

# **AGEING WITH SCOLIOSIS**

## **Briefing paper prepared for Scoliosis Association UK**

Gerry Zarb

University of Greenwich

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## ABOUT THE PROJECT

The research project - 'Ageing with a Disability: The Dimensions of Need' - commenced in March 1990 and was completed at the end of September 1992. Funding for the work was given by the Joseph Rowntree Foundation. A full report - 'Ageing with a disability: What do they expect after all these years?' - will be published shortly (see Appendix for full details).

The project has examined the experiences of people with long-term physical disabilities or disabling illnesses who are also experiencing the ageing process. The findings are based on responses from over 300 men and women with a variety of disabilities, including Diabetes, Polio, Multiple Sclerosis, Scoliosis, Parkinsons Disease, and Arthritis. 125 of these have also been followed up with in-depth personal interviews.

The project has also attempted to highlight the race dimensions to ageing with a disability. Attempts to locate older disabled people from black and ethnic minority communities through the membership of established disability organisations proved unsuccessful. Consequently, additional outreach work has been undertaken to consult with local community groups, identify older African Caribbean and Asian disabled people, and to discuss their experiences and needs.

Apart from the research itself, dissemination is also an important part of the project. The specific aims of the dissemination can be summarised as follows:-

- i) to raise awareness of the existence, needs, and experiences of people who are ageing with a disability amongst voluntary sector organisations, organisations of and for disabled people, and support agencies;
- ii) to initiate on-going dissemination and debate on the practical implications of ageing with disability, and to document proposals for future action aimed at addressing the needs of older disabled people;
- iii) to suggest some of the key practical measures which older disabled people would like to see taken;
- iv) to highlight any particular concerns of different groups of older disabled people who have participated in the project.

We are also planning to organise a seminar/workshop to discuss the practical implications of our findings. This has been provisionally scheduled for Spring 1993. We are also planning to produce a practice guide for disability organisations and statutory agencies based on this seminar.

Although most of the issues raised by the project are of universal significance, it is important that the findings are made available to the various disability organisations whose members have participated in the project so that they can utilise this information in their own work.

This briefing paper is based on information given by members of The Scoliosis Association who have contributed to the project. A total of 17 people who are ageing with Scoliosis (including 3 who gave Scoliosis as a secondary impairment) have participated following a request for volunteers sent to members who were known to have been disabled for 20 years or more. 9 of these have also participated in the follow-up interviews. The average age of this group is 46; they have been disabled for between 25 and 62 years, with the average being 42 years. 7 are women and 2 men.

Following an overview of some of the main background issues to ageing with disability, the views of people with long-term Scoliosis on specific topics covered by the research are outlined. Each section contains a summary of the main issues raised and (where appropriate) the possible implications for the Scoliosis Association and others. The briefing paper is organised around the following topics:-

- # Concern about ageing and the need for research;
- # The experience of ageing with Scoliosis;

- # Physical and health problems associated with ageing;
- # Health services/health care;
- # Practical/personal support needs.

## **BACKGROUND ISSUES**

The ageing of the population in Britain is having a profound impact on social policy, service provision and professional practice. However, the 'ageing population' is a far from homogenous group; rather, there are important differences between particular groups, sub-groups and age cohorts, which have to be identified, acknowledged, and responded to, if appropriate services are to be provided and individual personal needs adequately met.

One particular sub-group which has been more or less completely overlooked are people disabled in child or early adulthood who are now beginning to age with their disabilities. Changing patterns of life expectancy brought about by advances in medical technology, treatment and rehabilitation mean that the size of this sub-group of disabled people is increasing. While there are no completely accurate figures, we can get some idea of the numbers involved from the two national disability surveys carried out by OPCS in the late 1960's and 1980's (Harris, 1971; Martin et al, 1988). These surveys indicate that there are just under 100,000 people aged 50 plus and disabled for 20 or more years alive today, with around another 200,000 who will reach this age within the next 10 to 20 years.

This increase in the numbers of people who are ageing with a disability is also differentially distributed according to both gender and race. First, although the prevalence of a few types of physical impairments is higher amongst males, nearly all the largest sub-groups of older disabled people contain far more women than men. Second, largely due to immigration patterns, most ethnic minority communities are younger than the white ageing population; thus, the prevalence of ageing with disability is likely to increase at an even faster rate amongst these groups over the next decade and beyond (CRE, 1987).

Despite the growing number of older disabled people, next to nothing is known about the experience of ageing with a long-term disability. It is important to consider that, while there may be some overlap between the interests of ageing disabled people and other groups in the ageing population, each group will bring its own perspective to the ageing and disability experience. Within the population of people who are ageing with a disability, there are also likely to be differing experiences and concerns structured around race and gender. These contrasting perspectives may, in turn, influence expectations and preferences about what kind of support may be required, and how it should be made available. Furthermore, the present structure of support services fails to meet the needs of the majority of disabled people, let alone those who may be experiencing the additional problems often associated with ageing (Beardshaw, 1988; Fiedler, 1988). Almost inevitably, this means that many people in this group will fall through the net of existing support provision.

## CONCERN ABOUT AGEING AND THE NEED FOR RESEARCH

The response we have had from people with long-term Scoliosis indicates concern about ageing and the need for more research of this kind. There are several dimensions to this concern:-

\* Some people who have contacted us are concerned about the wide variety of physical and health problems they have experienced with ageing and feel that more should be done to investigate why these problems are occurring and what, if anything, can be done to remedy, or at least minimise, the effects. Related to this, there is concern that there is very little research on separating out the effects of ageing and the long-term consequences of Scoliosis itself.

\* Even where people have not yet experienced any significant problems, some are anxious about what may happen when they are older. Apart from the implications for their own lives, some are also concerned that future generations of ageing disabled people should not have to face the same kinds of difficulties.

\* While medical research is obviously important, many older disabled people clearly feel that there has been a marked lack of attention paid to the long-term implications of living with a disability in terms of quality of life issues and practical/personal support needs. Some people stated that they have been waiting for a long time for someone to undertake a study of this kind. We are very conscious of the fact that, in undertaking the study, we have raised people's expectations that the issues they are concerned about will now be given a higher profile. While the project will hopefully be able to meet some of these expectations, there is a clear need for organisations like the Scoliosis Association to take this further and incorporate members concerns about ageing into their own work.

### CONCERN ABOUT AGEING (Quotes)

*"Ageing does worry me, although I try not to think about it because it's quite depressing. I mean, here there are stairs - and I haven't lived anywhere where there was stairs since I was a child and I didn't know if I could cope physically. I mean, it's my husband's job and obviously we talked about it at great length. Financially, it was the right step to make. We were in a council maisonette on the ground floor. So, I said - there's only one way to find out. We'll go for it, and if it don't work then we've got to think of something else. I tried for a stair lift, but the ceiling is too low, so that's out of the question. The social services did put a downstairs loo in for me, which with my disability, I do need. So, that's great - but there is still the stairs. I mean, I can climb stairs, but I do find it exhausting and I don't go up very often - once I'm down, I stay down as much as I can. But, when my husband retires, we've got to move out of here anyway. So, in the back of my mind there is a little niggle - am I going to make it till he retires, or am I going to reach the stage where I cannot go up them - in which case he would have to leave his job. There's always these things at the back of your mind. But, I don't look forward too much. I'm a great believer in today - that's what matters. In the end, it all comes down to money doesn't it. My dream has always been to have my own little bungalow - but, that's never been financially possible, so that's just a dream - you can't live on dreams."*

*"You definitely need to be able to get information from somewhere so that you have some idea what to expect as you get older. Now, the Scoliosis Association are very good. Whenever I've wanted to know about something, they can help. But, I found out about them for myself, because that's the sort of person I am. What organisations like that do need to do more of is getting in touch with people who aren't already members - especially going into schools and talking to parents, because there are so many of the effects of scoliosis that can be avoided now as long as people have the information so they can get the right kind of treatment. That is a problem with people of my sort of generation though. Because they've improved the treatment of scoliosis so much since my day, the majority of people with scoliosis don't have the same kind of physical problems that my generation do. But, we are only a minority - we're not really typical of people with scoliosis now. Maybe that could mean that doctors overlook some of the older ones - but I certainly haven't experienced that myself."*

*"I mean, nobody has ever said to me - this would help you, or that would help you. Everything that I do is purely gained through my own experience. It's just knowledge that I've learnt - nobody's ever come up with anything constructive. I've never had any dealings with the Spina Bifida Association either other than a couple of years ago when they contacted me. They said there was going to be a seminar - strangely enough - on*

*ageing and disability, and would I be interested in going. I said - yes, I certainly would. But then, they said we would have to pay to cover the cost of the lunch - which is fair enough. But, I would have had to have my husband go with me because I couldn't have managed on my own. He would have had to take a day off work and lose money, so I rang them and asked if they could possibly cover his expenses because we couldn't afford for him to do that. But, they said that they couldn't so I said - well I'm afraid in that case, we can't come. That was the only time I've ever had any contact with them, so I don't know what they do do for people with Spina Bifida, but they haven't done anything for me."*

## THE EXPERIENCE OF AGEING WITH SCOLIOSIS

Although the main purpose of the project is to examine the practical implications of ageing, it is impossible to develop appropriate policies and support services without an awareness of, and sensitivity to the subjective experiences of ageing with a disability and the impact people feel this has on their lives.

