiday you see, my cousin lives there, her husband and I are very great friends, so we talk to each other on tape instead of writing to each other, I find tapes much more expressive as opposed to the written word, sort of thing.

How did other members of your family react to you getting M.S.?

I don't think my mother has accepted it yet, mind you she's eighty. And she's a diabetic so perhaps that's understandable. I don't think my brother, who's younger than me will accept that I can't walk. And I don't know why. He has never said as much but it's just a sort of a feeling between brothers that I feel that he

doesn't accept it you know. Sometimes he'll go to any lengths not to mention it, and I say to him: "Jeff it's not a dirty word you know." "I don't want to talk about it" And this kind of thing you know. And I said if you get near me you won't get it. We get invited up to the local comprehensive school to speak to the kids up there, and the headmaster will give us a ring and ask us to speak to a certain class. We talk about anything. We ad lib., as opposed to being stereotyped, we tell them about our various experiences in life, how we got M.S. but we don't stress M.S. They all know now that by touching us they won't catch anything. The children are super. You see kids are not evil, its other people that make kids evil. Or that's what we find anyway. Certainly that's what I find. One of the things I felt quite angry about was when I had to stop work, because I had a good job as a company director, and I had very good money. Fortunately Rosemary and I spent a little saved a little, so we are not on our beam end sort of thing and if we want to do anything, within reason, we can do it. But unfortunately what the government pays out is peanuts, and yesterday would you believe, my new pension book came, but it were twenty seven pound lower than it should be. So Rosemary rang the DHSS and said what was the game like, and the girl said oh dear they'd left my attendance allowance off. Last week I received a tax form, correct name and address, correct national insurance number, they had me down as a motor mechanic, on sixteen thousand pounds a year, plus fifteen hundred pound a year as a part time window cleaner. Well, I didn't believe this, I rang them up, I said "Are you bloody crazy?" "What's the matter?" I told them. I said: "I've not worked for five years, my wife claims for me, I don't claim for my wife." "Oh we'll have to look at it," they say. I stopped working because the building was unsuitable,

with M.S. you get tired very quickly and so this was another reason sort of thing. You could do a couple hours and then you wanted an hours sleep sort of thing and so it was more convenient that I finished. For the company as well as for me.

Did this make you angry?

Yes it did because, as I say I was sales director there, I had a very good job, good money, had a good car etc. etc. it well, it just made you feel a little bit more useless for want of a better word. I felt useless a lot of the time, because you weren't able to do anything, not able to earn your own keep and that sort of thing, which had always been very very important to me. It is very important for a man to be able to maintain his own standard of living and his wife's. You see Rosemary goes out to work five days a week, she leaves here at ten past eight on a morning, and she gets back about five. She runs an office, but I feel beholden to her to a certain degree which I don't like doing because she never had to do that sort of thing you know.

Do you feel less of a man?

Well I think women can still look attractive, made-up nicely, hair done nicely, dressed nicely in a wheelchair. I don't think there's any reason whatsoever why a women shouldn't look as feminine as a women should look. You look feminine, you know, you can't look in a mirror and say well this wants doing that wants doing, but instinctively you know. Would you agree?

Umm. How do you feel about being disabled now?

I don't think about it any longer. It's just a fact of life, that I've had to come to terms with eventually and I've now come to terms with and as long as people treat me as I am, that's all I ask.

Do you think it is easier living in a small town?

Yes I think it is. I think it would be very very difficult in a place like York. But in a small community like this, I mean there's a bus just gone by, and the bus driver he always gives us a wave, that kind of thing you know. Things like that start to mean something to you eventually and they mean more to you as a disabled person than to an ordinary working fellow. He would have said there's a bus gone by so what? But now that bus is controlled by another person who is doing his best to make you feel that you're part of the community. I find it very important anyway. It is super living here. I go to the young disabled unit three times a year for respite care, it gives Rosemary a break and she can get on with her life for a fortnight and I know some nice people in there as I say, she can get on with her life, she'll have her pals round or what ever you women do sort of thing, but er - there's Albert just waving to me, we call him our minder, yes we do, every day except Friday he comes out with us and he always sees that we're in O.K. He doesn't help us unless we ask for help, he doesn't intrude, but he's there if we need help. And he is such a reliable man. We go for miles. He borrows my wife's bicycle so we've all got wheels of a kind.

Can you make sense of what's happened to you in anyway?

No. Let me put it this way. I would think the man upstairs has ordained that it shall happen. Now I go to chapel every week, I get a great deal of comfort out of chapel, not from a particularly religious point of view but from a people point of view. Super super people. But there again I went to chapel before I had M.S. I don't explain it in terms of God, that's just a thought that I keep privately in there. No I think in this life it's a case of que sera sera, what will be will be, you know. You didn't ask to go blind, I didn't ask to get M.S. but as I say, it's like when you die, the fellow up there closes the page on you, it's time to go and that's one of my philosophies on disability and not being able to do this or that. What will be will be.

Are you ever envious of people who...

Yes I am. On the golf course especially. Yeah. Although like last night I went down to cricket, there was a big cricket match on down here and I went on down at six, it was nearly ten when I got back! Rosemary doing her paces! But we have a good relationship, she's a wonderful woman as far as I'm concerned and as far as a lot of other people are concerned. Funnily enough I was talking to her I think it was one night earlier on this week, I said you never tell me if you've got any problems these days, she said well I think you've got enough problems without listening to mine. I says that's untrue, we've all got them and if we can share them you'll often find a common solution that you find acceptable whereas

my idea of solving it is different to yours but there may be some bones in mine you can pick out and bones in yours you can put together and it's a better solution in total. She said she hadn't thought of it in that way.

Do you think that people try to shelter you from...

I think they did initially, I don't think they do now. I think they did originally but I don't think they do now as I'm a strong personality and if I find this happening I tend to growl a bit. You know because from my neck upwards I've got a perfectly good head base on me, one that I'm able to use, a voice that I'm able to speak with and a brain box that's quite adequate. The only problem I have is a mobility problem. But I never feel like I'm trapped in my body as I've had so much pleasure out of my body. Certainly from a sports point of view and from a works point of view because I mean I was made a company director when I was 39 which isn't a bad age to reach that sort of pinnacle for want of a better word, so I don't feel bitter about that. I get angry with myself sometimes because I can't do things but then I think to myself poor old so and so died last week, wouldn't he like to be where you are! We can all find someone a hell of a lot worse of than we are.

Do you find yourself thinking or talking in terms of "before I had M.S.?"

No.No I don't. I never go back to that life. I live this life as it is now. This is where we are. Occasionally I might think it, sometimes when I can't get to sleep

I play a super round of golf in my mind, but that's all you know, I don't try and go back. I think all you would achieve is a sense of misery for yourself.

Rachel.

I broke my back in a car accident, just under a year ago now, a year ago on Thursday. So it's not been very long at all. I went to the local hospital and then I was transferred to a spinal injuries centre. I went there and I was there for ten months and I've just come back here. I was at my end of my second year at university, so I was where I am now, in my second year. I came back last term to get orientated again, and then this term I've started work. So it wasn't so bad really, it could have been a lot worse. I am, well I should be paralysed from just about where my belly button is down, with no feeling and no movement but I'm incomplete. I've got feeling down to my hips and down to my knee on my left leg, and quite a lot of movement in my left leg, and movement and feeling at the back of my right leg at the moment. It's very...well they say two years at least for improvement, you know if you've got something to start with, and for the rest of your life you can improve as well. So I was very lucky, I mean it depends how severe the break is, well not the break the spinal cord break. It happened on the A64 just on the way to Scarborough. I knew I had broken my back when I was on the grass outside. You know how you don't know these things because I had never broken my back before! So I don't know why I knew, but I just did know that I had broken my back. And then when I asked the ambulance men they just said "Well let's just hope it's not that serious love." But he came to see me later in hospital, and he said I had this massive lump sticking out of my back. It was...he didn't know what to say, but I knew I had, I was, in that respect I was alright. When you know straight away it's less of a shock isn't it?

How did you find the whole medical experience?

I didn't find it that bad actually. The ward where I was was very open and very out going. It's a lot different from, if you have ever been to hospital just on a normal ward. It is very much different. People can sit around and smoke and chat and go to bed when you want and come in drunk and well you know it's very very lax. I finally got quite frustrated with doctors and things. Well one of the doctors was really nice, when I first got there. He was the houseman, and he used to come and chat to me when he was about to go off duty, and ask how I was and all. This was when I was on bed rest for twelve weeks when I first got there. And then the two consultants...one was nice and you could chat to him but you didn't feel like you were getting anywhere. The other one you just couldn't make any progress with at all. So I tended to go to the houseman or a sister or charge nurse to try and get anything sorted out. I found it quite frustrating at times. Especially because I had an operation on my back at the first hospital and after the operation everything was fine and three or four weeks later the top of the rod started bending backwards and this was causing me quite a lot of pain. And still three months later they hadn't done anything about it and I was in agony. I couldn't do my walking, I couldn't do my physio or anything. That really frustrated me and I just wanted to leave and get out but after I had my second operation I was alright. You just sort of carried on. There wasn't any counselling or anything. Unless you looked very upset, the nurses would come and chat with you, but there was no formal counselling process that you go through. But physio is very good.

Did you feel that counselling should have been available for you?

Yes. I don't know if I felt I needed it, but I know I did, Looking back and what I've gone through since I came back here. All the problems of being aware of yourself and that sort of thing. You need to go through it as soon as you can, as soon as you are able to because otherwise it just weighs you down. I think there should be some sort of...like your physio you start off slowly and then you build up to all the issues which are very personal and you perhaps wouldn't have talked about before. But you need to get it all over with and discussed.

How did your parents manage?

They coped very well. To me they seemed alright to me all the time. I mean I know they were upset and there was times when I upset them and we would all cry, but they coped while I was around very well. But I don't know how they coped when I wasn't there. I know they were very upset and still, you know, it upsets them but I think they are coming to terms with things. Because I can walk quite well, which makes a lot of difference. I know some people in wheelchairs who can walk a bit prefer to stay in their wheelchairs because crutches and callipers look so horrible. But I prefer to be walking, it has to be said, I know it's a funny attitude...well I don't know if it's funny but I do prefer to be walking because I am still young and it seems I'm too young to resign myself to my wheelchair when I can walk, well at least four hundred yards. I mean I never push myself further than that yet, but I mean that is quite a long way. I mean I can go

from here to Derwent and back. Or sometimes I'll wheel to Derwent and then walk in. It's however I feel. I mean sometimes I'm too tired but you do get...I mean it is tiring. The problem is that I can't walk and carry things, If I could walk and carry things then it would be completely different but... you know just with work...But I do prefer to walk ...I mean it does look a bit peculiar. People think I have broken my leg, because I have to keep this one straight as I have a long calliper on it, but this one only has a little half calliper on it so you can't tell...Medically it is better for me to walk and I always keep that in my mind. The more I walk and the more I do it then if there is ever a cure, which isn't completely impossible these days, if I haven't been walking I can't because my bones would just collapse if I stood up, so I've got to keep walking for that, And I like to be stood up, I like ...I just feel I look better when I'm stood up, even though my leg looks a bit bent. I feel better in myself walking. So...I suppose it's all part of my image.

How have you found friends are reacting?

I've been really lucky because I have come back to where I had friends. But they've been fine. Everybody has been great. Nobody has been over caring, or over friendly, but I know that they are thinking about it. When we go out ...sometimes they go somewhere where it is a bit awkward and I say "Well I don't feel like it". I never say "I can't go because of...the steps or whatever, because I just don't like...it's not fair to say that to people. But on the whole...I mean I go out quite often. In fact most nights I go out so...And people are really

helpful...they'll always help me stand up, which is what I have difficulty with, But...well I think I would have found it more difficult going to another university. You know where I didn't know anybody.

How about reactions from people you don't know - the general public?

I'm not sure. I don't think I've had a bad reaction from anybody. I've never...but I don't know what is going through people's minds when they look at me in a wheelchair. I noticed it really for the first time when I started a new course this term and I didn't know anyone in the group, and I don't know if any one knows about me having the accident, but I didn't think they did. And it was quite strange for the first time being with people who had never known me before, when I could walk normally. But it seemed alright, people chatted and things. People who I knew before know it's an accident and people who don't know, don't know what it is and so there is a ...in the back of their minds they don't know what's wrong with you and don't like to ask and they are not sure what you can do and what you can't do. Of offending you...They don't know that I laugh half the time about the things that I can and can't do and make jokes about it. There are limitations on the relationship before you start and until you tell everybody what is wrong with you and that it is not as bad and not as depressing as they might think. I think people are....well I know I would be...people are afraid of asking because they don't want to offend people. I have a car which gives me lots of mobility, I drive to the local pub quite often which is neat, but I couldn't go in to town or anything unless I got a taxi or a cab - it's too far. But it is much better - much

more freedom. I got it two days before I came back to university, and I was really nervous as I hadn't driven for ages and it was quite hard but you know, I got used to it quite quickly and it gives me a break now. Getting around campus I find O.K. I know people do find it difficult, but I can do wheelies and get up and down curbs luckily. I think most places are O.K. Obviously it's impossible to go upstairs. They just put my tutorials and lectures on the ground floor, but I mean I'm in the room I used to go in to in my first year so I don't think they have had much rearranging to do really. A lot of the English rooms are downstairs in Langwith, so...the only problem, is that both my departments are upstairs so ...I can walk upstairs but it is tiring that by the time I get there I just don't want to be bothered with anything. The only thing I think it excludes me from is going to visit my friends. You know I can't think Oh I'll go and see Dan, he lives across the road cos he lives upstairs, and if he is not there by the time I have got over there you know, it's such a hassle so I tend not to go visiting people as much as I would have done. I mean it stops spontaneity. That irritates me. It is one of the greatest irritations that I can't just think Oh I'll go and do something because I have to make sure I have got my callipers, my crutches, go out, get in my car, or get in my wheelchair...it's such a ...being a person who before was never organised, having to be organised now is killing me!

You're still doing the same degree as you were doing before, but have your long term plans changed?

Oh yes definitely. I was going to teach, but I am not any more. I want to teach

"A" level, it wouldn't have been so bad if I had wanted to teach degree level, but "A" level, I mean there is no choice of school where the facilities would be O.K. if you know what I mean. All the schools that I know have got steps and not ramps and classes upstairs and you know there is a big difficulty with that sort of thing so I wouldn't do that any more. Though I mean it wasn't the only thing that I wanted to do, there are other things, so I am not particularly bothered. Sometime I get a bit fed up because I really did want to teach "A" level but I'm thinking of going into doing research for television and that is quite an exciting thing so I'm quite looking forward to sorting that out. So it hasn't depressed me completely but on the other hand I would have preferred to do what I wanted to do originally.

Do you think you feel any bitterness?

No. Not at all. Sometimes I think I wish it hadn't happened to me, but I don't ever wish that it had happened to somebody else instead of me. I'm glad it happened to me instead of somebody else, if you know what I mean, because I know that I am coping with it vaguely well. Where as other people I think perhaps they wouldn't have done. You know I'd rather be the one who had to put up with it than somebody else, anyway because I don't like other people to be upset. I'd rather...does that make sense?

My wheelchair is very sporty. A lot of people who play a lot of sports use these chairs, it folds up and the wheels come off, so It's a sporty image. I do quite a bit

of fencing and archery and I swim. I don't play basket ball which is the standard thing to do if you are in a wheelchair. I used to go to fitness regularly, and I used to play badminton an awful lot and run, which obviously I can't do now. I miss playing badminton a lot because I liked it a lot. I still can play in my wheelchair but it's not quite the same. I miss, actually feeling really tired from doing some activity, because you don't get the same sort...you just get lethargic tired now. Before when you have done something really energetic and sit down and you start glowing you feel great, don't you? It's not the same when I get tired now from walking, I think I miss the exhilaration of doing something quickly. I think that that's part of the problem. I mean my walking will never get that fast anyway. But hopefully it will improve but I will never be able to jog around.

What about relationships with men?

Before my accident and after my accident I had a boyfriend who I had been going out with for three years. But when I came back to university we sort of finished the relationship. Not because we weren't getting on or anything, but more because we both needed some time from everything. Because it's very stressful, the whole business of, well just everything is so stressful. But I think we will probably get back together I don't think that is a problem, we are in close contact. But I do feel that, and I still do feel completely...well I don't feel I look like I used to. I never was very attractive anyway, but I just feel that I look worse than I did before all the time, I never feel like I look nice when I go out. And it makes me...I don't like talking to people particularly because of the way I look. I do

definitely find a difference there, Most of the time I'm O.K. amongst my friends I don't mind. But when I don't know people I feel really shy and I don't talk to them. And I keep thinking I hope they don't think I want to go out with them, because they'll be worried because I am in a wheelchair and everything. Do you know what I mean? I think being in a wheelchair sort of makes you look asexual, it takes away your sexuality. When I'm walking I definitely notice different reactions to when I am in my wheelchair. Because people think you have broken your leg, you know, and they think Oh she's just broken her leg, she'll be alright in a few weeks so it doesn't effect particularly the way they see you, but when you are in a wheelchair it's a bit more permanent. Especially my sort of wheelchair which obviously isn't a temporary thing. Nothing to do with relationships with men but old people drive me mad. They always want to be pushing you or helping you or...it's not that I mind exactly, it's just that I don't need it. You don't go up to someone who is walking along the street and ask if they need help in going up a step. That is definitely a big difference. But then when I am walking people don't think anything of walking right into you and pushing because they don't think there is anything wrong. I've noticed that. I go to a night club in town some times on a Wednesday, with my friends and I get quite scarred sometimes because I've lost my balance - that's one of the things I lost with my injury - and although I can walk quite well and balance quite well, if some one knocks me just at the wrong place, well, I just go flying, there is just no way I can control it. So I get quite worried about that. But if I'm in a wheelchair then the way just parts, you know they make a lot more allowances for you.

Do you see your life as a line? Or how does your accident fit into it?