The experiences reported by people participating in the study are vary varied, although there are also several important common issues. In many ways older disabled people feel very positive about themselves despite, or more often because of, negative experiences of ageing as disabled people. Several people clearly feel that, living with a disability for 20 or 30 years or more in a generally unsupportive environment has certainly taught them the 'art of survival' if nothing else. At the same time, the majority feel that ageing also raises the stakes as far as their continuing to survive and maintain control over their own lives is concerned. Many are very anxious about what the future has in store.

Some of the main issues identified are summarised below.

- \* Many of the people we contacted felt that their needs, and even their existence, have been overlooked.
- \* These feelings of having been forgotten go a long way to explaining why such a large number of people volunteered to participate in the project. Several commented that a project about this issue was long overdue and hoped that their needs would now at least start to get some recognition.
- \* Because of the invisibility of disability (particularly earlier in their lives), many older disabled people feel very isolated and unable to get anyone to understand their anxieties about ageing. For some, participating in the study had been the first opportunity to discuss this for maybe 20 years or more.
- \* People's perceptions of, and attitudes towards ageing cannot be understood without reference to previous life experiences. As the experience of disability will have been a major feature of the lives of all of the people participating in this study, it is not surprising that this frames their personal responses to ageing.
- \* This is illustrated by people's level of satisfaction with the quality of life. The findings indicate that, ageing is typically associated with a 'downturn' in people's level of satisfaction after they had been disabled for between 20 and 30 years. Also, this appears to be closely associated with the onset of the ageing process. About half of the people in the study reported that their satisfaction with the quality of life had risen again over time as they accommodated themselves to the physical and personal changes experienced with ageing. Others, however, remained dissatisfied.
- \* There are numerous factors which influence how older disabled people view the quality of their lives. First, some people feel that the effects of the ageing process itself are like the onset of a 'second disability'. In other words, they likened the impact on their lives to the kind of experiences they had when they first became disabled. Indeed, for some who had never really considered themselves to be disabled before, the main impact of ageing had been that they now recognised their disability for the first time in their lives. Other people felt that, while they had always found the physical consequences of their impairments difficult to cope with, the additional effects of ageing had made the situation much worse.
- \* For some people, this heightened awareness of disability had been a gradual or even insidious process. Often, however, the process had been triggered by a particular problem or crisis like the death of a partner, being forced to take early retirement, or a sudden or accelerated downturn in an individuals physical well-being.
- \* Several people talked about the kind of emotional changes they had experienced as they grew older. The most commonly reported changes were increased anxiety and frustration. Loneliness and depression are also a problem for some people - particularly older women, who were also more likely than men to experience anxiety or frustration.
- \* The realisation that ageing contributes to a heightened awareness of physical deterioration was a particular source of frustration for many people. For some, there were also additional consequences like having to give up working, a reduction in social and leisure activities, or the impact on personal and sexual relationships.
- \* At the same time, several people felt that they were so used to dealing with problems like physical pain that

they did not have much doubt about being able to cope with any additional problems they might face when they were older.

\* While the kinds of changes described above are often a source of considerable frustration or anxiety, some people also emphasised that they would be much easier to cope with if they had appropriate support (personal and practical). However, given that so many people participating in the study have lived most of their lives without any support outside of their own family and friends, several felt that they were well equipped to develop their own positive coping strategies; indeed, they would not have been able to survive without them.

\* Faced with this situation, many older disabled people become fairly expert in the art of survival over the years. But, this can sometimes be a two edged sword for people who subsequently find it very difficult to accept needing or asking for any extra help in dealing with some of the problems they experience with ageing. This has far reaching implications for how older disabled people define their own independence, and what they consider to be appropriate and acceptable forms of support.

\* A related problem is that, because many older disabled people have been isolated for so long, they are often unable to get others to recognise their needs. Also, the cumulative effect of this kind of experience may be that some people do not have the confidence to articulate their needs. This often tends to be a more common experience for older disabled women, many of whom are particularly isolated.

\* Older disabled people from black and ethnic minority communities were also particularly isolated and most did not have access to the support and advice offered by established disability organisations (either nationally, or locally). The fact that less than 3% of our original sample drawn from members of various disability organisations were people from black and ethnic minority communities gives some indication of the scale of this problem.

\* Many of the people we contacted expressed significant concerns about their independence, which they saw as being threatened by physical and/or personal changes experienced with ageing. In some cases, this only extends to personal or physical independence, but for many people ageing represents a threat to their independence in the much wider sense of losing control over how they wished to live their lives.

\* These anxieties are often closely related to the lack of appropriate and acceptable support for people who are ageing with a disability. Several people were concerned about the possibility of having to make major changes in lifestyle, such as seeking more personal assistance, changing their living arrangements, or having to move into institutional care.

\* For some, such changes simply represent an unacceptable degree of compromise with how they wished to live their lives. There were others, however, who took a more philosophical view and felt that, having extra help was probably the best way of maintaining their independence, or at least avoiding any further loss of independence - even though they would still resist such changes in their lives for as long as they possibly could. A small number of people, on the other hand, had either never placed much emphasis on independence (either physical or emotional) in their lives, or, had never felt they had that much independence in the first place. Consequently, they did not necessarily perceive ageing as representing such a potential disruption to their lives as some of the others.

\* These perceptions of the possible impact of ageing on independence have to be understood in the context of attitudes towards independence, autonomy and responsibility developed throughout people's lives. For example, several people perceive achieving their independence (however, they defined it) to be one of the most significant features of their lives. This was particularly relevant in the early years, when there was often no support or guidance available. Achieving this independence had often taken many years and certainly involved a great deal of effort.

\* Many people also talked about the efforts involved in maintaining their independence and how this had become harder as they grew older. Consequently, it is easy to see how the possibility of having to give up some of their independence was a source of great anxiety. The fact that some felt that loss of independence would be totally unacceptable and that death would literally be a preferable option shows just how important this can be.

#### **THE EXPERIENCE OF AGEING WITH SCOLIOSIS (Quotes)**

## **(1. Early experiences)**

*"I've no idea what caused it (congenital scoliosis). I don't think anyone knew much about it in those days (1930's) - certainly, no one ever said anything as far as I know."*

*"My mother discovered it (scoliosis) when I was at secondary school. Nobody knew much about it then so it hadn't been picked up. After that, that's when I was referred to the Royal Orthopaedic Hospital. Actually, that influenced my choice of career as well because I had wanted to be a nurse, but I knew I wasn't going to be able to manage lifting people about and all that sort of thing, so I had to choose something else."*

*"When I was a child, I was in and out of hospital and convalescence homes for years. I went to a special school for disabled children - it was appalling. We didn't receive any education at all, or the education we received was very very poor. The attitude was that we weren't going to do anything with our lives in any case, so they just didn't bother. There was so much ignorance about disability in those days (1940's). There was one time - I'll never forget it - when I was 7, I was sent to this convalescence home. They were very strict and I suffered from incontinence - I always have - but they just didn't understand and so they used to punish you. Whenever I wet myself, they used to make me rub my nose in it. That was the sort of thing you had to put up with. It has changed a lot since then, but there is still a long way to go. Anyway, all of that just made me very determined to be independent - I wasn't going to let them break me. Also, with my mother being a war widow, I knew something about the hardships, but I was never going to let it get me down. So, I did get my education afterwards because I always wanted to work. I went to secretarial college and I did get a job, and I worked up until when my son was born."*

*"When I was young, I was in and out of hospital constantly. I used to go to Great Ormond Street Hospital. Because of my Scoliosis, one leg was 3.1/2" shorter than the other. So I had to wear surgical boots and I used to go to the hospital about 3 times a week when I was very young. And, I remember I used to have electrical treatment - that was the greatest form of torture. I think it must have been experimental - people nowadays never seem to have heard of it. They used to attach a black box to my leg and plug it in and shoot electrical volts through it. I never ever discovered what it was supposed to do - apart from nearly kill you. I used to scream the place down - it was just excruciating. Then, I used to go to a place in Woolwich which was run by the Invalid Children's Aid for Physiotherapy. Then, when I was 11 I had an operation on the good leg - the longest leg - to stop it growing, to give the other one a chance to catch up. They said that, otherwise, once I became an adult the short leg would get shorter and shorter because it wasn't growing at the same rate and I would have had to have had it amputated. So, that worked quite well. It almost caught up - it's only 1/2" shorter now. It's not enough to make a great deal of difference. So, altogether, I was under the hospital up until I was 16. By then, I was going sort of every 6 months. But, surgeons - in those days - didn't talk to you. They were terribly high and mighty. They spoke to their students and - occasionally - they addressed a remark to my mother, but they never ever spoke to me. So, they'd say - how is she mother? and she'd say - the same - and that was it. You know - see you in 6 months. So, I got very stropky then and I said I wasn't ever going to go again - and I didn't. So, I've never actually been under the hospital for my disability since I was 16, other than I have had 4 toes amputated over the years due to disability because one foot is paralysed. I've just been to local hospitals for that and sort of said - this toe needs amputating, or that toe needs amputating. They just say - oh dear, what a state - and lop them off. It's mainly due to my circulation. Because I'm fortunate enough to be able to walk - walking on a paralysed foot doesn't do it any good basically. It just bruises, and that never heals and eventually the skin splits - and then you're really in trouble, and it rots. You see, you're walking on dead flesh basically - and you're just wearing it out. But, when they take the toes off, the pressure points just go somewhere else - so I do have constant problems with it. I suppose that it is to do with age because, the older I'm getting - I've only got the big toe left, and the hard skin builds up underneath it and then it gets to the stage where I can't walk because it gets so painful. The chiropodist comes once a month to hack all the hard skin off, but it's an ongoing problem - it always will be."*

*"There wasn't any (information), but you do figure most things out for yourself. The most pressing concern in my case was to get the kind of education so that I didn't have to do any physical kind of job - I did that, it was the most obvious thing to do."*

*"I wouldn't have had a third baby. I would have had a second child - because we planned that we wanted a baby immediately we were married, and we had one. I wouldn't have had that any differently, but I wouldn't*

*have had a third baby. I remember when I had my first child - I was barely 21. I felt that my back hardly showed at all at that stage. My Scoliosis has become very much worse as I've got older. And, I remember the doctor at the hospital expressing horror when she saw my back and I was expecting this baby and saying I'd probably have to have a Caesarean - which I didn't. But, I was given no advice or help at all. But, I don't think I could have been. I don't really feel resentful about that and, anyway, I had three completely natural births."*

*"Well, I was born with two deformed vertebrae which nobody ever knew about and the doctor - when I was about 5 I think it was - said that I had something wrong with my back, and that was it. The first treatment I ever had was when I was about 13 and I was sent to (Lewisham) hospital for physiotherapy which I think did nothing. I mean, thinking about it now and looking at my body, I think that the fact that I did a few exercises to correct this massive deformity was fairly pointless. What needed doing was the removal of the deformed vertebrae and a rod being put in, which is what has now been done. So, I was given physiotherapy at the age of 13, and it did nothing. But, it wouldn't have done - they didn't know any better then. The medical profession probably couldn't have done then what they've done to me now - I was born too soon. I should have had done at the age of 15 what I had done at the age of 46. But they couldn't have done it then anyway, so in that respect I don't feel resentful or anything else."*

*"They told my mother when I was born that I wouldn't live - that I wouldn't survive infancy. Because, in those days people with Spina Bifida often didn't live. So then they said - no, she won't reach 10, and then they said 21, and then they gave up - because they were fed up of me by then."*

*"When I was thinking of getting married I went back to the hospital and said - am I able to have children? It boiled down to the fact that they didn't know. In those days not many disabled women had children and not that many disabled women got married either - mainly because of the system and their expectations really. So, I took it that I could but I didn't really realise just how difficult it was going to be getting pregnant and giving birth with my particular disability. You see, my disability wasn't really taken into account. I did see a gynaecologist who sent for my notes, but I don't think he really gleaned very much from them in the way of information. He said - I'm, determined that you will have this baby naturally which pleased me at the time, but it didn't afterwards because it definitely made my back a lot worse. I think that could have been avoided. I mean, I now know of women with Spina Bifida who have had babies who are quite horrified at the treatment that I had. But, of course, the knowledge just wasn't there then. I was just treated exactly the same as any other expectant mother at the hospital - but at the time, it didn't occur to me to question it. I just thought that, that's the way things work. But, it was horrendous really and - after I had my son - I was so terrified of them thinking that I couldn't cope and taking this child away from me. I remember, the babies were in the nursery at the hospital and you were supposed to go and get your baby and carry it to the ward. Well, I never could carry my baby. I can't carry or lift. But, because I knew what the system was like - that you had to damn well cope. So I felt that, if they knew I couldn't carry this baby, then they weren't going to let me go home with it. So, I was going to the nursery and holding on to the wall and struggling along. The sister found me one day, virtually on my knees with this baby. But, once I got home, then I was fine because I could cope my way. I had a little pram on wheels and I pushed him around in that indoors and sat down if I wanted to lift him out and that sort of thing. So, I could cope. I do know a woman with Spina Bifida - a friend of mine - and she was very carefully monitored during her pregnancy. I think she was taken in several months before. And, she was given a caesarean. I do think that I should have been given a caesarean - definitely. I think that would have avoided a lot of the trouble I've had - definitely. I mean, I was in labour for about 20 hours or more and I think it damaged my spine far more than it was beforehand. Also, afterwards, I was so afraid of not doing what the other mothers did whereas - if there'd been more awareness - and if I'd known that it was OK because they understood my problems, that I could cope but not necessarily the same way as other women coped, then I would have been alright. But, it just wasn't like that then. You just didn't dare admit that you couldn't cope. The other thing was that, at that stage, I had one of those little invalid cars when I had my son. But, of course, you couldn't take a passenger in one of those. So, once I had my son, that was it - I was housebound because I couldn't take him out in the car and I couldn't walk with him. But, when he started going to nursery school, I used to take him in it anyway because it was either that or stay in for evermore. I used to sit him on a cushion on the floor. But when we started going to school, several people said to me - you know you're not supposed to do that, it's against the law and I should report you. I said - well, that's up to you but I'm going to do it. Then, they said - we can get someone to take your son to school for you. But I said - I can do it, and I want to do it. I hated that - they were trying to make you more helpless than you were - you know, taking away your abilities. Actually, it was just that the car wasn't suitable. But then the Ministry of Health changed the ruling that, if you were a disabled mother - they'd obviously heard of a few by then - you got a mini, so that was better. But now, I have a motability car which I lease. That's fantastic. The government gives you the money to pay for the car but*

*it makes you feel independent because you are using the money. I don't like this idea of being given something. I mean, I know we are given various allowances. But, that's something that's changed anyway because - when I was younger - there were no allowances at all. So, we're very grateful for them now because, being disabled is very expensive. Like yesterday - paying ,5 for a taxi to go to the shops - things like that. It is very expensive and those sort of things happen all the time."*

## **(2. Later experiences)**

*"You talk about counselling. But, why see a counsellor when you've got loads of friends. My friends give me very sensible advice. I think women perhaps talk more than men. You know, when I say to my friends - I don't want to go on living, I really don't. They say - oh for goodness sake pull yourself together, don't be so bloody stupid, you're going to have a wonderful old age. So, I think my friends are as good for me as any counsellor would be."*

*"With my generation, I always say there are two types of people. You have those who become so institutionalised - even if they have been living in the community - they become so institutionalised because of their experiences that it just doesn't occur to them that they have any choices about their lives. Then there are people like me - the bolshy ones - people who just say - No, I'm not going to put up with this. You have to do that - you have to assert yourself."*

*"I've always been a very strong minded person. Whether I would have been had I not been disabled - you can't tell can you. I mean, I really don't know. Obviously, the experiences you have make you the kind of person you are I suppose."*