I think before my accident I was always doing things, I was quite outgoing, and everything, and I think my accident has stopped certain things, but I don't see my life as any less for that. I just think it is different. It is still good but in a different way. I mean I know I am having a few problems at the moment, getting...adjusting, but I'm sure that will settle down. I'm not particularly worried. I think if I was going through that I would be more worried. I'd think I must be putting something to the back of my mind, or not coping with it. It's definitely different but it's no less enjoyable when I am O.K. about it. I mean every one has their moment of depression and getting fed up, but because I am in a wheelchair I think Oh well it must be the wheelchair that is making me depressed. When in actual fact I have all this work to do, and I have no money, I've got a huge overdraft, and all the things that used to make me fed up before.

The worse thing is that I can't do what I want to do. I can't help people. Say one of my friends is very busy with her finals and I can't say I'll come round and cook you dinner so you don't have to do it, and I'll wash up, and do you want anything, and although I can go shopping for them it is not the same. I can't say I'll go and do this for you while you are busy. And when I go and stay at people's houses it is constantly "Can you help me up the stairs?" "Can you..." I don't like that at all. I know they don't mind, it's just that I like...I'd rather be helping somebody else than being helped myself. I suppose it means I've lost independence, especially when I'm not in my own place, I'm O.K. then. It's like we were saying before

about lack of spontaneity...

How do you find it in terms of generally getting about, access to buildings, that sort of thing?

York's O.K. actually for the main shopping centre and shops. They are all on the flat but shops have steps in them, and they won't let you use them, not even just for the wheelchair. And then all down the Shambles and all those little shops there is no way I can get in there without somebody...I mean if somebody's with me then I can, but by myself there's no chance. And that upsets me, because I used to like rummaging in those shops and things. But at home some of the buildings are quite bad. Big buildings and new buildings are O.K. but little shops which have usually got nicer things in, and little buildings are you know, more difficult to get in.

Do you feel in any way that you are different? That you are forced to be different?

Yes. I feel..I feel that I can't get irritated with people because if I need them to help me later, that's really awkward if you have just shouted at them, or snapped at them or something. I feel that I have to be more polite to people because they think oh I'm helping you, you should be grateful, that sort of thing. And I feel the need to be cheerful, even if I'm not I don't want people to think that I am miserable in a chair. I suppose that is on me all the time. And also I don't...if

someone says: "Are you O.K.?" and I'm feeling pretty shitty that morning I would never say that I was not feeling too good because people never ask how are you and then be told that you're not O.K. That sort of thing.

You say that it is easier for you to be with the friends you knew before you had your accident than with people you are meeting now?

Well I did at first, I've got to know a lot of people I didn't know before my accident, but who know of me because of my accident. And that's O.K. It's not that I don't get on with people it's just the initial stages of the relationship are more difficult. I am more conscious of myself and conscious of what I've got to say and they are often worried that I can't do things when actually I can. I mean I'm not a china doll and I can do everything that I did before, it's just a bit more awkward sometimes. But I am conscious of my looks. Because I wear callipers I always wear trousers and I don't like that at all. Because I hardly ever used to wear trousers, I have loads of skirts at home, sitting there, and I want to wear those skirts! But hopefully if I get rid of this long calliper I'll be able to wear skirts again. But I know other people who are in wheelchairs all the time and they wear skirts and dresses, and their dress sense hasn't changed at all. I used to wear patterned skirts and lacy skirts and that sort of thing, rather than jeans and shirts which I wear now quite a lot. I can't wear them now because my calliper looks horrible on my leg, I mean I wouldn't not wear it because I can't walk without it but I just think ugh what a horrible thing. Especially when you look at it when you're taking your trousers off, and I think Oh God that looks horrible, I hope

nobody ever sees it. So I suppose that has changed me. I mean my body now...I don't like it particularly, and I am not keen on my legs at all. And my bum, although it's coming back it is not very firm. Ugh! And when I lie on my side it sort of droops over the side of my leg. I don't like that at all. I don't like that hanging fleshy business. And the fact that it just doesn't move, it's not part of me any more. And when my legs look O.K. my feet...they aren't swollen but because you don't use them the veins, and the tendons and the ligaments don't show to the surface of the foot like they do normally - it looks strange. When I get up first thing in the morning my skin tends to go blotchy because the circulation has changed. That looks horrible. I hate that - I really hate that in the morning. And also my rods, it's a big thing because I've got this thirteen inch scar down my back now which is very me and I am very conscious of it. And the rods are still sticking out which they still do. But they'll come out eventually - that's not a long term thing. The rods go down my spine like two pieces of metal to hold the spine straight whilst it is healing. Because I had an incomplete injury my chances are pretty good. And because this leg came back quite strong, I was walking with half a calipere when I left hospital, and the other leg is starting to come back, they think that eventually I will have just two short callipers, which is nothing, compared with two long callipers. Hopefully that'll mean that I can start learning to walk with just one stick, or two sticks and balance without any sticks. Which means I would be able to carry things and then I wouldn't need to use the wheelchair in my room at all. And also I could go somewhere, just dump my wheelchair and walk around. I'm getting a three wheeler bike, when I get down to two half callipers and that means I will be able to cycle all over campus, and

hardly use my wheelchair. That's what I'm hoping anyway. I think it does you good to have these goals to aim for.

Can you make sense of what has happened to you at all?

What I do think is that if I hadn't have had the accident in the car I would have had it some where else. I believe that, well I don't one hundred per cent believe this but I have thought it would have happened whatever I was doing, or if I was doing something different. At first I thought if only I hadn't had got in the car, if only I hadn't had done this, done that, and if only I wasn't overdrawn I wouldn't have had to work that day, but I think it would have happened anyway. There were two other girls in the front, and the man in the car behind. Everyone else was O.K. That was very difficult to cope with at first. I wasn't bitter I just found it difficult ...but I'm alright now, that doesn't bother me particularly. I was in the back seat and came out of the car, they had seat belts on, but if I had had a seat belt on I could have broken my neck, so there is no point in worrying about that. I was quite lucky because I didn't see the car so I wasn't tense. The only thing that I broke was my back, and I got a black eye and that was it. I could have been completely squashed.

Do you remember that day very clearly?

Oh yes. I wasn't unconscious at all. I remember even what I was thinking before the accident. I was walking along the road thinking I'm getting sun burnt here. I

was doing one of those road traffic surveys and I was like the relief person, between five different people so I used to just walk around giving the others their breaks. And I was walking up the road thinking that I was desperate for a wee, and hoping that the car would pass with the others in and give me lift. Which they did. And I got in the car and had the accident five minutes later, So I can just remember what I was doing, and what I was wearing, how I was feeling even on that day. Even afterwards I mean, because I wasn't unconscious and I was never that frightened, and I was the only one who was coherent out of everybody, giving telephone numbers, that sort of thing, because everyone else was running around like headless chickens. They were so shocked! It was a very sunny day.

Do you have any brothers or sisters? Yeah, one sister eighteen months younger than me. She was very upset, very. She didn't like it at all, when ever I feel ill she feels ill, if I get something wrong with me she seems to get some similar symptoms, I don't know why it is. We are quite close I suppose. But as I'm getting better and walking better, and coping better, she seems to be getting better as well. My mum, sometimes, when she sees me in the wheelchair, because I don't use the wheelchair hardly at all at home, because I can get up and down from the sofa myself - and so when she does see me in the wheelchair she says: "Oh that's strange, seeing you in a wheelchair". But she never says perhaps you should just walk. It's my initiative to walk. People are quite good like that they never say I don't need it. I think I would get quite irritated by that because sometimes you just feel too knackered to walk. And you just can't do it. And also you get days where you feel tired anyway and you just need a bit of a rest every now and again.

Do you find that people react to your wheelchair rather than to you at times?

They did when I had my Cartus wheelchair, you know those old tank like things, that are really hard to push, and they look horrible, but this one, because it stops so low at the back, they see your wheelchair then they look at you then they because they don't have to look at the wheelchair they look at you. So they don't tend to notice the wheelchair. And I think you look alright in these sort of wheelchairs because you haven't got big handles coming up under your arms. People can't push it the same because you have no handles. So I think they are a lot better. I certainly find a difference in peoples reactions when I'm in this chair compared to the old chair. This is a sporty, low back, flashy wheels - I really like it. I am quite pleased with this chair, being able to have different colours and things it just looks nicer than the old wheelchairs. They are very expensive though - they rip you off completely but because it is such a small market you either have one or you don't and that's the end of it. So you have to accept that the prices are extortionate, but it makes such a difference - they turn around in such a small space and they are so light. I mean it weighs twenty two pounds which is nothing - I can lift it with one hand getting it out of the car. And being in the car is great because people can't tell that you are disabled, and you can stop at traffic lights and people look at you and you think Oh they don't know! That makes me laugh, when you see their face, Usually I get my wheelchair out and I click it into position and their faces! But people see you and then you're out of their minds the next minute. I mean they are not dwelling on it. I think, these days, being in a wheelchair isn't the same stigma as it used to be. You see loads of people in

wheelchairs.

Are you involved in groups of any kind for disabled people?

No not really, although I was asked to go to the disabled access group. And I was thinking of going to that, now that I've got organised again. But not particularly in any type of pressure groups or anything, no. I know I don't like being in a great big group of people in wheelchairs, that's really wrong as well. But it is just the fact that every body stares at us, it is more of a focus for people's attention.

Beth.

I had a car accident five years ago, April '86. At the time I was living in Zambia, in Africa, I was out there on holiday. Coming back to the airport we overtook a car and the car we were overtaking tried to race with us and pushed us off the road and lo and behold I ended up like this. In a matter of seconds really. I remember everything - there were four members in the car, four of us all together in the car, my parents and my younger brother and myself, and I'm really the only one who can remember things, or from what I can get out of my family really. I was there, in hospital for two weeks, in like a cottage hospital, surrounded by people with things like malaria, sleeping sickness and god knows what. After two weeks I was transferred back here.

Did you know from the beginning that you were going to have problems walking?

Well yeah. I knew that em... that I couldn't feel anything in my legs, they were paralysed, so I knew there was something wrong, but nothing was ever discussed really. I was pretty ill initially, but I knew that there was something wrong and that it would be a long process if you know, I was able to get walking again. But the suggestion that I wouldn't ever walk again never came up. What used to happen was that visitors used to come and say: "Oh right we expect you out of bed by September". It was April at the time. So I was led to believe that it would be a long process but something would happen. You know that I would get out of bed and walk again. The story was very different when I came back to England.

You know...very matter of fact...accept yourself as you are now...but um... I'm quite fortunate in that I did recover some movement so it has been a lot of optimism all round really. I was in hospital for a total of about a year really, had a lot of complications. Normally the process I would have...of rehabilitation to walk again would have taken six months maybe seven, but I was in hospital for a year because I had about three operations and relapses and things. Each operation was to stabilise my spine, so it wasn't necessarily to improve my physical capacity if you like, it was a series of metal rods in my back. But when I first arrived at the hospital they assessed me and they just said: "No, very little movement". But then I did manage to get a little bit of movement back and that meant that they were constantly working with me. So I wasn't really led to believe I would return to some sort of normality. The doctors weren't very approachable at all. You know, very medically orientated, they were here to see to your medical needs and your physical needs but not necessarily your psychological needs. I've always been very matter of fact about things and a family who are very supportive and who I am able to be open with and also by looking around at ...I was on the spinal injuries unit so if I looked around at the nature of the other people's conditions it ...you are confronted with the situation you know. From there I gathered that my situation was going to be reasonably permanent.

Were you offered any counselling?

No. I would say that that's an area that is neglected really, and how I've really come to terms with it is by working along side my parents and well, just shutting

it out really and getting on with life. And by keeping busy. The rehabilitation I had was physical rehabilitation. It was like weight training and manipulation, hydro-therapy that sort of thing. But as part of the rehab. process I had lessons in how to use the wheelchair you know how to negotiate curbs in wheelchairs - I'm absolutely hopeless at that. Although because I was ...because I had potential for walking a lot of my physio was geared to using callipers, crutches and parallel bars - that sort of thing - so the wheelchair was like a side issue.

Do you now use callipers?

I've managed to just get down to a small splint on my right foot. I use crutches at home, but only to negotiate small distances. I use my wheelchair most, particularly here on campus. It's mostly for practical reasons but also psychologically it feels better when I'm standing up. It's easier to talk to people, say if I go out to a pub, I like to walk in, because you look a little bit more normal - in inverted commas - if you are in a standing position. And it - if you're using crutches it looks like maybe you've broken your leg or something like that. Whereas if you're in a wheelchair it looks like a more permanent situation.

How do you find that others - the general public - react to you being in a wheelchair?

Well I feel that there is a lot of stigma attached to being in a wheelchair. I still feel that you know - there's this automatic assumption that you have some

intellectual impairment, but I think that is gradually breaking down, and I deliberately try and present a more positive image. I have a sporty wheelchair, it's red and black, so it's completely different to the national health chairs, I try and wear colourful modern clothes and that sort of thing. So hopefully it dispels that kind of myth perhaps. My ...I mean in York it's very much better now because of the pedestrianisation. You see a lot of wheelchairs about and therefore the general public are used to seeing disabled people around. So you are not such a novelty. But I do feel that there is a little bit of staring and people looking away because they are embarrassed, but I've gradually come round to thinking that it's curiosity. Or at least convince myself that it's curiosity.

When you say embarrassed - are you made to feel embarrassed?

It can do, but I've tended to preempt people and over compensate for the embarrassment. You know I try to be more out going and assertive and speak first and that sort of thing - try to make people easy.

Is that something that you have had to learn?

With experience. Yes. I feel that if I - going back to my previous experience before my accident the interaction would be natural, whereas now I feel I have to make the effort more. It's more my side to make people feel comfortable.

Was this a conscious decision?

Yes, because I went to a six form college after my accident - I was in the middle of my 'A' levels and I wanted to continue my education, and you know going back into a college environment, with people of my own age, at the age of sixteen or whatever, seventeen, at that age everyone is very self-conscious and to have someone as a friend in a wheelchair is a bit of a complication. So I had to sell myself, if you know what I mean, to make myself look, em...what's the word... well, acceptable I guess.

How was it with close friends at the time of your accident?

They were very supportive. I know that there was a lot of reluctance and anxiety on their part to you know come and see me. Because you know...all they could think of was me as a an active sporty type of out door person. And then to be you know end up in a wheelchair it was difficult for them to come to terms with. It was a way of finding out who my friends actually are. You know one's who stick by you and one's who weren't really your friends before. I think that was a bonus really. But alot of friends who were initially supportive I've...well they are not on the scene as much now. And I think a lot of effort on my part needs to be made to maintain those friendships.

And you say your family have been very supportive?

Yes, although I think probably on the part of my step-father there was some guilt hang ups. He was driving and the fact that he was a step-father. Maybe if well it

made it more complicated...My mother is being by far the person who has been by my side all the time. I've got two other brothers and they have played a small part but you know...obviously not as much. But psychologically my mother has been helpful. She's done my physio along with me, she's helped in practical ways whereas my step father he has only been able to help intermittently, if you know what I mean. Take me to the swimming pool for physio...although I suppose he has been exceptionally supportive really. I think it has made us closer as a family...we do a lot more things together because of my situation I have tended to stay near the home so inevitably the bond has been strengthened. But I increasingly, not increasingly but I must admit that there is a little resentment on my part. Because of what's happened and I ...there's always been a bit of resentment towards my father even before my accident so it's tended to reinforce it a little bit.

Can you make sense of what's happened in any way?

I think inevitably you think why me? And at the time I remember thinking 'Oh I don't want to continue with my life if this is how I am going to have to be'. But because my mother was always there saying, you know 'come on, you can do it' and I used to do it for her. I didn't used to get upset because it upset her, and she didn't get upset because it upset me...you know we've just come forward really, rather than dwell on what could have happened...or why it happened. It's been overall very positive what's come out of it. So we haven't regretted it really...too much.

And how about relationships with boyfriends?

Um yes. Well, that has been effected, I think inevitably. But also I've tended to be very cautious. I'm a very busy person, so I don't really have time to go out and have relationships really. Although if I'm very frank that is probably a way of justifying the situation I guess. I have got a lot of friends...male friends who well, I think that men tend to be a lot better with me than females.

Would you have any idea why that was?

I don't know. Perhaps men are not quite so self-conscious...you know...although you've got this you know "I need a bird", " need an attractive blond", or whatever. I don't think that the men who I have come in to contact with feel that way. In some respect it might be a novelty to have someone ...a friend who's in a wheelchair. But in other respects it just shows that the men who I have met are very genuine kind of people. And it doesn't really matter if I'm in a wheelchair or not.

I've had a few boyfriends but not as many as I would have had if it had not been for my accident.

Is that something that you are very conscious of?

Yes I think so. But again because I don't really go out and look for boyfriends

and make a special effort I think that has a lot to do with it as well. It's not really that I feel unsexed by the wheelchair, I mean some of the boyfriends I've had, well I've only had three, they've understood my situation...they've been...I mean two of them had disabilities themselves...one was an amputee below the knee, and the other person I was actually in hospital with. So they were very you know...the disability wasn't an issue. I mean I very much...well I'm in correspondence with a person who I met at university, he graduated last year...so I guess...I don't know what the situation will be...

Do you think your own hopes and goals have changed very much?

Well, initially when I had my accident I thought there was no way I could go on to do what I wanted to do. I wanted to be a primary school teacher...so I had to ...I really did a lot of reassessing the situation, but then increasingly, because you know, academically I was O.K. still as far as I can see that has not changed but in other peoples minds it did...My goals are probably set higher now, I've been exposed to a lot of opportunities which I wouldn't have been exposed to before. For example I've got involved in a lot of voluntary work and because of my experiences as a disabled person, I've been invited to join committees which compose of statutory agents, service providers and you know there's a real need for user involvement and that's where I tend to come in. Because I'm pursuing a degree as well it some how makes it a lot more acceptable. So I would say that I can go on to be a primary school teacher still, but it looks like I might go on to do other things. I'm a lot more committed now than if I hadn't had my accident.