*"Independence - it's being able to get out without relying on someone and - ideally - it would also be working again. I'm not totally independent now. My husband took over two or three years ago when I wasn't well - so, he does all the shopping and things like that. I suppose, really, independence would be being able to go back to doing what I used to do - doing the shopping, getting out when I want, and getting back to work. Getting a job would be very important because you feel under valued. And, I do miss meeting people - I did enjoy working. I enjoyed helping people - it was fun."*

*"I'm less independent than I was up to my early 20's. For example, on holiday in France this year my husband said he didn't want to go to that place and nor did he want to go away for a fortnight anymore because of the bloody garden. Now, I want to go there and when I was 20 - perhaps up to about 25 - I would have caught a train and caught a boat and got there. I don't think I could do that now. My independence as regards travelling and seeing my friends."*

*"People say that we are 20 years behind the blacks. I think that's probably true. Disabled people are beginning to get their views across and the public are more aware. But, when it comes to translating that to changes in government policy - then the situation is not so good, although it is getting better. So, we do have to keep on pushing and pushing. I don't think there'll be any major changes in my lifetime but that wouldn't stop me trying to do my bit - you have to keep on don't you."*

*"Everything seems to be geared towards making life more difficult for disabled people. Obviously, the longer you go on the harder it's likely to get. It's this constant fighting you have to do - no wonder we're all so stroppy."*

*"There's a very large Black and Asian community (here) ... and so, obviously, I get to know a lot of the families through the school. That's a funny thing though because, I've often thought that, being black is a lot like being disabled - you get the same kind of obstacles, the same prejudices. So, I do feel some sort of affinity I suppose."*

*"I'm 38 but, I wouldn't say I've got the health of a 38 year old. I would say that my health - compared to a 38 year old - is not very good. But, compared to what it could be, it's not too bad. I am very aware that I'm ageing faster. I don't know if there's anything that I could have done above that - except, maybe I could have taken certain precautions. Maybe, when I was working, I could have saved more energy - I don't really know. But, I think it's probably important to find out and do the kind of studies you're doing. Because, if you can see that there are certain possibilities in the future, there's a chance for you to think of ways of dealing with it. I mean, I've always wanted to know what the good can be and what the bad can be so that, if it's slipping too much from the good to the bad, I can go back and look at what's changed and see what could be done."*

*"I used to go out and do a lot of fishing - about 3 or 4 times a week. But, I find I can't walk so far now compared to, say, two years ago, or even a year ago. The distance has gone down so much so I don't go out so often. Instead of going 3 or 4 times a week, I'm lucky if I go once a week. You know, it's just the amount of pain that I go through it's just too much. I have to spend about 3 or 4 days in bed afterwards - that's how it affects*

*me. It's putting me off going - although it is a sport that I love. It would have to kill me before I stopped completely - but, I just don't go as often as I used to when I was younger. It's very difficult for me to get mobile. I've got a walking frame - but it doesn't help me at all. The only relief I get is if I put my leg over the top of the chair - it sort of relieves the heat in the leg. But, that's no good to me - the thing I want is the operation. That's what I've fought for for the last 10 years. Now, I've got one of the best surgeons in the country. But, for all those years before I couldn't get anywhere (at Stanmore) - they told me they wouldn't do it. They thought it wouldn't help me - but I disagreed with that. So, they just refused point blank. I had a big argument with them. Well, more than a big argument - I intend to take them to court for the 8 years of pain and suffering they caused. But, I can't do that until I've had the operation so that I can prove I was right. So, perhaps a year after the operation I'm hoping that I can take them to court. I wouldn't even trust him (consultant) with my children - if I had any children. I mean, if he does that to a man of 29 - if he says you're on the scrap heap at 29 - if he said something like that to a kid, it's going to ruin the kids life."*

*"I don't know how much I will be able to contribute because, my disability isn't all that severe. But, when I heard about this (ie. the research) it sort of confirmed some of the things I'd been starting to think about already. The thing is that, I'm not getting any younger and while it (disability) wasn't really noticeable when I was younger, it is starting to catch up with me now - and that forces you to recognise that you do have a disability and you have to start thinking about what you're going to do."*

*"When I was a child, I never really thought of myself as being disabled. I remember my mother used to say - just stand up straight and no-one will notice - so that's what I used to do. I never got called names or anything like that - which I was worried about - so I suppose people didn't take all that much notice and that made me feel as if I was completely normal. Actually, to be honest, it was only quite recently that I really started to think about it. Physically I have been feeling it more, but then I started to have problems at work with things like - they changed some equipment we'd been using, and I found I couldn't handle it on my own. But, that's more a case of coming up against obstacles than the disability itself. When things like that happen - alright, you know it's not your fault, but it does make you feel like you can't manage as well as before."*

*"It's funny, but people who suddenly become disabled - like if they've had an accident and been paralysed or something like that - most of the people I've met always think that it's much worse for them than for somebody who's been disabled all their life like me they seem to think that it's easier for you because you've never not been disabled, and so they think the loss they have suffered is greater. I do find this with a lot of the people I meet. But, they just don't know how bad it can be - especially when you are ageing, because you do suffer a lot more as time goes on - it's just that it might not be so noticeable."*

*"We always live life for now. If we'd been more fortunate, we'd probably have a better house and things like that. But, I suppose, my husband lost his father when he was in his teens and he grew up to be the man of the family. Then, I lived so long going in and out of hospital. So, that kind of thing makes you more aware of the uncertainties and, because of that, we tend to just live our lives for now. It suits us and we don't look too much to the future."*

*"I try not to think about it (the future) too much actually. But, I suspect it will be pretty hard work just trying to keep my condition stable. I suppose the real problems would be - my wife is still around, and I don't expect her to pop off or anything - but, that would be really hard. Then, there would be all sorts of things I would have difficulty with. It's just the sheer hard physical slog of living - looking after the house, doing the shopping, all those kinds of things. I'm not sure how well I'd cope with that."*

*"It never ceases to amaze me how my own immediate family - they don't even seem to know that there's anything wrong with me, they're not the least concerned. It often seems to me that close family - perhaps not people you're living with - but close family are the least concerned. You're just the person they've known since the year dot. My friends are much more concerned about me than my family, and that hurts. I mean, you don't want people to keep playing on it all the time but they never ever ever ask me how I am. I really do find that quite hurtful. The family that you've grown up with are perhaps the least understanding."*

*"I know that, if I wasn't disabled, I would be at work because I have got a lot of drive. I did work up until I was pregnant but, after I had my son, my disability definitely got worse. My back was a lot lot worse and it wasn't just temporary, it was permanent."*

*"I worked for a short time part-time after my son was born - when he was younger. But I reached the stage*

where, physically, I just couldn't cope anymore - not with running a home as well. Also, I realised that I needed a tremendous amount of sleep and that that was the only way I could cope. So, once I'd finally got that into my head, life improved. I realised that it was no good - I just couldn't work anymore and I haven't worked for over 20 years now. But, I have filled my life with other things. I need mental stimulation - I've got all this drive, but I haven't got the physical ability to go with it. So, I do other things - I do creative writing, I'm secretary of this club, and I go swimming - I do masses of things. It's lovely actually, it's very self indulgent. I don't have any problems filling my time - quite the opposite, there just isn't enough hours - especially with housework taking me so long."

"I gave up work because I was expecting a child - the pregnancy was making me tired. I needed help when (son) was a toddler. He went to a childminder two times a week - because it was all too tiring at that time - it was a strain on my back particularly. It all began to make me sort of run down. Whereas, when I was at work before, I might have one day when things weren't so good - but it gradually got so as I didn't know how I would be from day to day. So, like now, I'm OK some days, but others I'm not. It's lack of energy - that's really what it comes down to. It happened gradually - I couldn't pin it down to a particular time. So, I couldn't really consider going back to work because I just wouldn't be reliable. And, even when I do feel up to it, I find that my concentration is going. It's like the handicrafts that I do - if I do something when I'm feeling off colour - when I look at it the next day, it's full of mistakes - it's not up to the standard that I'd like. So, with a job, it would be the same problem. What I'm hoping now is that, if I carry on getting better as I have been - the thing to do would be perhaps to work in a volunteer bureau. But, it would have to be on the understanding that they weren't relying on me - because, I'd hate to have to let anybody down. Then, if I'm able to do that, I'll take it from there - it is an aim in my life at the moment. Also, I have been thinking about the possibility of taking some kind of computing course so that I can improve my keyboard skills - that might be another possibility for later on. But, with a training course, it's the same problem - until I know that I'm going to be able to do it on a regular basis, there's no point taking it any further. But, it is a possibility for the future."

"I can only work part-time because of my back. That has definitely marred my career prospects. Not from the outside - nobody's ever said you can't promote her because she's got a bad back, but I know my own limitations and I can only work part-time. It's like, if there's a trip organised somewhere I used to have to make some feeble excuse. Usually I don't say - it's because of my back, although more recently I have come out a bit since I've been into hospital and everybody knows. I'm less coy about it now."

"My relationship with my husband has deteriorated, but I think that might have deteriorated anyway, who knows - I don't know how much that has to do with my back. It can't make life easy for anybody. I don't know if I can think of any other changes. It's been my great pride that I attended evening classes and got myself to a reasonable level of learning German so that I can now teach German. I think that was brave of me because I dragged myself of in a great deal of pain. It's the little things you remember. Like, the agony of those grey plastic chairs - and, eventually, being bold enough to - if I go to a concert or something I want to go to - to take a cushion in. It's a big thing for me. I walk in with a cushion now and I just say - sod it."

"I worked full time before my pain was really bad. But, then I wasn't married so I needed to work full time anyway. But, I don't want for anything, I can't complain."

"I think the answer to your question is no because the quality of life I want - if I want any life at all - is to be able to carry on teaching, and to be able to travel, which is one of the things which I very much enjoy doing. If I can't do that anymore, if I really reach the pitch where I have so much pain that I can't do that, then I really don't want to carry on living - it's as simple as that. In the cool light of day - I mean, lets not get emotional about this - I don't. My youngest child is now 12. When he's 18 - that's six years - I don't know what state I'll be in. Maybe I'll be fine, maybe this operation will have worked - because I'm only half way through the recuperation period - if after six years when he's 18 and leaving home, I feel lousy, rotten, ill, then I don't want to go on living - I have no reason to go on living, and I wouldn't want to. I think, I don't want to live in a wheelchair - with the greatest respect to people who are in wheelchairs who I'm sure are perfectly happy and lead very fulfilling lives - I don't think I want to do that. I'm not sure it would help my pain either because when I'm stationary is when I have my worse pain, so I think that moving - to a point - is what I need. But, you see, you've got me at a very depressed moment. I think that women certainly - I don't know about men - at this sort of age go through menopausal depression. But, I think that is very much linked. I think menopausal women with a disability have got problems because I think the two are intertwined and I feel horrendously depressed at the moment. But, I don't know why. I don't know whether it's hormonal, or whether it's physical, or a combination - I just don't know."

*"The doctors can't help you. I've been to see the doctor. I was given hormone replacement therapy and felt worse so I stopped taking it. Then, I was given some anti-depressants and felt certainly no better, if not worse, so I stopped taking them. Because, tablets don't help you - I think that one either has to save one's self or go. I'm ashamed of myself in a sense because I'm not like this. Usually I'm a very strong person. I mean, I've been through 5 horrendous operations - extremely painful, vile operations - and I feel much much worse this year than I did a year ago when I was about to go through the operations. So, I don't know what's happened to me."*

*"My major disability is lack of energy - will power just isn't enough anymore. I deal with it by - when I'm better, I shut it out of my mind and forget about it. But, when I'm down I get depressed. It's unpredictable sometimes. Like recently, when I've been coming out of a low health wise - I get over optimistic. So, when I get back down, I do get depressed. I find that it goes in circles - if you talk optimistically, you feel optimistic. But, you do need the support of your family - it's an uphill struggle if you try and face it on your own. The only danger is - if you ignore how you feel - then you will have problems."*

*"In the last three years my whole lifestyle has changed. Before I went into hospital, I was a director of my own company, I lived a very energetic lifestyle, I used to ride a bike and do a lot of walking - much, much more than I do now. Then, more or less overnight it all fell apart. But, I wouldn't say it's all been negative. I got another job and I'm doing a Masters and I'm enjoying it. Actually, I lead a much less stressful life now - which is a major advantage. I was lucky though - I thought it would be a lot harder to get a job. But I had a lot of help from the disablement officer at the Jobcentre - they really went out of their way to help me with getting work, so that made a big difference."*

*"Personally, I have quite strong feelings about legalising euthanasia. If I ever got to the point where I was completely ga ga or if, physically, I was completely incapable of looking after myself, I'd just want to end it. There's no point going on if you can't have a certain quality of life and I think you should have the right to decide when that time has come. Anyway, it already happens all the time - it's just that people keep quiet about it. I don't think it's right for doctors to make these decisions for you - which is what they always try to do. I mean, what is the point of keeping someone in their 90's going if they're just going to be a cabbage. If someone has made it clear that that's what they want, they should respect their wishes and just let them die. But, instead of doing that, they keep people alive when they don't even want it, and just send them back to their families so they get lumbered. It doesn't make any sense."*

*"There is a problem these days that, doctors keep discovering all these ways to keep people alive longer, but they never stop to ask themselves why. It's as if they just do it for the sake of it or because it makes them look clever. I don't think they care all that much about the people they're doing it to. I know it's a tricky question (ie. euthanasia), but there should be a sensible way to organise it. Like, I should be able to go to a solicitor or something and make a statement or something to say under what conditions I'd wouldn't want to be kept alive. Then, if it ever comes to that, you have made your wishes clear and everyone knows where they stand - you don't have to put someone else in the position of having to decide for you."*

*"When you don't seem to be particularly disabled - to other people I mean - that does cause problems of its own because people don't usually make any allowances. I don't mean that I want to be treated any differently, but it is a bit worrying that people in my sort of situation tend to get overlooked all the time. In any case, I would have thought it's in everyone's interest because, especially when you get older, there are bound to be little things that crop up that effect a lot of people just the same."*

*"I don't go out much in the evenings because my pain is always worse at night. So, my pain dominates going out at night."*

*"I think, inevitably, it depends on the partner you live with as well. Now, I live with somebody who is very un-understanding - who is not understanding - who lives for his job, his garden, and that's about it - his food, his television. Someone who is not very sympathetic and I feel that, if I'm going to stay with him for the time being anyway, then I've got to carry on and have a meal ready at the end of the day and have done the shopping and, you know, whatever. Also, I've got to have my own financial independence - life would be hell without my own financial independence. So, for the moment, I see six years as a deadline. Let's keep going for another six years. I can't really look at my life longer term. I'm 47 now and I could live for another 30 years or longer - maybe even 40 years. I can't look at that. I can't even begin to envisage 40 years, I don't even want to think about it. So I just think about the next six years and I'll see what I feel like then. But, I mean, I'm saying all of this to you*

*and I could be getting better. The surgeon who operated on me at Stanmore last year - he thinks he's made me better. So, maybe if I saw you in a years time I'd be saying I've got very little pain, I feel ever so much better. Maybe I'm just in a sort of depressed convalescence stage. I think the crowning blow was when I came out of this operation and found that I had problems in a different part of my anatomy (ie. bladder) and I've now got to go back into hospital in September to have tests to find out what's wrong, with the possibility of another operation - actually, the possibility of a hysterectomy. Now, that is just more than I can face the thought of. So, I think when you're facing a very common operation on top of very uncommon ones - it's just the last straw - it's too much."*

*"There are two things about that. The first thing is - I don't like the idea of growing old. I refuse to accept it - which I should. But, I won't accept growing old and that makes life even more difficult. If I didn't mind growing old and if I accepted the fact that I was growing old, it might make my life easier. Number two is that - I used to adore my children. Now, I suppose I still do, but I want them to go. They're too much trouble - and that makes me feel horrendously guilty. My little boy who's 12 - it's wicked really it's terrible, he's only a little boy. I had him quite late in life - when I was 36. I just can't be bothered with him, I can't be bothered with his friends - which is atrocious. I didn't think, I should have thought, but I didn't think that I wouldn't be in a fit state. I think I've gone rapidly downhill from the age of mid thirties. It's been a slow degeneration from the age of 25 and a rapid deterioration from the age of 35 and now, my children are just too much trouble, which is awful really. And the fact that my children are used to seeing me flopped out here with my legs up on the settee lying flat. It's a common state, but other people's mothers aren't in that state. I don't feel like a good mother - well, I don't know, perhaps I do myself an injustice - I try to be. I push myself to my limits. I take them shopping and buy them school uniforms and all the rest of it, and trail round and kill myself doing it and come home three quarters dead. I really want them gone. So, while not wanting to grow old, I do want the next 6 years to go and to be on my own - or to be free of kids."*

*"But I think it is linked to my disability because I constantly think of the mess they're making and - for me to clear up - it's the physical side of it that bothers me most - the physical work created. Before you arrived I was clearing out the garden room. Here am I heaving garden chairs around while the two boys are sitting in the tent out there. I did consciously think - yes, any mother would be annoyed - but I did consciously think - christ, they know I've got a bad back. My disability does come into it very much. I do think that I'm not just like anybody else's mother and they ought to bear in mind that I've got a bad back."*

## PHYSICAL CHANGES/PROBLEMS EXPERIENCED WITH AGEING

Members have reported a wide variety of physical and health problems/changes experienced with ageing. Some of those commonly experienced (eg. decreasing mobility) may well be associated with the 'normal' ageing process (although there is no universal agreement about what normal ageing actually entails); at the same time, there are a small number of problems/changes which seem to have a slightly higher prevalence amongst people with long-term Scoliosis. As mentioned earlier, several people felt that there is a need for more work on separating out the consequences of ageing and Scoliosis with a view to (hopefully) being able to prevent or mitigate some of the problems experienced. Clearly, until more is known and understood about the long-term consequences of Scoliosis, it will be difficult for the medical profession to develop appropriate medical interventions.