My mother increasingly says that I would have given up my "A" levels a long time ago, and that I'd be shacking up with some guy now. But I don't think so. I think I would have still pursued things but not to the extent that I have now.

Do you see any difference in yourself?

Absolutely. I'm a much stronger person, after my accident. I mean I've come in to contact with a lot of people and situations that have boosted my confidence and I feel that I'm a lot older for my age, I mean I'm only twenty-one. So you know I'm certainly, I think, a lot different to what I should...would have been. And I think that can have a...can present a problem in terms of my own peer group. Perhaps I don't relate as well to them as I would normally have done. You know I would be going out to night clubs, I would be doing all these studenty things, but now I tend to move on to the next stage. I mix a lot more with disabled people now, you know through the voluntary work I do. I still don't see myself as disabled so inevitably I think there is a lot of reluctance on my part to actively go out and socialise with disabled people. But I find increasing that the more I do with voluntary work and get involved with people then they are the people I have the most in common with. So perhaps that is where I am heading.

What gives you the feeling that you have more in common with other disabled people?

Because they can appreciate perhaps the obstacles that disabled people have to

come up against. The fact that simple things like you don't may be go out so much, and do as many social activities, in terms of going to the pub, going to the night club...they appreciate the fact that you get more tired easily...just subconscious things. But you have...I don't know really. You don't have to pretend to be normal, in as far as you can. I feel like I'm getting on with my life like every other non disabled person. In fact in some cases, without being too immodest, I feel that I am perhaps achieving more, so the only thing that is the problem is the physical environment and other people's attitudes. I mean campus is difficult. It is extremely hilly so there is a lot of physical upper body work. If I'm walking around campus with some friends, increasingly I have to go a different route to get to the same venue for example. I use a car mostly to get around. You know if I have to go from one side of campus to the other I prefer to go in my car and park, rather than have to push all the way.

How long have you had the car?

About two and a half years. It's great! It's like a status symbol as well. I feel normal and I look normal. People don't appreciate that disabled people can drive and the fact that I've got a normal looking car. I find it very funny that as soon as I mention that I've got a car I can see people thinking 'Oh this Robin Reliant type'. So I like to be able to say I've got a normal car, with hand controls and you wouldn't think it belonged to someone like myself. You have this sense of power and control, you can beat people off the traffic lights, you can compete equally.

I'm doing social policy which is upstairs. The department have arranged for all my lectures to be on the ground floor, in particular rooms. It has been a problem for them because they have had to exchange rooms with the maths department. Also I think other students get...they understand but I think if they well they would prefer to have a bit more diversity, variety in which rooms they have their lectures. So I am made to feel a little bit of a burden you know holding the group back, whenever we did visits in the first year...all the time it was well is the prison, the care home, the hospital going to be accessible. It did make me a special case all the time when I would like to have gone out and about like everybody else. However the students have been incredibly accepting and I mean, I've had to work at that you know...like for the reasons I said before - be more assertive and joke a lot more and make fun of my situation. I use words like "crip" and that sort of thing, which is not terribly attractive but some how it breaks the ice a little bit. So I hope they don't see me as a special case any more.

How have you found general social life on campus?

It is still difficult. I go into a bar. I don't like to go in without somebody else. Somehow if you've got someone by the side of you it looks as if you've got friends and this sort of thing. You don't look so conspicuous. I don't feel I can go up to someone in a bar who I know, I wouldn't talk to them because I am very conscious of how they will feel. I perhaps make more of my disability than I should. I am probably more self-conscious than I should be and I am constantly being told by my mother particularly, that...don't see yourself...I know this is

contradicting what I just said...In myself I don't feel like a disabled person, but it is always brought home to me by situations and other people. That's so difficult, but getting about, getting to know people, because as I've already specified, somehow people aren't very approachable. I think people see the chair before they see me. I mean that is one of the reasons why I got such a sporty chair, because it somehow looks not as offensive or sterile. But also it has become a topic of conversation as well. You know "I like that wheelchair" and from there the conversation progresses into other areas. Interesting I have a friend who is spinally injured and he actually has a dog as well because he feels that the dog detracts from the wheelchair, and also helps children...you know. So since my accident teaching has appealed to me a lot more because of that. Children are very accepting and if you can make them...you know, accept it from the early stages people grow up ... If more disabled people were seen around, if there was better access. I recently went to California and disabled people mingle quite...they are very integrated. Non disabled people are extremely...you know you are not a separate case. I am sure it is because people are there and you don't think about it. It's like black people here. If you are in Bradford you know, white children don't see ethnic minorities as somebody different - they have grown up with them.

Is there anything that being in a wheelchair really stops you doing?

Yes. I haven't got the spontaneity. Socially it really does frustrate me. And also I am not able to ...I am not exposed to the main stream opportunities which I feel I should be entitled to. Like I should be able to go along for a job interview and

compete against everybody else. There are these expectations that you should be better than the other candidates or perhaps that because you have physical problems employers will be afraid to employ you. Socially being in a wheelchair is pretty naff really.

Do you see your life in terms of one line leading to where you are?

Oh no, the accident was a side step, absolutely. The course of my life...it is difficult to say....I think there was a blimp but now I am continuing on the road again. And it is maybe heading in a different direction but it's going in a forward direction rather than coming to a sudden stop and going back. Something definite has come out of it. All the opportunities I've been exposed to and the people I have met. Very nice people that I have met. It's like a sorting process, people who I will meet. I won't meet the guys who mess people around because you know they are not attracted to someone with a physical disability. So it has had many advantages. But obviously there are disadvantages. I make sense of it in my head. I mean I think through it, but there are still blurred patches, I still get depressed and occasionally I do think 'Oh gosh I wish...' you know 'this hadn't happened to me'. And because I keep so busy I don't have a lot of time to dwell on those sort of issues anyway. I keep myself busy deliberately, I mean I have always kept myself busy, but even more so now. It's a bit of diversion therapy I think. But also I think that if you're not busy you reinforce this myth about disabled people. You know they are only sitting at home watching television, with nothing to do, whereas if you are out in the public view and doing all these things it breaks down

those myths I think. I used to play a lot of sports and I still do after a fashion. I used to fence and I still do that, sitting down in a wheelchair. I competed in the Stoke Manderville national games a couple of years ago. I did actually start to do the G.B. athletics and swimming. If I hadn't been coming to university and pursuing an academic career I would have made sport a large part of my life. Because it is very social and it keeps you fit, people well. you have other things in common with the other people and opportunities to travel. I am very much a career orientated person now. I want to be independent, I want to hold down a job, I feel I'm not capable of holding down a full time job for medical reasons, but I want to travel and be reasonable contented. I'd like to marry, but with my disability I think it might be....I am able to have children, but there are a few risks involved in that so I would have to think very seriously about it.

Beth (second interview)

I finished my social policy degree in June last year and between then and now I have been doing, well I've had a year out if you like, doing lots of voluntary work and...while I was here for three years I tended to neglect my physical fitness and that sort of thing so I've been doing that, physio therapy and weight training and sports and things. And just using it as an opportunity to try and find out what I want to do with my life - whether to get back to further study or to go out for a job. Social policy is one option I have been invited if you like, or encouraged to come back here and do a M.Phil/D.Phil in social policy but there are other options that I am considering an M.Sc in health education and health promotion and a M.SW.

Do you feel that you are being encouraged to do disability studies?

I think I am yes. But at the same time I am interested in it. The obvious thing in social work them wanting to encourage client orientated social work, in which case I come into that criteria. In the case of the M.Sc in health education and health promotion I personally am very interested in rehabilitation and that sort of thing. I think there is a need to try and influence policy there. Relating to disabled people, and in the case of the M.Phil/D.Phil I was going to follow up the work that I'd done on my first degree in access to primary health care services and also the health dimension of disability...so it's a combination of things really. It is unlikely that I would have been interested in these areas , but my experience

has given me an interest in this area, but I hasten to add that I still haven't discounted primary school, even after graduating but the recent changes in education have actually put me off....so it's not so much....that I have strayed away from teaching since my accident it is more what is happening in the education system at the moment.

What sort of voluntary work have you been doing?

Again in the disability field, I have been involved in various initiatives in and around York. Disability Action Group, in Selby my mother set up the Selby District Disabilities Forum and an action group so I have been involved in that, laying the foundations for policy and disability in that area. I also was the representative of partnership group for people with physical and sensory disabilities which again is a York Selby District initiative with the help of the authorities, social services and voluntary sector and that was quite involved, again looking at policy issues. It is quite good experience for me. But recently I have tried to diversify out of the area and also gone to a national level now and I got myself onto the Spinal Injuries Association committee and I am doing some research in the Harrogate district for the Yorkshire Association of Disabled people. I am looking at the feasibility of setting up a disability agency and information data base - that's all voluntary work. It is certainly pushing me in to that area for a career. There are lots of opportunities there or around the area of disability although I did, moving back a little bit... in my final year at York I put an application in to do general management training in the health service and

I did quite well in the process, I got down to the final stage...so that really was moving away from disability it wasn't the mainstream, as I say I got down to the final stage but didn't actually get accepted, but I realised it wasn't particularly what I wanted at the moment but it may be something I will go back to.

I suppose I am making a career out of disability, but it's like you can be a little fish in a big field or a big fish in a little field and in a way I don't really want to use the word duty or obligation but I think it is my responsibility to inform people and because I have done so much up till now it seems a shame to sort of abandon all that and go in to an area where I am not so well recognised or appreciated and as I say there are the opportunities there and I would be foolish to turn away from them. There is this movement now towards user involvement and getting the client there to actually work with or be the policy makers and because it is an interest of mine now I feel I should do it.

You say you want to "inform" people, is this the general public, or other disabled people or...

It is a combination of things I think initially it was to help disabled people and to work as an empowering mechanism, a self help group if you like and its spread to awareness raising of the general public but increasingly it is working on politicians on a government level, there are a lot of initiatives going on, working parties and so on, which these organizations are involved in along with other organisations such as RADAR and RNIB...

Do you think they are having an effect?

I think so yes. I think it is always easy to say there could be more influence or more action from the organisations because there is always a lot of resistance not least because of the economic climate and the financial situation of the government. But I think a lot of things are working out.

When you talk of policy changes are you talking about access, or attitudes, or legislation for equal rights or...

It's everything, it is all those areas. Anything that effects the quality of life ...I think they have strayed away from the access as there are other groups that do that but it is everyday issues like health care, education, those sorts of areas.

Having become quite well known in this area do you think your own view of yourself has changed at all?

Well certainly when I compare myself with other disabled people of my age I think so and also able bodied people I have become a lot more active now than if I hadn't had my accident or...but you can't always judge that because there might have been other areas that you might have gone in to. But yes I think I feel a bit more mature a bit more capable than a few people ...some people.

I have to be careful not to leave my decisions over what I am doing too late

because the academic year is coming up and in social work degree case the deadline has gone which is a shame...it looks increasingly likely that I will be going in to a job whether ...to get some experience first and through doing what I am I realise the importance of studying and become a bit more dedicated to the work. Lots of ideas are swimming around in my head. It's all a case of opportunities really, I do feel pressured in the sense that you know I shouldn't be turning down these opportunities, you know, of jobs available in April for example that I might go for but I feel under pressure and it does seem a shame not to go for it at this stage. But at the same time I think I am only young and I feel so much older than my actual age and I just want to do a bit of normal living instead of always being on the band wagon and being the voice box.

Do you feel that very much - that you have to speak for disabled people?

Yeah, yes. Because my mother is very much involved with disability I have a problem or a difficulty trying to persuade her to just ...we are always talking about disability. I live disability and I would sometimes like to just forget it and she doesn't always appreciate that because she enjoys it so much and also works from a carers perspective. She does a lot of work and her work is appreciated in the area so I am...I am sensitive to that but I just feel I want to be more in the main stream. I think I was quite conscious about issues in society before my accident but I would say that I was a moderate person I am not one of these who chain myself to the railings type of thing and I don't always agree with some of the things that go on in all the disability movements and organizations such as

B.C.O.D.P. I am not always in favour of them. But I am a lot more aware than a lot of people.

Why do you sometimes disagree with these organisations?

I am not one of these people who likes to go out and demonstrate. I prefer to be more I think, like chipping away all the time and sort of working, persuading people. I prefer to be more persuasive in terms of giving them a bit of sugar but if that approach does not work then I am prepared to go a bit further and be a bit stronger. But that's the approach that seems to work.

Are you involved in feminist issues at all?

No, it's not really...I mean I can equate my...the disability movement with that and I purposefully shy away from the feminist movement because I think it is too strong and well that's why I shy away from the B.C.O.D.P. and also some of the approaches you hear coming out of the States...I was there a couple of years ago doing some research and didn't like some of the things they were doing...but having said that it does have a place and it does bring things home. I think a combination of approaches is the best.

Would you say that you were oppressed as a disabled person?

I can sympathise with that argument but I personally don't feel that I am. I have

had this discussion with my mother because she thinks that there is a lot of work yet to do, for me to be perfectly acceptable in society but because...I suppose I am seen as an able disabled person, reasonably presentable and I suppose that's what...well I have opportunities like I said to you before, I've been to university, the fact that I became disabled so much later on in life in comparison to some disabled people means that I have been able to get on with my life you know get out in society and do reasonably O.K. things. So I wouldn't personally say that I am oppressed but I think oppression is too strong a word... handicapped yes not at the same starting point. I am very conscious of peoples attitudes though, if you want to interpret that as oppression...

One of the most difficult things is not being able to be spontaneous, got the physical barriers which are a problem to me as I am a wheelchair user although I have to admit that where the environment is suitable for me I feel quite happy and able to circulate normally. Having to always explain you know if I am going on a plane for example, having to always say I need my needs met in this way and I just want to turn up and be like everybody else. I don't mind explaining because it raises awareness and I think next time they might be able to manage to do something without having to ask me but flying the flag for disability gets on my nerves a bit. I am often seen as just being the disability and the active work that I do and not because of...I don't know...because I've got brown hair, go to the gym, do weight training or whatever.

I am not sure whether I could do a full time job and would prefer to do one part time, but again I feel pressured in to thinking a full time job because I am

capable. But the ideal for me would be a part time job but for financial reasons...since I've come to the university and all the work I've done alongside that I still think that I need time for myself to be able to have a bit of leisure and have energy to go to the gym and do physio and swim...

Are there times when you are able to forget that you have a handicap?

Well, when I am involved in sport and go down to Stoke Mandeville, I am involved with wheelchair tennis at a national level and hopefully soon on an international level, I feel quite happy. Disability isn't an issue, people I am involved with have spinal injuries, they have had an able-bodied life you know and a disabled life and they seem to be quite able. So no I don't necessarily always feel disabled, or handicapped when I am there. But when I go out with my able bodied friends I am very conscious of being disabled because it impacts on their lives. You know, you can't be spontaneous and just go to a pub, you have to think well where is there a pub that is accessible where is the disabled loo that sort of thing. I am also very conscious of my own expectations having ...if I'd not had my accident I would have liked to have gone inter-railing, this year out I would have loved to have travelled around and just sort of picked up jobs each country I go to...but because of my disability I am not able to.

You were talking about your able bodied friends, do you have disabled and abled friends?

I think I have equal numbers of both actually. I can understand when disabled people don't want to know other disabled people...I think it depends on type of disability...because I am spinally injured and involved in lots of committees in that field my friends are also spinally injured. When you asked me before I think I was alot more sensitive to being friendly with disabled people than I am now. But I do feel conscious of going out as a group of disabled people, and I personally feel better going out with able bodied friends...that I might mingle in and not be so conspicuous. But having said that if the environment is right, if the situation is right I am happy to go out with a group of disabled friends. I often have a better time with them than I can...we can relax, and we got on with one another and we have so much in common with one another. It actually happened....a situation actually arose a couple of years ago when we all went to the Lake District. There was a few of us spinally injured people and my mother came as a carer and she was very conscious of us all being in the pub, getting on with our lives, joking and laughing and the able bodied people around us looking at us, seeing what a good time we were having and nothing was getting in our way and she said in actual fact we seemed to be, if you like the envy of everybody.

You were saying earlier that your mother has become very interested in disabled issues?

It is a point of real contention I think between my mother and I. Because she is so passionate about these issues. I mean if it wasn't disability, she said before it would be something else, she is that kind of person she has always been like that.

I accept that it is something she wants to do, why I should I get in her way? She never really got in my way. I try and support her as much as I can. I think the only solution is for me to move away from home, be seen to be managing, getting on with my life and then she can then see that...well if she wants to do that that's her decision but it has nothing to do with me. She does say that she did it for me and that in going through the experience that we did she can see that there are people a lot more vulnerable than me and they do need her help. She has got a genuine interest it is not just personal gain. And a lot of people have said that she is helping them. It is a long term thing that she has got in mind not short term.

Do you think you can talk about disabled people as if they were a class of people?

No, I always try and emphasise that we are a heterogenous group and that we have one thing in common and that is we want to raise awareness and break down the barriers. But...I resent people saying, not resent but I have had it said to me, "people like you" "Oh we had someone like you come to see us the other day" and I think well can't you just see me as a person not a disabled person, being categorised I hate it.

You say you have been interviewed before - how do you feel about being "a subject" for...

Well places like S.P.R.U. should really practice what they preach. A lot of it isn't

necessarily their problem it is the university policy and money. And I often do wonder how committed their researchers are in involving clients in their research. I think there is a lot of vested interest which is sad. But I think however, there is a genuine feeling that there should be more disabled people involved in S.P.R.U. and organizations like it but it is just...well you just have to take one step forward to make it actually come about.

Do you think your notion of yourself as a women...