A breakdown of the kinds of physical problems and changes reported by people with Scoliosis is given in Table 1 below; those reported by other groups of older disabled people are also shown for comparative purposes.

\* While it would be unwise to draw anything other than very tentative conclusions from a sample of this size, there are a small number of problems/changes which appear to be closely associated with Scoliosis which should be highlighted for further investigation. For example, decreased energy levels, osteoporosis, problems with transfers, asthma/breathing problems, muscular atrophy, and speech and communication problems were more likely to be reported by people with Scoliosis.

\* On the other hand, there were some problems which have a lower prevalence, or are even non-existent amongst this group of people with Scoliosis. These include coronary disease, arthritis and rheumatic problems, circulation problems, weight gain, and strokes.

\* Some of the most common problems/changes reported are also very prevalent amongst the general ageing population. However, the effects of these when combined with pre-existing Scoliosis related conditions are often cumulative, and can have significant consequences for the quality of individual's lives. There are also implications for the provision of practical support which are discussed further below.

## PHYSICAL PROBLEMS ASSOCIATED WITH AGEING (Quotes)

*"I had it (Scoliosis) when I was born, but I only found out when I was 29. I had severe pain and I kept ending up on the floor all the time curled up with very very severe pain."*

*"It's a long time to go (29 years) to get it confirmed what's wrong with you. What he (consultant) said was that I was one of the unfortunate ones who slipped through the net. Well, I mean, they didn't know anything about Scoliosis in 1952. I was under the Children's Hospital at Great Ormand Street for an awful long time. Now, the thing that puzzled me was that they always used to build up my shoes. That must have told them something - but I'd never known about it. So, they must have thought something was wrong but that's as far as it went. Actually, they still don't know all that much about it these days - not as much as the Americans anyway. I mean, the Americans are pioneers in Scoliosis. I actually got a medical book written by some American doctor - that tells me everything I want to know."*

*"When I found out, it was the biggest shock of my life. It was like a bomb. I always thought I was fit and healthy. I remember, as a child, having a lot of pain. But, I always thought I'd pulled a muscle or something - I thought nothing of it. Then, as I got older, it's got worse and now I know that (Scoliosis) was the main problem. I can always remember not wanting to get up in the morning. That was all part of the Scoliosis - because that's how it affects me. I find it very difficult to get in and out of bed and move around first thing in the morning and at night. Especially at night - I'm in a hell of a lot of pain. I'm on morphine at the moment and sleeping pills to help me get off to sleep. That's definitely got worse over the years. So, I wrote to the head of the Scoliosis unit up at Nottingham to see if I could have this operation. He (consultant) put me on to another hospital who could do it - that's going to be some time this year. He said I'd have to be in for about 12 months - because it's two major operations. So, now, I'm looking forward to getting things sorted out. I mean, I know there's no guarantee - but all I want to do is to stop the pain. If they can do that, or even half of it, it will be some relief. Then, I shall see if I can get back to work. But, if it doesn't work out, it doesn't work out."*

*"I had my first fusion when I was 13. They think I had polio when I was 3 - I had it quite mildly. But then they*

*found - through doing these studies - that it can cause scoliosis. Since then, the scoliosis society have actually done more studies and found that it can be a cause."*

*"A lot of people are finding that they can be affected later. It's only by doing these studies that you can find out about it."*

*"After the polio there were no particular signs - apart from the fact that I was small. Then, I didn't grow for about 1 year - and then I suddenly started having growth spurts. So when I was about 12 my father got the doctor to refer me to hospital and - after about 6 months - they decided that it wasn't postural. Then I was referred to another hospital to have a spinal fusion. At that time, it was progressing quite quickly and I was still waiting. My parents were getting quite worried so they went to see the specialist - also my school doctor - and I think it was the school doctor who got things moving. So, they did the fusion and I had traction to straighten the spine out. Then, what was done then was that you were encased in plaster of paris. But, unfortunately - while I was in there - I had a growth spurt, so when they took it off I was worse than before so, when I was 15, I had to go again - by which time my breathing was also quite severely affected. The next thing they did was the Harrington rods and they also did another fusion as well - and that was all OK. Then after that, I went to work and everything was alright. Then, in 1985 - I was picking up my knitting machine, and I felt a click. The rods had shifted. I felt that something was wrong so I went to the hospital. They did an x-ray and they said - it's still fixed in. But, in fact, actually it had shifted and it was sticking up. So, after a lot of hassle of getting through to the specialist, I was taken in and had it taken out. After that, everything seemed to be OK. But then I found I wasn't getting any better and my spine was clearly getting bent over quite severely. I didn't know why, but now - with this HRT - I wonder if it was just natural bone problems - perhaps, I just needed that (HRT). So, once I realised that, I was down to go back to the hospital and have the rod put back in - that was about a year ago. So, they put the rod back in - but I do have to be very careful and I'm not lifting any heavy weights anymore or anything like that."*

*Researcher: So, has your mobility improved again now after that?*

*"Yes and no - because now, I get arthritis. That might be to do with the scoliosis - it might not. I mean, my mother has that as well, so I don't know. I've got it at the top of my neck and shoulders and, also, across the hips now. Hips might be to do with the scoliosis. Talking to other people - a lot of people with scoliosis do have it because of the pressure on the hips. So that probably is to do with the scoliosis."*

*"I've had 5 operations. I still have a lot of pain - I don't know whether that pain will eventually go or not. I have added complications from my last operation in that I have great problems with my bladder now, and I don't know whether that's going to go or not."*

*"I was born with Scoliosis. The pain started when I was in my early 20's."*

*"With something like scoliosis - you put a strain on your muscles and joints all the time and - as you get older and you've been doing that for a number of years - it's inevitable that something has got to give. The trouble is, though, that you find out too late, you can't get the strength back again once it's gone. That's why I think it would be a good idea if you had more warning about what can happen in the longer-term so that you can maybe be a bit more careful. I mean, I used to rush around lifting and carrying and things like that - as though there wasn't anything wrong at all. .... I'm sure that, if I'd known, then I would have made at least some alteration to my lifestyle, yes. I would have taken it a bit easier."*

*"This is the first major operation - the one I'm going to have. But, I've noticed over the years that it's got worse - so it's got to be done. He (previous consultant) said it's not getting any worse. But, I disagree with that - I feel in myself it's getting worse. I can feel the difference - I ought to know, it is my body."*

*"I've just recently found out I've got a growth at the back of my neck, next to the spinal column. I don't know what that is. I asked my doctor about it and he said - just wait a little while and see if it gets any bigger and we'll investigate. I used to smoke a lot when I was younger, but I've cut it down a lot. I've got to give it up anyway - because of the operation. I have been having some tests for my breathing because they want to find out about that - I've been having problems."*

*"They're going to do an anterior spinal fusion with Harrington rods. It's quite a new operation, but it's been tried out in America and been successful. But, it does mean a long stay in hospital - with being in traction and*

everything."

"I started having very serious problems with my breathing three years ago (50 years from onset). That's really my only disability now - it changed my life more or less overnight. It had been building up for a while I suppose, but it didn't really cause any serious problems up till then. Then I started having these terrible pains - I thought I was going to die - I ended up in hospital for two or three months, and I've been under more or less permanent treatment ever since."