I think they are different from if I hadn't had the accident. I don't feel as ..I think...my personal perception is that the wheelchair does make me less feminine, not as appealing as I might have been before my accident. Yeah I mean my image of myself...I don't feel in relationships and things like that, I don't feel I can always go about them the way I would have done before. I don't like rejection for example and I never put myself on the line, so I guess...I've not a boyfriend at the moment. I am interested in men and having relationships and things but I am very cautious, I am very independent and I don't like things to get in the way of my life. Sometimes relationships can. I would like one more for a companion rather than anything else really. Plus it is seen to be normal, you know I should have a boyfriend and all that, you should have a relationship but...I am very conscious of how people see me in that light as well. That is not to say that I don't have offers and I do, but they are not the ones I want. I am very much, I hate the term, a one night stander at the moment because that is the way I want it - because of the people that I have met I wouldn't want a relationship with...if there was

someone then I would. But the people who I have met tend to be very aware of disabilities, appreciate that I want my independence, and I am an assertive kind of person, I know people are aware of my needs and how I want to operate, I can sympathise with disabled women who are frightened of getting involved though. But if you do feel that vulnerable then I think that there is something wrong.

What do you feel about the television and media portrayal of people with disabilities?

I do try and make a point of watching disabled programmes, Link and the recent debate on genetics - that sort of thing. I think a lot of programmes actually do a disservice to us. 'One in Four' springs to mind, even though I know the presenter quite well. I think it emphasises segregation and separateness, makes a point of disability and it is not always done in a very qualitative way, it can actually come across as corny. I mean when they have pop singers on in their leathers pretending that they are Jimi Hendrix, I think that is quite... so corny and it doesn't do the cause good at all. However I think 'Link' for example, and I do watch it, is quite good, it is very informative it has a genuine empowering effect and I think that non disabled people can watch it. I think generally over the past couple of years there has been a lot of legislation for community care...childrens act and so on and that has really brought out the issues, put it on the table for debate and I think actually it is quite worrying because we are all being socialised in to thinking that disabled people are people who are a burden to society, and that they need looking after and that if we could get rid of all the disabled people

then the economic system and the benefit system would not be such a problem. So I think it is quite worrying. Certainly in the community care philosophy it is "take a friend in - befriend a disabled person" and I think that is the wrong approach. I don't think the media portray disabled people like this intentionally, I think it is an unconscious thing.

There is the M.S. advert where there is an able bodied person at the top and crippled legs at the bottom and it just emphasises the able and the unable rather than everyone seen to be having some degree of ability. It's all around raising money. I can see everyone being manipulated by the P.R. companies it really is quite bad.

What do you tend to think about charities?

I might sound hypocritical, contradicting myself because I do get involved with some charity work, for example the International Spinal Research Trust, because they are working towards a "cure" in inverted comas - I think they are, if you like, a necessary evil. But like the Spastics Society for example I think they are a good example of an organisation for disabled people which should be of disabled people and it is manipulated by non disabled people.

How do you feel about programmes - events - such as Children In Need?

I don't feel so passionate about those things as some people do, but I do see that

they don't help the cause at all. I think their approach has improved over recent years but not without encouragement from disabled people themselves. I don't actually watch those programmes, basically because I am not interested in them and I don't like to see myself as a recipient of charity. I like to be seen holding my own.

Do you think you take more care with your appearance than...

I think I do. However I think I always was quite particular about my appearance, but yes I think it is what people have said to me, if you look smart it undermines the disability in some way. I don't feel I can go out without any make-up on, whether I have actually made people expect that of me I don't know I don't feel I could go out looking a mess. People might then turn round and say that girl in the wheelchair she looks...poor girl it's because of her disability she looks like that. So yes I like to be seen going to nice functions like balls and things...things that I choose to do not the disability.

Do you think people's attitudes are improving?

When I look back over the time I have been disabled I think I can see an improvement, but maybe I am better at handling people. It is very difficult to say. I am a lot more aware now of the barriers if you like that disable disabled people. Before mum would do all the battles ...I am more assertive now I am a lot more aware of the ways people react towards me. I speak first that sort of thing and I

try not to make myself a nuisance...if we are going somewhere I try and minimise the inconvenience to other people. And certainly now all my friends are a lot more aware if you like flying the flag for disability in their own areas, in a much more mainstream sense rather than...so yes I think things might be a bit better - they could be much better. I mean you can't just change people's attitude it has to be on an individual level and a national/international level. Someone said to me the other day don't you think that you would be better working on an individual level rather than a collective level. In the context of education be a primary teacher rather than plugging away in the disability movement to make sure schools are accessible. If I am honest I would prefer to do it on an individual level but then as I said I would rather be a big fish in a little sea than...I guess I am a bit selfish about it but... well the fact that I have joined the spinal injuries association must say something about the way I think change will come about and I have got personal reasons for doing that - it looks good on the C.V. Also it is a good movement to be involved in as it is pro-active so I would say a combination of approaches is best.

What do you think would help people who have become disabled the most?

I am very much into training because it is empowering, we have an initiative locally to try and develop training, in the form of counselling, assertiveness training, awareness training for disabled people, we do need awareness training in a very organised way, advocacy for disabled people, communication skills, self image presentation, how to make the best of yourself...I think it is so important

and I think it is an area that has up till now been overlooked. A thing that is difficult is like the self fulfilling prophesy idea. I used to get so angry with myself when I do it but you know it's like the way you behave to a man, you sort of take on a subservient role ...and when people talk to me very slowly and they... and I feel myself shrinking in to this image that they have of me and I find it very difficult to bounce back. I am not ever aggressive, I don't believe in that approach and I do like to win people over in a very softly softly way. I do not like having anything to do with shaking tins I used to but not any more. Because I don't think it helps.

From a very selfish point of view I suppose I am getting a lot out of being involved in disabled issues, as well as improving the situation for everybody else. It seems right for me at the moment, As much as I would like to say I wish I wasn't disabled I wish I hadn't had my accident, I am having a good time if you like, I have a good quality of life. A lot of it comes down to money at the moment, I have my family to support me. If I was not qualified degree wise, if I was a lot more disabled if I physically looked distorted in any way, I think the situation would be much more difficult. I mean it is all to do with class. As a middle class person I have had so much support and that has helped me go on with the expectations and aspirations that I had before my accident. And because I became disabled they didn't really change. But I am aware and I know a lot of people who perhaps they are in a different class and they haven't got the support there, been away to a special school, they come back and they haven't got a job, they live on benefits, and the family can practically enslave them to stay at home

for the benefits...I mean when I had the accident we were placed in a very vulnerable situation - made to be dependent on social workers, educationalist assessing me to see if I could go back to school or not, health care services they were all ...you were just completely - your status and rights are just taken away from you even though we were in relative terms capable of looking after our own interests. At St. James in Leeds I was having an operation and I was so dependent on the medical staff to look after you and my mother used to come and sit with me all day and she had to....well she stayed with me much longer than someone visiting someone else would get away with. You are just made to feel so dependent on the system, don't rock the boat we can easily take this care from you, we can easily make you go home at eight o'clock instead of visiting all evening. It was only through that experience that we realised that we are doing what we are doing now because we have come through it and we wanted to help other people.

Steven

I was in a car crash. Well, I was driving down the M1 and er I fell asleep at the wheel. It'll be eighteen months ago now and I was just driving since seven o'clock in the morning 'till two in the afternoon continuously. Going down to a meeting in London and er just a split second and that was it. Woke up in hospital didn't know what had happened to me. I had broken my back and T-five and six which is just below your chest and I badly broke my right arm, both bones were broken and basically they told me in the hospital that I had broken my back. I was pretty shocked to start with.

How did you find the hospital experience?

It was O.K. really. I wasn't...there was a really good student doctor who came and had a chat with me and explained the situation and the surgeon came afterwards and they sort of broke it really well in fact. I've got this sort of attitude anyway in life that if something happens you've got to crack on with it you know. My parents died when I was young, my mother died when I was eight and my father died when I was eighteen, so there is just me and my brother left. So I've got the sort of attitude that you have to carry on. I was the guardian of my brother so, well you get the attitude that because you have to look after yourself and I've got that attitude that if anything happens you have to crack on with it. Death or whatever.

Did you have rehabilitation?

Yes, well the accident happened in Nottingham, so I went to Nottingham Infirmary and they fixed my back with a wire brace at the base of my back and then I was transferred to Lodgemoor which is a spinal unit and after that six months rehabilitation. I was on my back for eight weeks, they test you to see if you have any feelings with pins in your legs etc. It could have been...you get like a spinal shock to start with and sometimes you get feeling back and sometimes you don't. After about three months if there is no feeling, well that's it. For me no feeling came back, I am paralysed from about the waist down.

Is it purely physical rehabilitation or...

There is no counselling side to it. Because there is a lot more people...well in my case there were a lot more people who were worse than me, with neck injuries and that and you think 'bloody hell at least I have the use of my arms and things'. And when you see, well, when I first got there I was laid in bed and really pissed off and that and this girl came up to me, she was about seventeen and she just had an accident about six or seven months ago, neck injury and she could just about move a cigarette to her mouth with her hand and she was in an electric chair and she was just full of beans honestly. And you think 'well I haven't got so much to worry about'. There are a lot more people worse of than you and you get that attitude being in a place like that because it is really, well it brings you down to earth because you think well at least I've got the use of my arms whereas neck

injuries...there were three of four people who had dived in to swimming pools and that ...that was serious shit. And you think 'bloody hell at least I'm not like that' and at least when I did it with my driving, at least I didn't bring anybody with me you know.

How did your brother react?

Well, he was living in America at the time so he was a bit shocked and he wanted to come across but he was a bit skint, and I didn't want him to come across. So he was really wiped out when he did come across and saw me in the chair. I always knew I would handle it really. I was a bit shocked to start with but you know I like to look at the situation now that well at least I have got what I have anyway and I have the use of my arms and everything. I just try to live my life as much as I can. Get out with the lads as much as I can, do whatever I want to do...I don't want it to hold me back.

Do you ever get bitter?

No not really. I mean the only times I get bitter is really it comes down to sport and stuff like that. I was sporty I used to do a lot of skiing. I mean when all the lads go skiing now like they did last year I thought well it hits you a little bit. But there are things now, well I can still do quite a lot of things anyway. I look after a football team that I used to play for. That gives you a lot of pleasure you know, but it's just trying to sort of...the worse thing is how people take you you know.

As soon as....people that I knew before the crash you know if they were a bit funny to start with, the thing to do is just say 'how you doing' and all the rest of it and tell them about the accident, you know say I had a car crash and that and be my normal self after that. Once we've been for a night out for a drink with us you know, just see I haven't changed not really. But it's getting across that bridge to show that you haven't changed. But because I am quite out going, extravert, or whatever that they realise that there is not something wrong with my brain or something like that, cos you get that as well. Once they have realised that and because I am out going people take you that way or whatever you know. I meet a lot of people through my job, through work and I've lived here for ten, twelve years now, it's just that...I think that once they have seen you, that you are still the same but you are just sitting down, they'll speak to you but some people are just dead shy. I know a lot of lads who'll say hello but don't want to sit and talk to you. So I have to go and talk to them. I was exactly the same with wheelchairs, I mean before the crash, a lot of my friends were as well, 'bloody hell the lads in a wheelchair!' I don't know why the reason is. I mean I was exactly the same. I mean I used to go and see this farmer who had a horse riding accident and I was always on a nerve when I used to go and see him because he was sat in a wheelchair - it always used to put me on a bit of a nerve you know. There is no explanation for it it is just well I don't know, nobody knows what it is do they?

Do you feel disabled?

Yes I do feel disabled you know but O.K. you can't get into places and stuff like

that but I have a good bunch of friends which helps as well, they are a great help to me. I mean where ever I want to go they will always take me. I don't drive at the moment I am waiting to see what happens with my arm. To see if I can drive. But they are a big factor to me, I think if you have good friends behind you they will help you a lot. I mean they didn't know what to do to start with. I was lain in hospital, the European football matches were on, so they all came over to watch the game. Eight of them were sat round the bed and we had a few beers and I was just trying to be normal really and there is this lad called Duncan who is a real joker type and he goes "God I'm glad you are in the position you are now". I says "Why's that?" and he says "I can have your ski boots can't I". Everyone was just shitting you know! But I just burst out laughing and that just about broke the ice with everyone else and after that it was just well back to normal really. But it needed something like that and then all the jokes were coming out about it all, you know...but I do think you need your friends a lot to sort of help you come back and I was fortunate that I have a good bunch of friends round here. But I can't see that I feel disabled by not getting into things. A lot of them are places that I wouldn't want to have gone beforehand you know. I think society is changing now anyway. York is pretty hard. The majority of the places you can get in to but there are some places with lots of steps and things but theatres and things like that, the new Warner Brother cinema complex is good.

What do you think the public image of disability is? From things like Children in Need campaigns and...

It doesn't really cross my mind at all. I don't think about it. I try not to. I don't really want to get in to a situation all I want to do with myself is to try and get as normal as I can to what I was doing before. I am doing exactly the same job but doing a lot more on the telephone and basically I've had a good response from the farmers you know I go out there and try it again. But I've been fortunate in the job side that I could go back and do my job but I'm sure if I was not able to do it I'd get another job and get myself involved in something. It is important that your mind is occupied during the day and that. A lot of them in the hospital people were just like hangers on - people just used to come back and they used to really piss me off you know. People who had been in there two years ago still coming back to the hospital two or three days a week. I think, you know what's up with you? You know to keep on going in and just hanging around all the time and not actually doing anything. But it does depend on the sort of person you are you know. I can't go back like that because I like to do things but I can't understand why they have to keep on going back every single day. If they miss a day out to play basket ball ... but mind you I was talking to one of the physios and we were discussing this about hangers on and a lot of people in wheelchairs like bikers...she said it really changed them because they got themselves a better life and met a lot more different people and their basic standard of living was much better. She said they seemed to have a lot better standard of life which seemed strange but ...well going into the future is just sort of to keep my job going and just taking it each day as it comes really.

What about relationships?

Well, I was going out with a girl for four years before the accident and she just found it really stressful you know the whole situation. She had a lot on her plate and the situation when I was in hospital and I could see this and you think bloody hell. You know cos I was nearly a goner anyway and we discussed it and she said she couldn't cope with it and I thought well that's fair enough because I didn't want to put any stress on our relationship because it's really pointless and when you first come out of hospital things start going wrong until you get organized. It's just you know you are best without a relationship really, you are best not seeing another person until about a year and a half until you are actually in to a routine and got things organised from there. Like now I feel I could go in to a relationship and be happy with it. A lot of people can take you, you know as you are, you know and really it is just sort of finding somebody who you know is the person. Being a bit of a tart really like I was before!

A routine is very important really. Certain things like I have to wear a sheath now because you have no control over your bladder and you have to do your own bowels on the toilet, that is one of the worse things of the whole thing because you have to put the sheath on and if that comes off then you just piss yourself really. That is the worse thing. That is the thing that pisses me off the most. But some days when you have no problems with it fair enough but when you do, like in a meeting when the sheath comes off...but all the people I work with now in the offices and that, they know I have a sheath on and that and they don't see it as a problem any more. But that is one of the main things really...you know it is little things, it is not the big factor of it, not being able to walk and things. It is

you know a thing that has happened and you have got to get on with it.

Were you living here before?

No I was living in a house in Teddington, we had a converted barn sort of in the countryside. I was pissed off giving that up as it was sort of like the house you had set your heart on you know and well it was too isolated and it was like everything was upstairs really, so well when my girlfriend and me split up we sold the house and she bought a house and I bought this place. So I mean it is just actually...I'm getting myself together now, I've got the house sorted out, that's taken, it's time...this arm been a problem, been a big factor...but hopefully it'll be alright after christmas and I can start using it properly.

Do you feel less masculine?

Well with sex I try to get round it really. I mean there is other things apart from sex, apart from the old bonk, there are a lot of other things you can do in bed as well. So I just try to get around it that way. The worse thing is that the women when you do it she gets more peeved because she can't really please you - that's the worse thing about it on the women's side. But if you explain the fact that you know it's in the mind really as well as I get pleasure out of pleasing her and er you are working that way really. That's the best way to do it. But it doesn't really worry me that you are not more of a man or anything like that because in a relationship sleeping is a minimal part of it really it is like ten percent and ninety

percent of the time you spend together...

What about other aspects of masculinity...?

Well I never did handy things around the house to start with! Give me a drill...I was horrendous! I was not one of those ideal men you buy a workmate for! I always used to get someone in to do it or a friend to sort it out but no I mean masculinity and things like that it has got...it doesn't feel anything like that at all. You know you don't sort of think I'm less of a man because I am in a wheelchair or anything like that. It never crossed my mind, no not at all. I can't really understand people who really think it's manly to do stuff like that. I mean to a certain extent things are getting more liberated now - the New Man and all the rest of it. It's all ...I don't know it never crossed my mind.

Are you very independent?

Yeah to an extent but I take advantage of the people, well no I don't take advantage of people but I take advantage of the facilities which they give, home help service, someone comes in to do my washing and ironing, cos I'm working during the day and I don't have time to do it, well I do my washing and that but they do the ironing and clean the house, well I might as well have it...

What about your relationship with your body? Do you get annoyed with your body?

No not really, I mean your legs get a lot thinner and that than what they were before but I'm not embarrassed about it. Not really at all. It's just your legs and that they get a lot thinner, but I'm not embarrassed by it...I wouldn't wear shorts on the beach, if I went on a summer holiday I'd wear jeans all the time but... it's there and you have just got to cope with what you have got. It's happened and that's it. Can't see the point of doting on it really. I accepted it from the first...as soon as the doctor said well you know that's it, there are so many things you can do and all the rest of it I suppose I accepted it from there, got on with it. Actually in about four or five days, after I was just making plans for the future I mean I was mostly worried that I would loose my job. That was one of the main things which really crossed my mind was Christ my work. But I was working from hospital I got a mobile phone and was working from hospital all summer...I spent all the summer in hospital and about harvest time is our busiest time so I spent a lot of the time on the phone ...but I stressed that I really wanted to carry on, and the directors had a meeting and one of them knew a bloke who sold cars and that in a wheelchair and, you know, he said he was doing a good enough job so they said lets try him for a year and so they tried us for a year and...but you know they paid us in full.

Your wheelchair is...

Its just a light one really. It's just one you can get in and out of a car easily, folds up, you can actually do it yourself in the car, fold it up and put it in.

Do you feel like it's part of you in any way?