"It's all to do with the transfer of blood gasses to the lung. With scoliosis, the lungs and rib cage tend to get deformed so it gets harder - it takes more energy than your body has got, and the blood gasses sort of get diluted. But, it doesn't stop there because, it turned out I've got asthma as well and the other thing was that I'd been getting these really bad headaches which seems to be related to having very high blood pressure. Then, with all of that, I get extremely tired, so I don't have anywhere near as much energy as I did before all this happened."

"I've partially lost the sight of one eye. That was around the same time I started getting the headaches. So, it may well be connected to that and the high blood pressure, but I don't know for sure - the doctors weren't able to say."

"I didn't really have any major problems physically for a long, long time. But when I was in my late 30's I did find that my muscles were getting weaker and starting to ache - that sort of thing. Then, all of a sudden, my back went and I could hardly walk. So, that was when I started thinking about it (disability) - when I was around 35 to 40. That's when it started to dawn on me and I started to think, you know, what it might mean in the future as I got older and everything. At first, I started thinking in terms of wheelchairs and walking sticks - that's how bad it was. So, that's when I knew I had to really take it seriously. You see, I'd never really thought about it in terms of disability before. But then, when I was 45 - that's when I found about this osteoporosis in my neck. After the trouble with my back - and I'd had some nervous problems as well after that - then this thing with my neck - it all seemed to be catching up with me. Actually, that's when I first started thinking about retiring and, although I am still working now, I really am going to stop just as soon as I can now."

"What's happened in the last year is that it's affecting my left hip as well as the right. If I walk any distance, or do any strenuous things, or bend down, it really gets me - even though I'm taking drugs. They have no effect on the amount of pain that I go through. I mean, I don't just get it on and off - it's there 24 hours a day, 52 weeks a year. There is no relief from it. And, of course, it wears you down after a time."

Researcher: Are there any other changes or problems you've noticed as you've got older?

"Yes - pain. Pain is my biggest problem. I mean, Spina Bifida and Scoliosis are both painful things. I am very mobile for somebody with Spina Bifida - the majority of people with Spina Bifida can't walk at all, and I'm very aware of how lucky I am in that respect. But, I do have a lot of pain. I have a wheelchair for outdoor use because I can only stand or walk for very short periods. I can drive - I drive with hand controls - which is great, but I'm limited to where I can go because I can't walk very far the other end. So, I can't go to shops without a wheelchair. But, the pain - it's become far far worse. Certainly, when I look back - I mean, I didn't need a wheelchair until 15 years ago (32 years after onset), and the pain has certainly got worse - it gets worse and worse all the time. So, you look back and suddenly you think - last year, I could do that and now I can't do that anymore. Housework - I can't Hoover now, I can't sweep. Physically difficult things which at one time I did used to do."

"It was a lot of things. It suddenly occurred to me that I was hearing more and more often my husband say to my son - no, we can't go there because mum won't be able to walk. So, I suddenly realised that I was being very unfair. Pride was stopping me - I mean, I knew I ought to have a wheelchair, but I fought against that because, to me, that was the ultimate giving in. I thought - no - I really didn't want to do that. But, it's such a gradual process - I realised that I used to be able to go round a couple of shops, and then I could only go round one, and then only round one counter - you know. Then, we were going on holiday and I thought - oh, this is ridiculous. So, the Ministry of Health gave me a wheelchair - but I couldn't wheel myself because it was too much of a strain on my spine. Then, on top of that, I have asthma - so, I'm a physical wreck really. A lot of people with Scoliosis have asthma. It's because the spine twists round, and the lungs are affected. One of my lungs is virtually collapsed. I use an asthma pump - an inhaler - and I do yoga breathing. I've done that for a long time, and I do find that beneficial. And, I swim - I go swimming once a week. I'm a great believer in self-

help."

*"My growing older, and my having had 3 children. I think it (pain) became worse after each 3 children and I'm very very angry about the fact that I was told by a surgeon in the early 70's that having babies did not make Scoliosis worse. I am certain and positive now that it does and has. In fact, the latest surgeon last year said that having babies does make it worse and, logically, it would. So, I think I was given the wrong information there - while, at the same time, I'm not sorry I had 3 babies now I've got them. So, growing older, and having babies - yes, it has made it worse."*

*"The toughest thing of all would be if anything else happened with my eyes. That's my biggest worry - what would happen if the other one went. But, I don't have any way of knowing what the chances of that happening are. It was a haemorrhage that caused the trouble with this one and the doctor can't say whether or not it could happen again - you never know with something like that. But, I do think it was connected in some way with all the problems I'd been having with high blood pressure and the headaches, so that's why it's important for me to try and keep my condition stable like it is now. I think I've got more chance of avoiding problems later on if I can do that. That's why it's important that I can keep up with getting the right kinds of drugs and everything - a lot depends on that as far as I can see."*

*"I have a neighbour who used to be very active. She has had arthritis - but, she's been into the hospital twice but as soon as she comes home, she just sits down. It seems to me that, that's because you're in pain - so you just sit still. But, I think - OK you're in pain but if you move then at least you are still moving instead of giving up. It's a matter of attitude isn't it."*

**TABLE 1: PHYSICAL PROBLEMS/CHANGES EXPERIENCED WITH AGEING**

Proportion reporting problem/change (%)	Scoliosis	Total sample
Changes in energy levels	45	27
Difficulties with walking	36	40
Decreasing agility/mobility	36	51
Increased pain	27	27
Brittle bones (osteoporosis)	18	5
Problems with transfers/turns	18	7
Limb deformity	18	7
Asthma/breathing problems	15	10
Arthritis/Rheumatic problems	9	29
Drug dependency/side effects	9	12
Problems with vision	9	22
Bladder or kidney infections	9	7
High/low blood pressure	9	7
Respiratory problems	9	11
Contractures/muscle wastage	9	6
Muscular atrophy	9	3
Speech/communication problems	9	5
Incontinence	9	3
Problems with circulation	0	12
Problems with shoulders, arms or hands	0	18
Spondylosis	0	4
Spasms/spasticity	0	5
Ulcers	0	2
Headaches/dizzy spells	0	2
Fractures/dislocations	0	9
Proportion reporting problem/change (%)	Scoliosis	Total sample

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Viral infections	0	3
Stroke(s)	0	5
Heart problems/angina	0	12
Problems with hearing	0	6
Weight gain/loss	0	21
Thyroid problems	0	3
Pressure sores	0	1
Balance/co-ordination	0	4
Edema (swelling of joints/limbs)	0	4
Epilepsy	0	1
Scoliosis	n/a	2
Other(s)	0	13

## IMPLICATIONS FOR USE OF HEALTH SERVICES/HEALTH CARE PROVISION

The experiences reported to us suggest that the provision of health care for people with long-term Scoliosis is erratic and that, in general, there is a lack of appreciation of the problems they face amongst the medical profession;-

\* Some people complained about the lack of specialist clinics for people with Scoliosis. As many disabled people find travelling more difficult when they are older, getting to clinics is also a problem (particularly for people who do not live near large general hospitals, or the teaching hospitals and specialist units in London).

\* Some members felt that there is a lack of routine check-ups for people with Scoliosis, and that this aspect of long-term health care has declined over recent years. On the other hand, there were a few individuals who felt that check-ups were unnecessary. Nevertheless, it seems clear that routine check-ups in specialist clinics should be available if/when they are needed.

\* Some people expressed the view that there is very little treatment offered to people with long-term Scoliosis, and very little understanding about the long-term effects of Scoliosis amongst the medical profession. This, in turn, is a reflection of the concern about the lack of research discussed earlier.

\* Similarly, several people expressed varying degrees of concern about the lack of advice from doctors about problems they had experienced with ageing. In some cases these were problems specifically related to Scoliosis; in others, these were more general problems (eg. impotence). Whatever the specific nature of these problems, it does appear that the medical professionals are not as supportive/understanding as people would like. It is also significant that a few individuals had actually volunteered to participate in the study in the hope that we may be able to advise them on the problems they had experienced because they had been unable to obtain this support anywhere else.

The minority of individuals who did have access to specialist facilities were mostly very satisfied with the health care they had received.