No not really, I just think of it as a wheelchair you know! No I just think of it as a wheelchair it is not part of me. You know when I sit on the coach it is just there and I don't think...hopefully if people look at me they look at me and not at the wheelchair. They just look at me and not at the wheelchair but some people...well it is just there as a convenience.

Before I used to take every week as it came anyway, I had no idea what was going to happen...Kids and that? I don't know...hopefully...No I don't think in terms of a medical breakthrough or anything like that at all. I used to have dreams when it first started about a year ago, a couple of dreams on a night where I would be just getting out of bed and taking the dogs for a walk or something like that...that was very strange but I don't dream any more. I never forget either, you know like waking up and forgetting because you are always planning ahead what you have to do. I mean if I wake up at half past seven and I have to do this do that and you try to plan ahead. I suppose it has taken away spontaneity, I was always doing things...but I try to fit in as much as I can do.

Has it given you anything?

Bit more relaxed attitude about life you know. I was always doing something I always wanted to do something quickly getting there quickly, do that quickly... just doing lots of things all at once and its stopped me doing that. You know I don't

rush about and I don't worry...well I do worry about things but I don't think oh shit I haven't done that, well I do but not like I was rushing about all over the place. I wanted to do this I wanted to do that, get this done, get that done, I have just become more relaxed really, a bit more laid back. On the one hand I have to be more organised but on the other I am more laid back. I mean you just have to enjoy what you have got really. You know could have been dead that day and instead I am still down here so...it's made me think I should enjoy what I have got. Whatever happens in the future it just happens. I can't sort of put a finger on anything and say for that reason this has happened. It just happened. I don't try to make sense of it. I just try to carry on in my own little small world. This will probably sound a load of gobbly gook but I have become a lot more relaxed than what I was before, I used to get hyped up a lot and be wanting to do this and that, be off booking holidays everywhere when I couldn't afford it and stuff like that and now you just sort of sit back and...well money is not a worry to me anymore. Like it was before. Now if I haven't got a lot I haven't got a lot what the hell you know. I am roughly the same financially as I was before. I mean I used to think I haven't got enough always lived on the bread line before, because I was away booking holidays and stuff ...but it's just taken the edge of it. Everything is a lot more smoother over than it was before. Which is probably better I would think.

Just to go back over a few things...you said there was no counselling? Do you think there should have been?

No ...well yes there should have been in some cases yeah. I am quite sure, I mean there were people in hospital who just couldn't handle it at all. And I think they needed it. They got a lot from the nurses. The nurses were very good, they were like a different breed all together! A lot of them get involved with people, some were married to ex-patients...but they were certainly a different breed, the nurses I admire them quite a bit. But for myself having counselling, no I don't think it would have done any good. I have a very strong mind and I don't think anyone trying to persuade me to think something else...I'd go against it anyway. I have never really been counselled anyway. I mean it's good to have someone to talk to and the nurses would tell you anything you wanted to know, about sex or if you had a problem all sorts of things.

Do you keep in touch with anyone from there?

I try not to know other people in wheelchairs. I don't like going back to the hospital. I try not to. I just try to get on and keep away from it because I think that if you hang around people in wheelchairs people think 'Oh here comes a clan of them together'. I try to keep away from what the others were like you know. A lot of them used to go to the pub together, four wheelchairs in a pub together all the time and I just try to keep my distance from the whole situation really, just try to get back with the people I used to mix with before, and go out with them instead of mixing with people in wheelchairs which a lot of them did do. With my friends it was normal within about an hour or so. They took us up to Sheffield for a couple of nights out and we weren't getting back till about three in the morning

and stuff like that. But I mean it's just like it was before really. They are really good lads and I can talk to them about anything, it's not a problem. I mean they took to it very quickly in fact as long as they found I could talk about it and tell them the situation - I am not able to walk but I am exactly the same person. It probably took them one or two visits to sort of get used to it...Somebody was a bit shocked but he didn't really know me personally...

What about the general public?

Just everybody, everyday? They seem to be alright, I mean people in the pub and they just seem to take it, if I break the ice and sit around talking to a couple of bar maids or whatever, if I break the ice then they just seem to take you as you are. I think it is up to each individual really. If you act as though you are very shy and secluded and you don't really want to talk then people will feel that as well. But you know putting other people at their ease ...there is a lot of that anyway. But I suppose it does in my case because it ...well I was like that before, just a big flirt before anyway! So I haven't really changed. I used to get told off by my girlfriend. I was just a big flirt beforehand so it hasn't really changed. But there are some people who you get an uneasy feeling that they think he's in a wheelchair and I'm not. And in that case you have to try and break the ice yourself. People sometimes talk to the people I am with and ignore me, so I usually try and talk first to get round that. You do get that.

Do you think there is such a thing as a disabled role which you are expected to

play?

I have never thought of it in that way or whatever. In my case I just crack on with it. Things like that just don't cross my mind at all, probably will now that you've brought it up though! I try to distance myself away from it as much as I can. A lot of disabled people...well if there is a disabled programme on television I won't watch it. I mean I make a conscious effort not to watch it. Just because I want to keep myself as normal as I can. I don't get in to it and think should I be thinking that, why should I be thinking it, people take certain attitudes towards you and everybody else at least it doesn't worry me. If I see a programme about a bloke sat in a wheelchair going oh well I don't like to go out because people can't talk to me because I am A or B or whatever, why do I want to watch that for? Can't see any point in that. Watching something which I don't feel ...if I think Christ what if that happens to me...What if it does? It's tough shit. That's my attitude towards it. But I watched something on Challenge Anneka where they all went deep sea diving that was O.K. quite entertaining really. But I mean I won't sit down just to watch something because it's about disablement. Whether I am scared of the...but I can't say I.m scared. Better things to watch!

Chris

My accident happened on the sixth of December 1983, when I was in town with some friends. I'd been drinking, a bit pissed actually, and I got my bike from Priory Street and I was cycling home, to here, the same route that I used every day to go to work, 'cos I worked in Priory street at the volunteer centre. I was organiser there - it was a good job, I really enjoyed it - you know, organising people, helping people out who came to see me with difficulties, sorting out why people wanted to work with children, if they were molesters, if they'd lost their children, things like that. I was quite good at the job. Anyway, I went for a drink with some friends and I was coming back from Priory Street and I was a bit pissed, as I said. I was cycling home and down Cromwell Road they found me. I have no memory of what happened, no consciousness at all of what happened. I'd been knocked off my bike, probably a hit and run, although I've got this thing in my head, I was hit by a scaffold pole - where that came from I don't know but, er, I was in a coma for three months. When I came out of the coma I wanted to live in Jamaica or New Zealand, and another thing that I was going to live till I was 142, which is quite fantastic really, but still ... and, er, following that my parents were known on the Tuesday night, the police woke them at twenty-past four in the morning, told them I'd had an accident, so my Dad did nothing but came straight to York to see me. From York I was moved to Pinderfields where I had a brain haemorrhage. They opened my skull, so I had a cracked skull, they got the brain haemorrhage out and I was in Pinderfields for a week on a life support system, and they gave me up a couple of times, but I still lived. I came

back to York, still in a coma, then I was in York and they said go to Bootham Bark Hospital, which was in the MPU unit where they had two accident beds which are for people like myself who have been in an accident, they look after them. I hated it there, I had worked with them and thought it would be good, but the charge nurse was a right old fascist pig, you know. Physically I couldn't walk at all, my left hand was closed totally and I couldn't open it, I couldn't straighten my left leg at all, it was bent. I had spastic, all the muscles down the left side went spastic, the right side of my brain got damaged, so my body was pretty shit up, really.

You were well aware of what happened to you?

Well, I knew that I had been in an accident. When I asked the nurse what had happened to me she said I'd had an accident on my bike. I thought she meant my motor bike, you know, then someone said it was my push-bike. I couldn't account for that. How come I'd come off my push-bike and got in such a state, you know. I'd fallen off my bike before and had just bruised my legs or something like that, I'd never been in hospital with it. Anyway, then people came in to see me, people were all sitting with me when I was in a coma, all sitting with me, I think it was that that brought me round, people just willing me to live. My dad, as well, sat with me for hours and hours and hours, he was pulling the hairs out of my chest to try and, you know, stimulate me - rotten sod! No he's a good bloke is my dad. And then I just gave up, I never thought I'd walk again, I just gave up and was totally lost, but my father came up and bullied me and said, you know, of course

you can. I gave up completely, thought I'll never walk again. But my father really bullied me into doing the physio - they'd do things like strap me to a board and strap me really tight and straighten my leg which was really hurting me. Then they'd put the board vertical and I'd have to stand there for half an hour and I'd be in such pain and crying out. My favourite term for everyone was "Fuck off", even my friends who'd come and see me I'd just say "Fuck off, I can't stand you any longer". It was terrible. I got really low and gave up. From there I got round a bit. They put me in a calliper on my left leg to straighten my leg, which was a real shit, you know, 'cos I had to put my leg straight and then strap it in the calliper and then walk. I walked with a Zimmer frame at first, they tried me with sticks, crutches, but I just couldn't manage them at all, so I used the Zimmer frame. From there they got me a place in Farnham Park, which is a very good rehabilitation centre down south, which is really good. It's sports injuries mostly, you know, a really sporty place which didn't suit me at all 'cos my idea of sport is going to bed and fucking, but still ... or going out to make a cup of tea, that's my idea of sport you know. But anyway I went there and I saw the doctors at the local hospital and they looked at my hands and asked why nothing had been done in York. I said "I don't know", so the surgeon said "I'll have you in and straighten this". So he took me into hospital and straightened my fingers. You can see the scar here on the end of my forearm. If I was in York I'd still have folded up fingers, whereas now I have trouble bending them. From there they also operated on my leg and I could straighten my knee. Also my left foot was bent right round so they straightened my foot for me as well.

How long was this after the accident?

Oh, about two years, I suppose. And from there - I got discharged from the rehabilitation centre, I was there the longest time anyone had ever been there, I was there a year three months which is the longest anyone had ever been there. This was all physical rehabilitation - it was a good place. I kept myself intact pretty well, I mean I wasn't, well I was on Damtron, a drug for spasticity, which is horrible 'cos I came off it and suddenly felt wide-awake, you know. I think that has affected me a lot really, it's only since then that I look back on the drug and think it must have been terrible - it was like being permanently stoned only much worse, 'cos there wasn't a high of being stoned, it was just being blank, zombie-like. The rehabilitation centre took me off them. I felt like a new person. Like a breath of fresh air entered my body. I was also on anti-depressants when I was in York as well, but I got off them as soon as I could when I was down south, 'cos I went into hospital and they didn't say anything about me taking them, and when they did my hand I just didn't tell them I was on them. When I got discharged from the rehabilitation centre I was walking with sticks, with two sticks, and I was at home with my mother and father who really care for me, who really love me, you know. Apart from them I'd be dead, you know, or in some institution somewhere and, er, my dad got me to walk again, walk without my sticks again. My dad did it not the doctors or nurses, my dad, you know. He did it just by really working with me. At first I couldn't straighten my legs when I was at ... when I went to the rehab. centre I went there, but at weekends I could go home to my parents, which was really nice weekends - so my dad would work on me all

day Saturday, all day Sunday. He'd be doing physio with me, trying to force my legs straight, getting me to do sit-ups and things like that. I was crying at the time, saying "I can't - I can't" and he'd say "Of course you can do it!" So I did it and he was right, I could do it - this took months.

When did you return to York?

Four years ago in October. October 12th 1986.

When you returned to York had you kept in contact with friends?

Some friends, yeah, but a few friends just dropped off, they don't want any more contact with me. One friend who I was chummy with, a psychiatric nurse, he says I was just too demanding and he just left me and didn't want to see me ever again. Other friends ... well, people use me, I'm a good touch always got dope or something like that round so they'd come round and see me, drink my beer and stuff like that. I'm a good cook as well, something I've not lost, I'm a real good cook. I'd like to open a vegetarian restaurant one day, that's one of my ambitions and I'm keeping to it, which I'll do eventually one day.

Do you find it easier being with people you've met since you've had the accident?

No, 'cos there are some friends, my old girl friend who I was living with before I had the accident. I wasn't living with her when I had the accident but I did live

with her, she still sees me and she's a really nice lady, she's been really faithful to me as a friend. She says I haven't altered too much either which is good. I don't think I've changed really, I mean I'm still into what I was into before really, which is my music, reading and all that ... I've started weaving which is good and macrame. I do a lot of weaving, I really like it.

What ways do you think you've changed?

I don't see any dramatic change. Some change but not dramatic. I've always been into Taoism, you know, placid personality which I think, I've got to be. Otherwise I would have died, you know. Actually I don't find it difficult to relate to people after the accident, I find it really easy. My faculties, my intelligence is quite good.

How do you find it walking around in York?

Well, people locally know me and take interest in me, and say I'm doing well and things like that, which is good and supportive. I find tourists are really pigs, you know, they just bump into you, treat you as if you are not there, you know, that I find really trying. I swear more now than I ever did. "Hey, fucking watch it, I'm here, you know", that sort of thing. Usually gets peoples attention, they'll give you a dirty look, but so what, at least I'm able to walk and not be pushed over. Pavements in York are absolutely chronic, some of them are really rough, you know. I never thought about it before my accident, I'm really into walking, I loved

walking before my accident, I used to walk my dog ten miles every day, you know.

What about work?

Well, this ET scheme is the first thing I've done for six and a half years. Getting up at seven is chronic, it kills me. But that place there is OK but you have to keep going upstairs all the time which I can manage quite easy but it just tires me. I'm disabled, yet healthy people there are always moaning about the stairs - you know, people who are overweight and stuff like that, it's just chronic.

Even though as you said you were quite rude to friends when you were in hospital, do you find that your friends have accepted you now?

Well a couple of friends have accepted it, but also a few friends took me at my word and just fucked off and left me. I think this was because they couldn't handle the fact that as far as they could see I was different, and they just couldn't handle it. Also the one bad thing was that I was really sexually active before my accident, I had about four girlfriends, I had a woman every night as it were. I'm not boasting but that's how it was. But after the accident I didn't have anyone. In fact I didn't have my first fuck till four years ten months after the accident. 22nd of October 1988.

Do you find relationships with women a difficulty now?

Not really, I mean most of my friends are women. I really like women, I had a girlfriend for a year actually, it was really nice, she just picked me up on the street and asked me "What's the matter with you?" So I said I'd had an accident. And I asked her back for a coffee. So she came back for a coffee with me and stayed the night, you know. We went out together for a year but she just pissed off with an old boyfriend who was ten years older than her - she's thirty and he's forty. She was a bit of a religious maniac, she couldn't talk about novels or anything like that, all she could talk about was the Bible, you know, Isaiah said to Joshua and Joshua said to Jacob and Jacob said to Mary, so it got really boring. I mean, I believe in God and that but I'm not overtly Christian. I think Christian is your attitude and the way you behave, not churches and things, I don't believe in that. 'Cos now I get people who come up to me in the street, seeing me walk, and they say "Oh what's happened to you, oh, I hope the Lord prays for you" and all this sort of stuff, and it just turns me off, you know. Or they stop me and tell me "Oh, I've got a bad knee, I've got arthritis in my knee", and they talk to me for ages and it drags on and drags on. I hate that, it really drags me down does that. Just because I walk with sticks they think they can intrude on me. Does your story help me walk into town? No.

Does this happen a lot?

Not too much, but it's happened quite a few times.

How do you react to it?

Well, if I'm in a hurry and going somewhere I say "Sorry, I've got to go somewhere", now I do. Otherwise I just listen to them, you know. I used to listen more. It makes me feel very bored, and after they've left I usually swear about them, but I don't actually say it to their faces. The doctors said I wouldn't be able to live in my own house again, that I wouldn't be able to walk again. In fact when the surgeons in York District saw my father they said I had no chance of living, if I did live they said I'd be a vegetable, you know, I wouldn't be able to care for myself or anything. So it's quite an amazing recovery I've made actually. A lot of it is just the people who love me and a lot of it is my own will power and determination to keep going, you know. It's funny, I'm not bitter about my accident at all. I rarely think about it, actually. It's something that happened, there have been mistakes that have gone on in my life as it is.

Has the accident changed you at all?

I'm more patient with life but peoples problems, I've just had enough of them. I just think well, unless I'm really interested in that person, in which case I'll listen to them all night, but if that persons a stranger to me and just wants to talk about their problems, well, I've got something else to talk about, something also to think about, you know.

One thing I do really regret, though, is my lack of mobility. When I try to do something, you know, I can't just suddenly get up and kiss you or hit you now. I mean by the time I got up the spontaneity is lost. But this applies to everything from being in this room to popping down to the shops. Also, like I said, I used to

enjoy walking. I'd like to get a car, 'cos I used to drive, but it costs money to fix one up, you know, I haven't got that sort of money to have a car anyway. That's another point, lack of money. It's quite a difference, the job I had before wasn't that well paid but there was always enough money, whereas now I've got to be really careful. And before I knew that I could always go out and earn more money, whereas once you're disabled you can't just go out and get a casual job to bring in a bit more. Another thing I've been thinking about recently is holidays. I really miss going on holiday - I haven't been abroad since before my accident, though I went to Lourdes when I was at (.....), down south, there was a good church 'cos my Mum's Catholic and I was brought up a Catholic. They organised a trip to Lourdes, and they paid for me to go , you know, which is good, you know. It was a really beautiful place, the people there were really happy even though some people were obviously going to die in a few weeks or something they were still happy. Still pleased to see you ... it was great.

You say you think that people just come round and see you 'cos you're a soft touch?

Well, it did seem to happen, but most of my friends now don't do it. I think they were people just on the make for themselves, they just kind of turned up.

Did you put up with it in a way which you wouldn't have before your accident?

I suppose so yeah, 'cos I need company. I can't get out, I mean before I had my

motor bike so if I was pissed off with anything I just got on my motor bike and went up on the moors or something like that. I used to love going up on the moors, it's beautiful. I've walked most of the moors too, I used to know every inch of the moors. I walked the Cleveland way once, took two weeks to do it. Some people do it in about seven days but I wanted to enjoy it so I did. Up on the top of the moors, just yourself, you wouldn't see anyone all day, it was really beautiful. It was a gradual thing, realising what was wrong with me. It is more now, now that I'm thinking about it, 'cos I can now think about things and think if it's possible for me to do, whereas before I didn't think about it. One thing that really pissed me off was when I was thirty in the hospital. I suddenly realised that I had said all along that I would get married when I was thirty, and I sat in hospital and I hadn't seen a woman, and as for my sexual problems they came out more and more, they really just went round and round in my brain, you know, hammered and hammered and hammered and hammered, it was really boring. Well, I suppose they do now but, you know, that was why it was nice to have a girlfriend, you know, that was beautiful, not just the sex, but someone to be in your company a lot of the time, you know. Being thirty in hospital, being out away from my sex, one thing has changed though, I never wanted children before whereas now I'm quite into having children. I think that's because my parents have been so good to me, you know. They have been so good to me I couldn't praise them enough. I owe my life to them, I really mean that. Beautiful, wonderful people.

How did you get into weaving?

At the rehabilitation centre. They had a loom there and I had a go on it. I made the two rugs outside, then I got this small loom from the York Health Authority. I used to work for them for five years before my accident.

Do you see your life in terms of a linear development?

I suppose so, yes. It was just an unfortunate something that happened in between that mucked me up a bit.

In between?

In between, yeah, I suppose so. I'm saying it's two lives aren't I? In between my life! Yeah, something that happened in between then and now. I don't think that much about it, you know. I want to live my life now, not in the past, that way I just get depressed and maudlin, but now I think in the present. Like today I thought "Oh Fran's coming round tonight, I wonder what she's like", you know, going to meet someone who's going to interview me. That's really nice you know, I don't think "Oh ten years ago if I'd have met Fran I'd tell her to fuck off if she'd wanted to interview me." You know it's not that sort of thing. You know you live for now. Did I tell you before - I'm really into Taoism, and things that I read years ago, how much they are really true, and they are true in my life now you know.

What sort of things?

Being peaceful and restive and not putting yourself too high, you know. Just sitting back and accept what happens to you. It's fate I suppose, and you can't try and change it.

Have your goals changed?

I suppose in the fact that I am less active. I mean I always wanted to live in a croft somewhere and go out and get the firewood and stuff like that. Whereas now I couldn't do that sort of thing, I couldn't go out and get the firewood. In many ways a lot of my looking for a girlfriend, my ideal Miss X, that I keep telling myself is going to come my way, is that she'll be this beautiful lady who'll be able to go out and do these physical things that I couldn't do. You know I'd make up the other half of the bargain, cos I'm a really good cook, so I'd do our cooking, stuff like that, do our weaving, our macrame. So there are things that I can give, it is just that they are reduced, greatly reduced. Also things I dream about. I couldn't go off travelling on my own now. I'd have to go with someone, I'd have to book the train, and book the taxi to get me to the station, and all that kind of thing, book the ferry...

You used the word 'reduced' in respect to what you could offer. This perhaps implies that you see yourself in a more negative way than before the accident.

No I don't. Mentally I think I am the same, but physically I think I am different. I mean I can't run now, I used to be able to run, you know. I had a dog, I could

run with the dog, a beautiful animal, I used to love racing the dog, chasing across a field, and diving at him. But I couldn't do that now you know. I always think that I'll be able to again, so when I can run again I'll get myself a dog. You know, I will be able to run again as well. I mean there is progress all the time. It's good. It's getting better. People are really good to you, some people really love you, you know. It's good because people are basically the same. I mean, I am conscious of being the same person, but it's just physically that I am different. I mean, when you asked me about this girl friend, I mean I wouldn't have stuck with her before, I would have just said "fuck off", you know. But having someone to come round and see me, someone to care for me, that was really good and you stick with it. One thing that was sad was after the accident they cut my hair. I used to have a long plait half way down my back, it was beautiful, I really loved it. They shaved my beard off when I was in my coma, so they asked my father and he said "If it'll help, shave every hair of his body off".

I get really frustrated at times, not frustrated but I day dream a lot, about how I would like my life to be, you know, things like that, you know, things I could be doing, people I could be with, you know. I think that it is because I am disabled that I have the day dream now. I used to dream a lot before but I day dream more and more now... Sometimes it's with me walking properly, but the same things I want, you know, like I'd like to get married, I'd like to open a vegetarian restaurant, I'd like to go on our honeymoon to Jamaica, you know, maybe have a restaurant in Jamaica or New Zealand. This is what I day dream about. One day they'll come true.

Do you have any brothers and sisters?

I have a younger sister. She went crazy when I had the accident, she went around the house crying that we must get this house exorcised, that it was evil and the devil was there. But she is so concerned with herself, she get's on with her own life in her own ways. She has never taken me out for a drink when I go home, which really hurts me, but she never takes my father out for a drink either.

How do you feel about your body?

Well, I hated my foot in particular, but I had a friend and he said to me "you should love your foot, you know", and he was right, 'cos then I got in to loving it, which is better and I love all my body. It has taken a while, well it's still going on. I am not really back into it yet, I am trying to get back into it. Trying to get the nerve cells to, you know, go down my arm, so that I can move it and do things with it. The other night I was really stoned and I had my foot on this chair and I was moving it a bit, just about half an inch, which was good 'cos I haven't been able to do that. It takes a lot of concentration. It's really good, you know, I can notice improvement all the time. You've got to really 'cos it keeps you living. Keeps you enjoying life and you think this is really good. You've got to give yourself little goals. One bad thing was that I put on a lot of weight as well. I was nine and a half stone at the time of me accident, I was really thin you know. I didn't have this stomach then. I went to twelve stone four when I was in hospital. I was stuck in a wheel chair all the time and then I went to ten stone two which

is good, but I would like to get to nine stone nine. That's my ambition, I will too, one day as well. Won't eat for a week or something. It was a big shock when I got my gut and my face has got really fat too. I shaved my beard off when I was down South and I thought "Oh you ugly sod!" and I grew it back straight away. My face was really fat you know, wasn't nice and sharply profiled which I thought it would be.

Kay

It was last January, I went to the diabetic clinic as I had problems with my legs due to my kidneys. The doctor said: "Well have you noticed your eye sight going at all?" And I said: "No, not really, I drive the car and everything." He said: "Well it is". So I started off with some laser treatment, and that, I had the laser treatment up till about June and my eyes were going a bit and I got some glasses from the opticians and I thought everything was fine. And then in June I had a haemorrhage in my right eye, at the back. Just woke up one day and it was pink, like a pink film at the back. I mean I went to work, I didn't think anything of it. Anyway they said: "Oh, it will probably go, not to worry too much". And so I carried on with the laser treatment but I ...at that time, unknown to me I was pregnant which didn't help because that caused lots of diabetic changes in my eyes and I lost the baby. A week after I lost the baby I woke up and my left eye had gone as well and that was it. Everything was like blurred, completely blurred and I couldn't see. So I went to the eye specialist and he just said: "Oh well the left eye, we can't do anything for that." It was a matter of two months that just went completely, I can't see anything out of my left eye. They did a three hour operation on the right eye for a detached retina which they said was like successful, but there is eye damage, so what is successful to them isn't successful to me. I mean some people who have had detached retinas can see quite well. I can't see to read at all. I've got a special lenses so I can see to read bills and things but it's hard work if I want to read a letter or anything. And basically it just shattered me. Completely. You know, I had a good job, I enjoyed my job, I drove

the car. I just didn't expect...kidney failure I expected to happen but I always thought "Oh no" My eyes were always good I never thought anything at all would happen to them. No pain or anything. It just happened. I woke up and I couldn't see. And you think God you know...if I'd had some sort of warning, cos they didn't tell me at the hospital, they just sort of keep on with the laser treatment and I just thought oh I'm going to be fine. They're going to zap a few lasers at me and I'm going to be able to see. So really I lost my sight in August because that's when I couldn't see anything you know.

What did you do before hand?

I worked for Scholl. Foot care, and I worked in Leeds, and then when I did have my eye problem they transferred me back to York - it was too much - I had too much stress on so they all thought that maybe it would be better if I sort of stopped in York and didn't have to travel as much, and not as much commitment, because I was dreadful for well you know just work and work and work. Get up at six and go home at ten, it wasn't doing my diabetes any good neither.

Are you working now?

No. That finished as I'd been off six months and I couldn't do the job, I mean I could do the job to a certain degree, like serving people, but it was only through my knowledge of being there a long time that I fobbed my way off before really. When I had the first haemorrhage I actually sort of looked through a spy glass to see prices and things but because I knew the till and I could feel it everybody

thought that I could see more than I could you know. But no I've finished now. And I think that's the worse, you know. Sat at home, going to my Dad's for my dinner, luckily they only live around the corner, but I've always since I was eighteen lived on my own. Bought my first house at twenty one so I didn't want to give up that independence. As much as they wanted me to sell up and ...but I bought a bungalow instead. It's a nice house. I bought this in October, it was all going through when I had the eye problems. Everything was sort of...well, I thought well I've got to be sensible about this, I fell downstairs, not badly but em, I ripped my shoulder and I thought oh this is silly, they were very steep stairs and it was a very dark house as well and I found that I was tripping over things. So I thought I can't you know there's no way I can live there, not on my own, so I bought this which is round the corner from Mums.

When you lost your sight in August, when there was a dramatic loss, how did your friends and family react?

My mum, well she cried in front of me a couple of times you know, but generally she'd go "It's alright, it's alright." But I did ask her at the weekend I said "How did you react?" Because I didn't know really. She said "We were devastated. Absolutely devastated." But in front of me they were brave, you know: "Oh it'll be alright", but they were devastated. I've got some family quite close, but they don't really talk about it much, because I can see a little bit they think that everything is alright now, You know she can see a little bit, even though it's as bad as it is. And I can do things one day, when my eyes feel quite good, but the

next day I can't do the same thing. I need to hold hands etc. and I think that they think that sometimes I put it on a bit. But I don't. It just depends on the weather conditions being right, the light and how things are. I mean they've been brilliant, they've been good. I've never had any counselling or anything. I think what happened with loosing the baby and everything, I mean that didn't help, I never had any time to grieve over that. I mean I was due to go to work the next week and then Bang! My sight goes. I had so many things to think about at once that I don't think they knew what to tell me, or talk to me about because things were happening you know. My friends have been great, They sort of well, they're good but they expect me to still go out round town for a drink like I used to do. And if I say well I can't cos I can't, you know, they say "Oh go on, course you can you silly thing. Kay, you're still the same." And I say "How many blind people do you know who go down Micklegate on a Friday night? I've never seen anyone with a white stick going into the pubs". You know and er I feel I'd rather go in the country and have a drink you know. But they're always saying that they must get me to do this, they must get me to do that, and at the moment I feel I daren't. But they say, "Oh I'm sure you could go so and so, get to the shops", and I think "Oh alright then I'll go." I've been to my Mums using my white stick and when I've been out I've nearly cried because I'd made it down the road, well I'd only gone down the road, I'd only crossed two roads, but I was so sort of oh fantastic I've been, you know. It was such an achievement that em... They sort of tend to think I'm the same old Kay that can do everything except for drive the car, which I aren't. I'm just coming to terms with it myself.

Are you saying that you're not the same person?

Well, I'm more rattier, and I get mad easily and I'm jealous of people who can see. Definitely jealous. And why me you know. Why can't it effect someone who is older and you know I get jealous. I say to people I'm jealous of you, like friends who are learning to drive and they say something like it's so difficult to learn to drive and I say "Well thank God you've got your sight. I wish I could bloody well learn to drive." You know, I do get a bit mad, but em... At first I just couldn't quite believe what had happened. I thought everything was going to be fine you know, I'd have this treatment...I didn't think it could happen to me. I never in my wildest dreams thought I was going to wake up one day, cos I'd woken up, when my left eye went, I'd woken up in the morning, at eight O'Clock, had a cup of tea etc. and it was a Sunday, and I went back to sleep and I woke up at eleven and it had happened. So between eight and eleven, I was feeling fine, it happened you know, and it was just shock I think you know like my God what am I going to do now? What am I going to do about work? My first thing was work, you know I had to go to work still, but I mean there was no way that I could go to work but...it was really a shock. I wouldn't say that I cried a lot. I cry more now and I got sort of frustrated I think.

How did you find the doctors? Were they supportive?

Not really, well, I went to, on the Sunday when it happened, to the York District and I saw a foreign man, I can't even remember his name, and he was all doom

and gloom, you know: "Your eyes are badly diseased and I don't think we can save them, but come back on Monday and we'll refer you to Leeds". So I went back on the Monday and I saw some one else, who wasn't actually from York, he'd come in, he said: "Oh yes, we'll just take the jelly out the back of the eye, and put silicon oil in." I said: "Will I be able to see better?" "Oh yes". So I went away thinking "Oh great, I'll be able to see". You know, if I just sit for a couple of weeks like this I'll have my operation and all and I'll be fine, I'll be able to drive the car again... You know, so I'd got it in my head that after the operation I'd be fine. Having to see a specialist in Leeds was just a formality, which it wasn't. When I went to the diabetic clinic I said to the doctor: "They say I'll be fine after the operation." And the doctor just said, very quietly: "Yes if the retina isn't damaged." Which, at the time I didn't realise that he was saying: "Your retinas are damaged." But he didn't come out and say that. They were very nice, just very quiet with me, you know very "don't say too much to her". And then I was poorly before I went into Leeds hospital, but nobody ever told me what was going on till I actually got to the hospital, then they explained it. And I think on the day of the operation I asked if it didn't work what would happen. Because I could see a little bit through all this fuzziness, and she just looked at me and said: "If it doesn't work you'll just be black blind completely." Then I didn't want to go for the operation cos I thought I'd rather live like this in a cloud, than I would in total black. But em, like I say, as it was they did the right eye, but they can't do anything for the left. You can see to get around the house, but you know I can't see to read or write. What sort of job can you do when you can't read? I haven't got any training or anything, I think I'd be better if I did.

I think it was really bad that I didn't have any counselling. But at the time I didn't really want any. I saw the social workers in the hospital, but they only really was trying to help about work, about money, about getting money and they didn't help the situation. Can't say they did.

Did you feel that the doctors explained things well to you? Were you able to talk to them?

I did in Leeds, the eye clinic, they were pretty good and explained everything. But the doctor who did the operation he's, I mean he's a wonderful man, the work that he does, I mean fantastic and he is probably one of the best in the country, but he's not a heart-to-heart man. The house doctors were better because you felt you could say things to them and I kept asking them more questions than I did the actual specialist, because he was a bit "right everything satisfactory" and that's it. You know "Can't do anything with the left eye but we'll soldier on with the right". And I was so thankful that he'd given me a bit of sight back that I daren't ask any more questions. I didn't really want to know. I didn't want him to say "Oh in six months your eye might go". I was quite happy with what he said. If he said it was successful I was quite happy to think that, although there was still damage. And when my social worker came for the first time she said she'd have a look at my sheet and she said "Can you understand what's wrong with your eyes?" I said "Not really". And she told me and I thought I didn't really want her to tell me, and I said "Don't tell me, because if it's bad I don't want to know". But my doctor isn't very helpful.

Is this your G.P.?

I mean, I think they're ignorant, as far as what goes on with eyes, I know they are complex things so when I tell him what they've done he just says to go back to the clinic. I don't think he realises. I think you're just a number or a pair of eyes to doctors. They are not interested in anything other than: 'this is what has happened and that is it'. Not that you're still young or anything. I didn't like being registered as blind what so ever. One doctor said I'd be registered as partially sighted but then he said: "We're going to register you as blind because you can't see." You know I always thought that registered blind people were actually, you know they couldn't see a thing, you know black blind. I thought well no I'm not. I'm not. And I didn't want that at all. It was horrible. That happened on New Years Eve. It took them six months to register me blind you see, which I wasn't impressed by.

Was it the label "registered blind person" or fear of becoming black blind that ...

I think it was the fear not the actual label, because I knew what I could see, I knew what my limitations were, but er if I do wake up and I can't see anything and it's completely black, well then I'm still registered blind, it's not going to get - you know to me registered blind that's it that's the worse you can get, you can't get - there's not a black blindness after registered blind that is it. Nobody is going to bother because I am registered blind already. So if I loose it people will say "oh well she's registered blind anyway so it doesn't really matter. It was a shock and

that. I didn't like it at all. I spent New Years Eve sat just crying, my boyfriend kept coming in the bedroom thinking that I had committed suicide because I was so quite and I'd shout "Get out! Get out! Go out and enjoy yourself".

You say your friends often suggest that you could carry on doing the same things as you used to do. Why do you think that is?

I don't think they understand fully. Because em, say if one of them comes and visits and has had their hair cut and I can see and I say "Oh your hair looks nice." They think "Oh she can see perfectly well". Well I can't. I can see a shape of difference, but they think oh when she gets her specs on she sees great. And I feel I'm ugly, I'm so ugly with these glasses on. Awful, and they say "Don't be silly". And I say "Well you don't have to wear them, I'm not going out in them". How can any one think I'm attractive with these thick specs on? And they just look at me and think it's Kay in a pair of specs, and oh you can do this, you can do that.

Do you think that having to wear thick specs, use a white stick ...

Oh I hate it. I hate it.

Do you think it has changed your sense of your self? Your own body image?

Oh definitely. I hate myself and I go through, I mean I can't. I mean before when I used to go out I used to probably spend a couple of hours curling tongs my hair

and I used to put my make up on, put my eye make up on - can't do that. I put my mascara on now and I know for a fact that it's all black under my eyes and I've got to get Richard, as he usually takes me, to wipe under my eye, but I mean I'm determined to do it myself, and if I say to him "You'll have to do it", and he'll say "Oh I can't touch your eye". I can do it quite well, I can't look in the mirror and see and think oh yeah that blusher looks nice or that's a bit...Like we went to Tesco's with my Dad shopping and he had to pick my foundation for me. Well you know, my Dad's nearly sixty and I'm asking him what colour foundation to get. It's hard for me, you know. I can't go in and think I'll...you know that looks a nice colour lipstick I'll get that because I can't see that well to pick things out. And that's hard. Not being able to just go and do something that you want to do on your own. Always having Richard to take me, he comes and makes sure I'm alright.

He's your boyfriend?

Yeah, yeah. He was my boyfriend when I lost my sight. I think he was upset, because he is here most you know he comes home from work makes sure I can get my tea or, I mean don't get me wrong, I cook tea and now I've got my specs I can do my ironing so I do his ironing, and I do his washing for him because I can do that. If I can do something, do it quite well I love it. I say "I'll do the ironing for you!" I'm really proud of it, whereas before they'd be ironing piled up and I'll say "Don't you want to do it? I don't fancy doing it." But I feel trapped in the situation in that I can't just go out and do something. If I have an argument

with Richard at midnight I can't get in the car and drive off. But he can. You know - that's hard.

Do you think it has changed your relationship with him?

Well, I had problems with my legs before, I wasn't very well before this happened, and it was my kidneys. So I was quite poorly then. So that sort of helped in a way that I was poorly before this. I think that if this just happened and I hadn't been poorly before he wouldn't have been able to cope. I think he has coped quite well. But there again if he wants to watch something on the telly, for instance, and I want to watch something else, I'll make it an excuse: "Well I can't see and if I want to watch something that I want to enjoy..." You know, and "...I can't. you go and make a cup of tea because I can't see". Whereas other times I'll just make it. I do play on it. He said "Don't forget to tell her when she comes that you play on it". I said "I do not". But I do. I thought I must be honest, I do.

I'm dreadful I can sleep all afternoon, like at the weekends we'll go to my Mums and have dinner and he watches telly and I go for a sleep, I say: "I'm tired, I have to rest my eyes!" You know I make them the excuse, when ever I don't want to do anything it's my eyes. And then if he says I can't do something because of my eyes I say "I can!" And I'll do it.

I think other people say things like at the moment anyway with the job front and things I'm frightened, no confidence to think right I'm going to get a job, or retrain for something or what ever. I couldn't go down to Torquay to the

rehabilitation place on my own, frighten me to death, I just daren't, so they think well it's O.k. because she can't get around, she's alright in her own bungalow, she's quite happy, and they keep saying "When the summer comes you'll be out in your little garden and..." It's alright, I don't have to prove myself because I can say "I can't see." I make like sometimes I tell...I don't want people to know but sometimes I tell them because I think well they won't expect too much of me then. Although I don't really want them to know I can't see. Like I don't like using my white stick, but I do it sometimes, like in town, if I'm with my Mum or whatever I don't have to use it, but I get it out, and people say "Mind that lady, get out of her way!" YOU know... I do it so people don't bother me so much. It's hard. I don't want to be like classed as disabled I hate that word, I mean I remember before, I mean I've been diabetic since I was five, so I've had twenty five years of "Oh you've got a disability - you're diabetic" and I didn't think that I thought no I'm not I don't want to be. And my worst thing that happened was when my sight was going I couldn't see the air bubbles in the syringe, someone would have to come in the morning and make sure that it was O.K., then if Richard came on the night I used to shout at him: "Are you sure there are no air bubbles? They could kill me". You know...everything was so dramatic and then I got a click syringe and I can do, other than change the capsule, I'm alright, I'm quite...I'm more independent now because I've got these things, you know I could go away for the day and not bother, I could go on my own if I wanted to, but I haven't the confidence to go anywhere at the moment. Although I think I am getting more confident, I've started to go out a bit more but I'm getting quite bored so I want people to take me places and I think that they should do. If I'm

going out one night and I want something to wear I ring Mum: "Can you take me into town this afternoon?" And if she says she's a bit busy I say: "Well, I need to get out and no one will take me!" So they take me to keep the peace. And I think I'm like that at the weekend with Richard. I say "You've been at work, you see people, I haven't seen anybody, I want to go here, there and everywhere!" Even if we just go for a drive around. Not that I can see like I used to do, but it's getting me out of the house. And like my Dads good he helps all the time. I go round have my dinner and we have a look round, my sister is expecting a baby so she comes round... and that's nice, but then when I come back I think they can nip into town now, or they can jump in the car and drive over to so and so and what can I do? I've just got to sit here, waiting for someone to come and pick me up. There's no spontaneity and I have to rely on other people all the time. And I don't know if people are looking at me, if I'm sat in a pub and I haven't got my glasses on, because I'm too vain, and someone will say, we go to the local quite a bit and I know quite a few people in there, but when it all happened obviously I didn't go out and a lot of people don't know, and friends will say "Oh so and so's walked in" and I say "You'll have to go and tell them I'm not ignoring them, tell them that I can't see." Instead of waiting for them to come over and me telling them I'd rather them be told, and so when they come up to me they know, you know. I can deal with it better like that than having to say "I'm sorry I can't see you," or "You're only like a shadow". I recognise the voice, you know cos your eyes look perfect people think well she's focusing alright, they expect blind peoples eyes to go all over the place. And I know, because I had to ask one of my friends if I stare at them they think that I can see them perfectly and I can't. They

could be ... anything you know.

Do you find social situations quite difficult?

It is to a point. If people know then I find it fine and I'm quite confident. I'm very independent. If I want to go to the toilet I'll go myself. On Friday my friend said "I'll take you to the toilet", but because I had been to that pub so many times I said: "No I'll go myself." I wanted it to look... I mean I probably looked very drunk because when I first stand up, with one eye being completely blind I'm a bit unsteady. So I probably looked drunk when I...but I had to do it myself. So you know...I say to them "I'm still the same person just because I can't see, I'm still me." I think I try a bit too hard sometimes to be a bit too independent or confident - it doesn't always work.

I don't like self help groups or things like that. I don't want to go where other people are blind. I don't want to be classed as a blind person, and everyone sat round with their dogs and their white sticks in a semi circle talking about their experiences, which when I got your letter I just looked at it and thought: "No I can't do it." But I thought "no, this is stupid this is silly, could be one of my ways of talking about coming to terms with it more". I don't think you can block yourself off and think I only want to be friends with people who can see, cos I expect people who can see to be friends with me. And I thought it would be all doom and gloom to talk to one of these groups. It's depressing I think the thought. I always used to think, well there's a lady called Mrs. Brown that I know

that used to come into our shop, about three years ago she got a dog and she used to come to me to serve her, and she was very nice. And I used to think - that poor woman what must it be like to be blind. I used to close my eyes and think Oh God I would absolutely kill myself. And I say to Richard now, "I'm going to kill myself if I get any worse. If I wake up and I can't see a thing I'll kill myself". I know I won't cos I haven't the courage, I'm not strong enough to kill myself but I feel, some days I think I can't cope and it's only, I don't know, for attention probably that I say it. So he'll come in and say "No, no no no you're all right, give me a cuddle". And I think oh maybe I won't! But there are some days where I feel I don't want anything to do with anybody else. I just wish I could go away and be on my own for ever, you know.

What do you feel about the future?

Well, the next thing I'm going to have to think about is some sort of job, because I'm being driven crackers. But there again it's very difficult for me because living on my own I've got a mortgage and to earn the sort of money that I need to pay my mortgage at the moment I get sickness benefit and income support, but my ex employers have messed that up at the moment, they pay the interest on my mortgage. To get a normal nine till five job in an office and get no benefit what so ever I just couldn't afford to live because my mortgage is too big. So I think oh crikey if I went part time I just wouldn't survive. I just don't fancy going down to the rehabilitation centre in Torquay to be honest. I don't like the idea of it you know, I once saw a girl, we were on holiday in Torquay, and she was being

trained with a white stick and a man behind her, and I thought: "Oh no I couldn't bear that". And the leaflets that I manage to read with my special lenses, was like welding and doing all these jobs that I could never do before. There was a girl there with a pair of goggles on and I thought that's not me anyway. It never has been. So why would I want to do a job, say an office job that I wouldn't enjoy anyway. So I'm going to have to... It's all this you can water ski and go rock climbing I'd be frightened to death. I wouldn't want to go. I think people have to be a bit crazy to want to do that. So I thought it's not for me, but like at the hospital no one has ever said "We think you ought to do this that or the other". Nobody has ever said anything. That's the only contact I have with the hospital. I don't see anybody else. My social worker pops in occasionally, but she can only give me advice. I mean she was good about my disabled stickers and got me a white stick and things. I wouldn't have got a clue about that and my free bus pass. I had no training in using the white stick though. She brought it in and put it on the side, and that was it. No mobility training - nothing. To be honest I don't know how to use the stick or anything. I just sort of tap it against the curb. I think it's really for in town so that people don't knock into me. I carry it sort of half folded so really it could be anything, could have bought something at a DIY, so I don't really use it properly. Before it happened and I was having problems with my eyes you know my friends said to me once: "You're all right Kay, I've bought a car so I'll be able to drop you off at the blind school, or I'll take you to REMPLOY to make dishcloths". And I was so disgusted her saying that, it really upset me and that was the first time I felt that that might happen and I might end up a vegetable. I'm still the same me just cos I can't see very well... I don't want

to see myself as disabled, but then I can't imagine myself ever doing anything...I don't know how you cope I'd rather sit at home... I think that everybody thinks that blind people are in their seventies , but being diabetic for twenty five years, people who usually get it like that, I mean I got it like this but usually people get it when they are middle aged, I mean people do get it when they're young but, so when they've had it twenty five years, if they got it when they're fifty they're seventy five - so if their eyes go they are old aged. I mean I've seen them at the diabetic clinic and they are in their seventies. I mean I've not looked twice at them, thought oh well their sights gone poor things and that's it. But when I see somebody young with a white stick I think Oh dear and you do. You think that is sad. And friends say they told other people that I couldn't see and they said "Isn't it tragic, tragic." Well it is tragic but life goes on. You know it's hard to explain.

Can you make sense of what has happened to you at all?

Not really, I mean I know these things happen but I can't... I think I'd rather have anything happen to me than this. Why should it effect your eyes so much? Why just because you've got sugar should it destroy you...You know they can do heart transplants, you can have kidney transplants, but you can't really have an eye transplant. You know what will be will be, but there again with me not being able to see anything out of the left eye - it's just like black with a little bit of white light, you know if a bright light was on I'd see the light shining through like splattered blackness, and I think well some people...I mean all diabetics when they

go blind, do they go black blind or what can they see? And nobody has said well some can see a bit, some can't see a thing, some get worse, some don't get worse you know. Nobody has ever said, because I've never spoken to anybody else with it.

Do you think it would be helpful to speak to other people in similar circumstances?

I didn't think so because I didn't want to know cos if I did find out that every body eventually got black blind or whatever, then I wouldn't want to know that. If I wake up in the morning and I can still see what I can see then I'm quite happy. Of course I've got to go through two more operations on my right eye cos he says I've got a cataract which was caused through the silicon oil in that eye so may be I'll be able to see a little bit better with the cataract off. He wouldn't do it if it wasn't going to be better. Why can't they transfer retinas - it's so annoying!

Just to go over things a bit - what are the most dramatic ways that it has changed how you see yourself?

Confidence. I've no confidence. Meeting people, I don't know how they are looking, how they are reacting to me, I haven't... I mean the job I did I used to stand up in front of people and talk, WI meetings etc and I had lots of confidence, now I think I've nothing to say to anybody. What do I do? I can't see

so I'm sat at home. I've no confidence in social...meeting other people...I'd rather stick with my own little group of friends. I can't imagine walking into a place where I didn't know anybody and having to talk. Which wouldn't have bothered me before. I feel like a tailors dummy. I mean when you can't see the other persons face I don't know if they are bored talking to me or what they think or you know say they glance across at anybody else I don't notice it. Just communication really. It's like if I say something to someone and they nod or shake their head I think well what was that? Were it a yes or a no because I can't see what you're doing. And I get frustrated then and I say: "Would you mind saying Yes or No?" Even to my friends and they say: "Oh sorry" and then they shake their heads vigorously! So I say: "I still can't see cos you are in a shadow", or it's dark and I don't know if it's a nod or a shake. It's like on holiday, I'm going on holiday to the same place as I went last year, it was in June last year and I was O.K. But there's lots of steps to the apartment block we're going to, and I'm dreading this year cos I know I'm going to have to use my white stick to plod along and when Richard says something like: "Look at that over there, Oh isn't it lovely". Now I can see ten yards in front of me and it'd foggy and I say: "What bloody view? I can't see anything, it's just foggy to me."

Does that sort of thing make you annoyed with your friends?

I get annoyed with Richard more because he'll say stupid things, or what I call stupid things, he knows very well that if he just sat and thought about it that I couldn't see. Or he'll say something like "Do you think my eyes look a bit blood

shot?" or "Do you think they look sore?" And I say: "Don't be so stupid! How can I see?" You know. "I can't see - I'm blind!" That is what I say to him all the time, if I'm annoyed: "Don't be so stupid - I'm blind, I can't see!" So yes I get more annoyed with than before. He's put up with um...hell really. I mean sometimes I've been very very nasty and it's because I can't take it out on anybody else so I take it out on him and I mean I can be as nasty as hell to him and the phone will ring and I'll pick it up and I'll say: "Oh hello, are you alright?" I'm just completely different with other people. Yeah I am frustrated, I get mad with him and I've got a very good memory and if I ask him to do something and he forgets I'll shout. I do. "I wish I could do it myself, but I can't do it myself, I'd do it if I could see!" You know. I think why I look, ...it probably wasn't anything to do with it but I blame the doctor. Because I was very poorly with my legs, and they were swollen and he gave me surgical stockings and said it was travelling on the train to Leeds and back each day, for a year and a half. Always said that there was nothing wrong, just to keep my legs up. Went to the specialist and he just took one look and told me it was my kidneys. And they are scared now because I went in and lost four pound off my legs over night in fluid, and if they had done that in the first month when it started, the scarring of the kidneys wouldn't have happened. Another lady had had problems with her kidneys and her sight went, so I think that's why it's happened. I can blame somebody and although it probably would have happened anyway I think it's better if you blame some body. Or for me it is, I think: "Oh it's the doctor that's done it". You know. But it probably wasn't anything to do with the doctor but there again I don't know. It's like when I went under general anaesthetic they tried to set up the drip, once

when I had the miscarriage the week after my right eye had gone, but my left eye went, then when I went into hospital for my right eye operation the left eye from being quite bad went worse. So I now think, I've got it in my head that it's the anaesthetic that had caused my eyes to go worse. So I'm dreading going back in cos I think it's going to get worse, you know so...

Kay Interview 2

Well, I'll tell you what's been happening since I last spoke to you...well we went on holiday and came back and I had the operation on the eve of my thirtieth birthday, so I went in and had the operation, bandages on my eye. And that was like the only eye I could see out off, which I could see pretty good. Took the bandage off and you just wouldn't believe it...I could see so well! It was absolutely fantastic although I still had a cataract on but I could see so well... I could see my way around without my glasses, my very thick glasses...I was absolutely over the moon you know...I could do my hair , I could see in the mirror my face clear...and oh everything was really good. Anyway they said they'd have to operate again to take the cataract off, and they said that if I do need glasses that eye would be well not normal but as near as damn it. So you know I went away very happy. Three weeks later I went for a check up and the first week after that they says I've got a slight hole in the retina but it should be O.K. But the third week he said my eye was detaching again. But he said he should be able to put it back alright. So I went in, not too worried cos I'd had the operation before and thought they'd just put the oil back in and everything would be O.K. And then when I came round after that operation I had an eye like a football and I couldn't see anything, you know it was twice as bad as before I had the first operation. Put my glasses on and thought I'd be able to see a bit better, but no. So, I thought 'Oh God'. But anyway I went back to the check up and it wasn't getting any better and he said there was only one thing. He would have a word with this professor at Manchester, you know the one who did Frank Bruno's eye, and I thought that

would be my claim to fame! You know if he can do Frank Bruno's...You know I went from seeing quite well and two weeks later I couldn't see a thing. It was such a shock. Even though I had woke up with the haemorrhages before you know...I can't explain it I couldn't see well when I woke up with the haemorrhages but there was still more shadows and shapes than when I woke up after the other one. So anyway I thought Oh well, I'll go down to Manchester he is bound to be able to do something. It was all very traumatic and we went down...Anyway he said we'll give you a ten per cent chance of it working and er...I seem to get ten per cent chances in my life! Every time I see a doctor there is a ten per cent chance of that working or this working! And he said I can't really tell until we get in to the eye but he said he's only ever had one case like mine that's gone like this, in Edinbrough somewhere. So I had a few hours to make my mind up. He said that they could do it with the ten per cent chance of it working but it could leave my eye very red looking and very nasty, you know visually looking nasty, and painful for the rest of my life or I could just leave it completely blind. So I thought well what do I do? Anyway I decided I would have it done. On the following Thursday I had a six hour operation on it, they took half the retina away cos it had scar tissue on it etc. they took the cataract off, they took most of my iris away, so I've got one eye which has a big pupil and the other has a very tiny bit of blue. He said that I was very unlucky because I was diabetic and had fair hair and blue eyes and that was a very bad combination. Blue eyed diabetics tend to go blind more than brown or green eyed. So, of course, well, I never saw again. They were quite pleased with it said it was a successful operation but I never did see again. That was in the September beginning of November. Day after Guy Faulks night

I woke up with what I thought was a bad chest, couldn't breath, I even stopped smoking for three weeks! And the doctor came out to me and thought it was a chest infection and gave me antibiotics and on the Sunday night I rang the doctor up because I was going to bed and my back was all swollen with fluid, and my feet were all swollen, I mean I had been suffering before with swollen legs, but I hadn't had symptoms like that for a couple of years. Although I had been feeling sick, but everyone thought that I was so naughty because everytime I went to my Mum's for tea I wouldn't want any I wanted what ever took my fancy...and I couldn't understand why I felt sick all the time. Anyway phoned the doctor up and I said I think I am going in to kidney failure, I can't hardly breath. He said "You don't sound breathless to me". But it was like short breaths you know and I told him my back was swollen and he said: "Huhm you don't get kidney failure with a back swollen". Anyway he wouldn't come out to me. So I rang my dad and he stayed up all night with me, and I thought I was having a heart attack. Anyway Mum was absolutely furious and she rang him up and he came out and gave me water tablets and that was it. On the Monday I had to go to a check up in Manchester, so we drove all the way there. When I got there they said: "Oh my God! You are so white!" I was unbelievable. They asked me when I was going to the diabetic clinic, I said: "Wednesday", and they said: "Make sure you go." On the way back I was as sick as a dog in the car...anyway got to York and they said I had a lot of fluid on my lungs and I had to go in for a couple of days. At that time I would have agreed to anything...to chop my head off. So I went in and two days later...I wasn't going to the toilet and to make things worse they were giving me like litres of water because they wanted that for my kidneys and that blew me

up even more. I mean I hadn't eaten properly, well for four months I hadn't eaten really well. And I was eleven stone, I had always been about ten stone, so I put on a stone of fluid. Anyway the doctor who you must know said that they would have to send me to Jimmy's for treatment on an artificial kidney machine. I knew he meant dialyses but that is the nice way of saying it. This frightened me to death, absolutely...but anyway to cut a long story short they didn't send me they sent me to Leeds infirmary for the weekend. They said things aren't as bad as they made out in York you know. They told me in York that I had had heart failure as well...but that was because I was anaemic but they couldn't give me blood because I had too much fluid in me you see. So I went here and felt much better, didn't feel too bad and on the Monday one of the doctors said I could go back to York. I was over the moon laughing and joking with everybody in the ward that I was going back you see. I was the only young person in there. But when they came for the ward round on Monday morning they said I had to go on what they call CAPD. Well I had been told about CAPD and all I heard from the other patients that were on it on the ward, was that they put this tube in your stomach and it sticks out a foot and four times a day you put a litre and a half of fluid in your stomach through this tube and drain it out and it draws the fluid off you. You know I had to learn this blind. Everyone else was sighted you see. Well... he just came in, the specialist and he said I'd have to go, we'll have to arrange for you to have the operation. I said: "No! No! No that's not right they said I wouldn't have to have..." He said that that wasn't right and walked off. Well I was absolutely devastated you know but I felt that poorly...a week later I had the operation. Everything should have been fine but it didn't work. The tube leaked,

fluid, I mean they'd start you off with a little bit of fluid in you ...cos what it is is a tube what goes in your stomach, not your stomach where your food goes, your perineal the lining on the outside of the stomach which goes through up to your abdomen and they put the liquid in gently and build it up until you take a litre and a half of fluid and then you start your training see. So it didn't work you see so they said I had to go home for the week...this was like November and this went on till Christmas and I was blowing up and blowing up with fluid. And then they said that they would have to operate to take the tube out and put another tube in. Well the tube you know - don't get me wrong - the tube now I don't know it's there but at the time when they put it in it is agony you know it's like an open wound. Anyway...so I had I went through Christmas I didn't eat a thing well I say I didn't eat a thing the only thing I ate was a dry cracker. On Christmas day I had one mouthful of Christmas dinner and that was it. It took me about three hours to open my presents I couldn't breath I couldn't get up and er I went back in to hospital to have the operation and they got me all ready for theatre and I had two litres of fluid on me so I had to go on the haemodialysis. What they do is put a line in your groin and it takes all your blood out and then I had the second operation and another tube put in and touch wood, everything is fine with this tube...didn't hurt as much as the first one... it hurt for the first three days ...then I went and did my training which is its very...I mean it isn't complex, you could do it I've no doubt...but anyone with no patience and half a brain wouldn't be able to you know what I mean. They said to me that they were planning on a month to train me in from scratch, from doing everything and I did it in just over a week you know so...which they said was absolutely brilliant because they said

they had never seen a blind person do anything so quick. And I was the first person to use this one in Leeds anyway so...but you know you have to like scrub up, wash your arms your hands four times before you start, everything has got to be sterile. Only thing I can't do is draw my own injection up. But you don't inject yourself anymore you inject the bag of fluid. I do this four times a day. It's a pain. If anything touches you you have to sort of swab yourself with anti septic...you have to do that about six times every treatment. If anything touches your hands you know you could get perentinitus. It takes about half an hour...I've got it down to half an hour anyway. It doesn't hurt, it makes you feel fantastic, I have never felt so well, don't get me wrong, I get tired. I usually have a sleep in the afternoon because it does tire you. I think if any organ doesn't work. There are two forms of dialysis, one where they take all the blood out of you and they do in four hours what your kidneys do in four days, so you have to go to Leeds because they don't have anything in York, about three times a week. But what I have is what they call continuation dialysis. I never knew there was such a thing. I mean don't get me wrong it is not nice having the tubes stuck out of your stomach but it doesn't hurt, the treatment doesn't hurt and because it is continual it's like your kidneys working properly only you don't go to the toilet, well you do but I can go a whole day and then I make myself, you know. Your bowels don't work so you have to take laxatives which isn't a nice thing because you can be up and down to the toilet all day and when you are doing your dialysis...that side of it is unpleasant but as I say I feel a lot better. And if anyone else had to go on it you know that I knew and was petrified...although saying that they said to me do you want to speak to somebody ..you know I said no. I felt why do I want to

talk to you know like the blindness I don't want people that are blind near me you know what I mean. I'm sure they all wear purple hats and orange trousers - I suppose that's actually trendy! But you know what I mean - the crimpoline look! I always think I'm supposed to buy all my clothes from Oxfam and wear anoraks with hoods...I still think that actually, I have still got that in my head. I mean we went to the blind, I only went once to the blind centre and I came back very depressed, you know. The only thing that I could play with , that I could get that wasn't braille because I can't read braille was dominoes. God! Its come to something hasn't it when I have to sit playing dominos. But I play with my Dad and we have such fun! He is really quite good and instead of just sat talking we play dominos with the raised dots! We have such a good laugh you know but em ...I'm learning braille at the moment. It is driving me crackers, I haven't practised for about three weeks my teacher will go crackers! I rang her today and told her I couldn't get in to it. But I still you know I can't come to terms with it. With not being able to see. And I said to the professor and he said there was no point in me coming back and forth to Manchester I might as well have my check up in Leeds, because he said that what they had tried to do had failed you know. And I said:" Is there any chance in the future...will they be able to do anything for retina people?" And he said: "When we can do brain transplants yes." So I took that well it's not around the corner...when they can do brain transplants... So I took it well I don't know how to take that. I'd like to think that yes one day they will be able to do brain transplants! I've got to have some sort of hope because I can'tI can't say Oh I'm blind and that's it for the rest of my life because I can't come to terms with it like that. You know...

I sort of think of myself as disabled but well I don't want to. I have a ...I don't know I feel people are embarrassed to be around me. Like when we go out to a restaurant and things they all make a fuss of me, my friends taking me out they all fuss...I think it is easier for them now that I am totally blind, it's easier for them. They sort of think well she can't see anything now so ..where before they would say there's a step and I would say Yeah I can see that. Well I could if I had my glasses on, but now... well it's harder for me because I can't see anything and I've got to depend on them like they say "Step" and I don't know if it is up or down. It is hard for me I haven't really... I think I've come to terms with it in the way that I don't get so fed up but if anyone says anything you know, if I'm in a ratty mood I'll shout "I am Blind". I am blind you know - or they say: "Oh look at that!" "Well how can I? I wish I could". And when they say "Oh work on Monday" Well they should be so lucky they can go to work. I'd do anything to go to work! You know I sort of rub it in you know and about driving "I'd do anything to be able to drive". It came last month my driving licence you know and I just didn't bother to send it off. That's like part of my life that I have to sort of forget about. So I didn't even write and explain which is wrong really but... I just thought...

Is your life very divided between when you could see and now?

Well I'll tell you what I do, I dream that I am back where I used to live in this country village and it's all things that have happened before, you know it's not.. well the past year has gone so quickly that I can't really remember. You know I

don't want to remember. Whereas I can remember everything that used to go on before I can't remember what I did three months ago...and the weeks just go by in to months and I just sit here and listen to the tapes and listen to the telly. Don't go out much. Because I can't go...I mean after I had spoken to you last I looked after a dog for a week, looked after a spaniel for a week, nearly two weeks and I used to play in the garden with it but I could see it, not well, but I could take her for walks...and I used to go to the shops every day with her and I used to tie her up outside cos I could see well enough to go in and I would go to the butchers and chemist...and she was very good and didn't pull and she would like guide me and I could see her. But when my eyes went I thought no cos I daren't go out of the house. I wouldn't dare go out with a guide dog. Now I wouldn't go to the end of the drive...I mean I got out of the taxi the other day, I'd been with my sister and she said right you are at the end of the drive and I walked off straight into the garden. And she said "You veered off to the left". I said "I didn't. I walked in a straight line". I couldn't believe it what was a straight line to me was absolutely cock eyed. No I have no confidence like that.

Do you think that as time...

I can't see it changing at all. I don't know...there will be times when I think you know that I'm going to have to...I do walk you know with people alright. But I need the security of somebody there. I don't feel that I could walk on my own. I don't know where I would walk anyway! I don't think I would manage with a stick...I probably would if I got training with a dog but there again...it wouldn't be

fair on the dog to just go to the shop and back. When I got the tape books from the guide dogs they said that you know its unfair on the dog just to ...you must make sure that it goes to plenty of different sort of places, get used to bus routes and that. But oh my god! Well.. I got the second cat after my birthday because I could see so well, I felt that it was fair that I could see so well that I got the cat and I didn't go for a dog because it wasn't fair as someone with no sight...someone who needed one...cos I know there is a long waiting list because you said that you had waited two years for your dog. And I thought it was not fair, me seeing really quite well...but I couldn't have one now because of the dialysis...and I'm waiting now for a kidney transplant...I'm on the list. It's usually about a two year waiting list but it could be ten years or it could be tonight. My friend, Betty, who was in with me, she had two offered about the start of January. One was a reserved one which she didn't get, it didn't work anyway and the second one it was hers it was a perfect match she had fluid on her lungs so they couldn't operate and the kidney would have died if they hadn't given it to someone else. So... she had two ... I could be waiting for ages.

Your day to day life is very different then from how it was when I saw you last year?

Well, yes. I could watch a bit of telly before and go for walks and things. Now I don't go to my parents house on my own or anything. Dad comes, luckily he works where he can come at dinner time, you know he either works nights or...I do a bit of my typing you know but I haven't done that for a bit, I got sick of

that. There is only so much you can type. I got bored with that so, yeah, it has changed dramatically. I feel trapped, more trapped than before. I can't see the green grass, can't see you know everything is just grey or black you know so you know no contrast. Completely changed really. Richard had to come and stop which I despise really. Not despise in the fact like I did before but people don't understand how frightening it is. You know when you can't see anything. You know I couldn't see anyone walk by, you know they could walk right by me, unless there was a very bright light on, if it's a very very bright light I can see my hand, or bright light like a heat lamp, then I might see bright colours.

Do you think that your relationship with him has changed?

Well yes it's strained. I mean the times I would have run away if I could see, and I would if I could get in the car and go I would. I would love to go away on my own just for say six months and be somewhere, you know...I am on my own during the day but I'm never independent I can't just do what I want and go out, somebody has got to bring me things in or you know I don't know where things are "Can you get me this Richard?" "Can you get me that Richard?" It must drive him absolutely crackers it really must. It drives me crackers! Where you can't just go and do something but that's me...everybody at the hospital praised me, they all praised me and I thought Oh I'm such a star I'm so good at doing the dialysis, touch wood, nothing drastic has happened, but they don't realise that it's not that, it's everyday things that I can't do for myself that get on my nerves. Like not realising that you have got a period, having to ask somebody if your period has

stopped I mean how degrading. I mean before I used to do everything you know I was self sufficient I didn't need anybody, never needed a man never needed anybody. You know I could have coped on my own. I'd been hurt in love and thought it weren't going to happen again and you know if I had my eye sight I properly would be on my own I think. That's a cruel thing to say but I don't know maybe things would be better, maybe we'd be married instead of just as I am.

Do you find you make less decisions?

Yes but I still like to be bossy though! I still like to think that I can do everything but I can't. When people say... like just simple things like buying clothes "Oh I've bought you this, everybody's wearing them", it isn't my decision, you know, yes I want something to wear but...In major things not really, still you know I still make decisions, not quite in charge but independence like the last time I spoke to you I hadn't got my independence. Also, I don't know but if I go out, like with the girls and a man comes up, that knows I can't see and chats me up, you know what I mean, doesn't know my situation that I have a boy friend or anything, I think they don't fancy me. I think I am ultra fat and ugly. Not that I was fantastic looking before, you know what I mean?

Does your eye look different? Is it scared?

No there is no scar. They look normal except that one pupil is slightly bigger than the other, but no one would know that I was blind. No I look like a normal

person. But you know I think 'Don't patronise me, you are only thinking poor girl she's blind I'll chat her up to brighten her up'. But no way! So if they ask me for a drink I always say "No, no thank-you". Not that I would anyway, don't get me wrong but I think why would they want to go out with a blind person, are they kinky or something. And I just can't cope with that, and not being able to see what people look like, I mean you can't tell by feeling someones face, a few lumps and bumps. Alright you can tell I have a right puggy nose, you could feel that or a long pointy nose but I can't see a whole picture ...no but everybody in my eyes have all stopped everybody I mean if I am alive in twenty years, not that I think I will be, they will still be the age they are now to me. If I meet people I have never seen I get a picture in my mind of what they look like...from their voices...I can usually tell from a voice how old people are, it is not very often I am wrong but I think 'Oh she's got dark hair' or ...I'm probably completely wrong but I always have a picture of someone, she's tall thin or...I get it like that. I always ask what people look like. I have an awful fear because I hate tramps because I am frightened...one spat at me once...I can't bear them they frighten me...If I'm in town and I brush against someone I think it is a tramp. I don't know why ...I always say to the person I am with - "if you see any tramps don't take me near them". Not that if one spoke to me you know I wouldn't know that it was a tramp but no I am always asking what people look like. Like on the telly you know...if I don't know them like Coronation Street, obviously you know everybody on Coronation Street cos I could still see, except for Ted who died, I didn't know what he looked like, but I always ask "Is he good looking?" Like tonight there were these two girls and one were married to this man and one of them was

coloured you see, and Richard said "She's coloured", and he came on and he said "Good God he's about twenty five stone!" By his voice I would have thought he was very tall, very white, he didn't sound coloured or anything...so yeah I like to know what people look like. In a way I tend to think ...I say to friends I'm so ugly and they say don't be silly you look better than you have for ages because you have lost that bloated look, you know because I was blown up I weigh nine stone now, and I am probably fitter looking, and brown because I've been out in the garden this summer, than I have ever looked. And if people didn't know I was blind probably think she looks really quite nice you know and I always make sure my hair is done when I go out. But for me because I can't see myself I have a poor self image. I think I am fat. I think I am ugly, you know. And I can't help that. I think I'll have to grow my hair cos you know when I can see again I'll be able to do it you know. When I can see again.

If some one said to me "Look Kay, I can see into the future - you will never see again, ever, so just don't think about it you are going to stay blind", well then I think I would kill myself. If there was a painless way. I think I would honestly. I wouldn't want to go on because my quality of life is so poor, to what I had that I don't think if there were no hope I don't think I would. I couldn't survive.

Do you think people expect you to behave in a certain way?

I think alot of people daren't come and see me anymore. Cos they don't know what to expect. Because I can't see they don't know how to treat me. I don't know

because I have this thing about blind people being old fashioned, really old fashioned, and nobody could be attractive if they were blind because they couldn't see so what was the point. You know what was the point of them having nice hair because they can't see, because they can't see it? What's the point of them having nice clothes because they aren't bothered because they can't see themselves? But I think that I've made more of an effort in my dress now that I can't see. I want to walk in somewhere and people think "Wow! She's blind and really nice!" That's awful isn't it, Richard says I shouldn't think like that but I want people to look at me and think "Gosh she's blind and she looks really nice". That's why I had my hair all plaited up, I sometimes go to the beauty shop and have my make-up put on for special occasions you know. But I want to make more of an effort because I can't see than I did before.

APPENDIX 2

Appendix 2.1 - Letter sent to organisations of/for disabled people

Department of Sociology
University of York
Heslington
YORK
YO1 5DD

Tel No:430000
EX.3060

Dear Sir/Madam,

I am currently studying for a D.Phil in sociology at the university of York. I am researching into the effects of sudden, unexpected disability upon concepts of self, and need to interview a few people who have experience of this. I am writing to you to ask if you could put me in touch with anyone who might be willing to talk with me. To this purpose I enclose five letters which perhaps you could give to anyone falling into this group and they could then contact me if they felt they wanted to participate in my research.

Thank-you very much.

Yours sincerely

Fran Branfield.

Appendix 2.2 - Letter sent to interviewee

Department of Sociology
University of York
Heslington
York
YO1 5DD

Tel No: 430000
EX.3060

Dear Sir/Madam,

I am currently undertaking research for the university of York. My area of interest lies in disability and the notion of self-concept. I became interested in this topic as a result of my own personal experience of losing my sight five years ago.

I am writing to you as I would like to interview you for this work. The interview would be informal and last approximately forty-five minutes. The questions I shall be asking would cover such areas as whether or not you think people in general react differently towards you since the onset of your disability; whether or not close friends and family do; whether you were offered any counselling or rehabilitation and if so what you thought of it; whether you could talk freely with your doctor; whether you have encountered any social difficulties.

I would be very grateful if you could spare me the time and I look forward to hearing from you.

Yours sincerely

Fran Branfield.

Appendix 2.3 - INTERVIEW GUIDE

The following areas will be covered in each interview:

- the respondents 'disability' biography,
- interaction with significant and less significant others,
- respondents sense of continuity/discontinuity,
- effect of disability on sense of masculinity/femininity,
- changes in employment, housing and financial situation,
- counselling or rehabilitation offered,
- if respondents can make sense of what has happened to them,
- if they feel as if they are different,
- if their goals and aspirations have altered,

This will be used merely as a guide and the respondents will be free to talk on areas that are of concern to them.