## HEALTH SERVICES/HEALTH CARE (Quotes)

*"I've been under (the consultant) for 8 or 9 years now and he's done absolutely sod all - he's not interested, he doesn't want to know. His argument is that it's (operation) too risky, so he won't do it. But, I know something can be done so I've gone somewhere else. You see, I know what's causing the problem. It's a nerve trapped against the disc in the spinal column - which obviously causes a lot of other problems as well but he said it hasn't deteriorated, but I've noticed over the last year or so it has - I've felt the difference in myself. I've had all sorts of problems. I mean, I'm on morphine drugs for the pain, and it's affecting both hips now - it never used to. So, that really affects my mobility - I can go about 30 yards if I'm lucky."*

*"I'm a bit annoyed with the hospital. I was down there last Friday actually - and they told me I had a diseased right hip - which I knew already. I reckon I've had that for around 2 years - but it's only now that I've found out."*

*Researcher: Are there any other ways you think the hospital services could be improved?*

*"Yeah - certainly. Waiting times - I mean, when you're in this amount of pain, you don't want to hang about. I mean, it was 2 years I had to wait before I got into Stanmore. Then, they did a few tests and, after that, they refused to do the operation. Two years just for that. I said to him (Consultant) - you're talking a load of rubbish mate. I was fuming. I went to see the Citizen's Advice people and they advised me to have a talk with him. But, I had a talk with him and I still wasn't satisfied with the answers because I knew full well he was talking a load of rubbish anyway. I mean, I was asking specific questions and he'd say - it might make your pain worse, it might make it better. That's just like saying how long's a piece of string - that's no answer. That's the sort of thing you have to put up with. I've got nothing against the hospital at all - it's just the surgeon. I don't think he should be allowed to treat people and possibly ruin their lives."*

*"I've been trying to find out the results of the investigations on my back. It's very difficult but, just recently, the Patient's Association have fought so that you can insist on seeing your own notes and see what the surgeon*

*has actually put in there. So, I shall be pursuing that and - after the operation - I shall be taking them to Court because I think he (consultant) was totally out of order."*

*"The Patient's Association have been a great help to me. They helped me to find a solicitor who specialises in this sort of case and helped me with other things to do with the laws - you need to know about all of these things if you're going to have any chance. So, I'm definitely going to take him to Court - he's not going to get away with it. I'm not going to allow him to ruin other men's lives. He was wrong in his diagnosis and, now, I think I can prove that. But, obviously, it all hinges on the operation. If that's a success then, he's got no chance. I will make sure that he never practices again. And, not only that, but I will be looking for financial compensation. I mean, it's not as if he didn't know about the operation. When I was in hospital, there were three other people and they'd all had it - he done that. So, he does know about it - he just refused to do it because of what, he said, his medical judgement. But, I say his medical judgement was wrong - well, I know it was wrong. He just didn't want to know. You get some doctors like this. They don't get on with disabled people - they're a threat to them. They don't have the knowledge and so, when you go in there, you're exposing them - and they don't like it. It would be more constructive if they just talked to you and try and find out what they need to know. But, instead of that they just get aggressive. He was very aggressive right from the start. You know, he's the type of bloke who thinks he's god. But, he's not, he's just an ordinary surgeon."*

*"Most hospitals and doctors are thinking in terms of - can we make this person better. Can we do anything. And if we can't, send them away. I mean, but with pain, I've found that yoga is very good - and swimming - both for pain, and for my asthma. But, that's purely through finding out for myself. There must be a lot of people who don't know, or who don't find out - and they would find the advice very useful. Actually, my general health has improved over the years because I've learnt to have more common sense and pace myself. But, it's taken 47 years to get to that stage - it is difficult."*

*"They (medical profession) have been very helpful, they've been very kind, but - in the long run - totally incapable of really doing anything. I've been to numerous pain clinics and I've tried all kinds of fringe pain reliefs. I have met some lack of sympathy and lack of understanding - harshness I would say - from certain people, but on the whole I can't complain about the kindness. But, in the long run, they have been incapable of doing anything for my pain."*

*"I'm going through a bad patch - that's for sure. When I had this operation - I thought about when I could take of the brace and everything was going to be bliss - I was going to be OK in the summer. I didn't envisage I was going to feel so ghastly. I don't think any medical person gives enough thought to the psychological after effects of major surgery. I do feel that very much - as a categorical statement. I've been depressed after every operation I've had - and nobody gives a damn. I mean, if the district nurse is coming in - she hasn't got time to stop. It's not her fault, but she hasn't got time to stop and have a coffee or anything. She's got time to do the dressing or whatever and go. You're on your own - unaided - psychologically. For months and months you have the horror of the operations drumming through your head - the ward, the nurses, the doctors, the injections - you don't forget it for months. I did go to the GP. There's a practice where we go to - one of the GP's was fairly helpful, but the other wasn't very helpful at all. Again, they're so rushed - you feel like you're rushing them. Even private medicine. I had this last operation done privately - and even going to see the private consultant in Harley Street, he had a waiting room full of people and I felt rushed. The GP I did see - he was kind, but the most help I've had was talking on the telephone to other members of the Scoliosis Self-Help Group, one of whom had the same operation with the same surgeon. So, we've been able to compare notes - I can feel the rod in my back, can you feel the rod in your back? Yes. So, I'm not going mad - she can feel the rod in her back too. So, it's self-help rather than GP help. I feel very angry that my GP has made no attempt at all, knowing that he has a patient with severe Scoliosis, to do any kind of research. If I had a pupil who had a particular problem, I'd look it up. He hasn't made the slightest attempt. I asked him - how is the Scoliosis angle measured? He hasn't a clue. Why doesn't he bloody well find out I've been going there 25 years. The GP told me I did not need to see any kind of psychiatric or psychological person because I was analysing myself very clearly - that I knew myself as it were and he did not think that the psychologist would help me in any way. I was once sent to see a behavioural psychologist in Guys Hospital Pain Clinic who was a woman - Ms. somebody. She was younger than me and she really got under my skin and seemed to me to be implying that a large part of my pain was psychological. That just makes me so boiling livid it's not true because it just isn't true. My pain can be just as bad when I'm perfectly happy. It doesn't bear any relation to my state of mind - it's physical. So, it might be true of some people, but it certainly wasn't true for me. But this young woman just annoyed me intensely."*

*"I don't know if that (counselling) would help. I mean, I'm talking about it now aren't I. You see, I don't know whether making a huge thing of something - writing to too many members of the Scoliosis Self-Help Group, phoning too many people, thinking of one's self too much as being disabled - whether it's a bad thing. I've got this friend who is potentially a alcoholic. She went to a meeting of Alcoholics Anonymous and then said that lots of people phoned her up afterwards and kept trying to chivvy her into going into more meetings. She said to me - I've got this fixation in my head now that I am an alcoholic and it's becoming so much of a fixation. It's like - I am a disabled person. Is that good? Should we be saying that. Should we be saying - I'm a normal person who happens to have a bad back type of thing. I don't know if it's good. I don't know if I want to go and see a counsellor - because I'm not sure if they could do anything to help me. I think I do have a fairly clear mind. I know my own husband, I know my own family situation, I know my own body - I'm not sure that anybody can do anything to help me really. Find your own solution and you may be happy - or happier."*

*"I would like to have immediate counselling after surgery. I don't mean with minor surgery - major surgery. Counselling - once a week for a month, or two months maybe, or maybe even three. I felt very alone very panicky. It's rather like when you have a baby and you're in the hospital and everybody's cossetting you and looking after you and then, you go home and suddenly you're on your own. It was just like that - it was awful. Your husband goes to work and you're stuck at home on your own. So, counselling - I don't know if that's the word for it, perhaps it is - immediately after surgery at home. Don't just chuck them out and hope for the best. Then, number two. I think the actual consultants should give you more information - if they know - about your recovery. How should I feel now 9 months after the operation - I don't know. I've been told very little. Nobody ever said to me - you feel the rod in your back, you'll feel the screws, it will hurt, you will have awful nights. Nobody really told me what to expect from the point of view of recovery. They just say - see you in 6 months. That's a fat lot of help. I feel abandoned. I mean, if he doesn't know, tell me - just give me some indication. I need to see somebody more often than at 6 months intervals. After such major surgery 6 months is too long. I can't last 6 months not knowing whether I'm OK or not. Another huge non-comprehension is the logistics of how you're supposed to get to places (ie. for check-ups) when you're in such pain. You're in a brace and you can barely sit - sitting is the hardest - and you're expected to go to London. Because we live here, and because it's complicated, you're supposed to just get there - for 11 o'clock or something. Nobody thinks how the bloody hell I'm supposed to get to London. And you can't park and this kind of thing - I don't know what the answer is but there should at least be parking for people who - even though they're not necessarily registered as disabled - but if they can't walk. We had a £30 parking fine for going to see the surgeon - it's appalling. Another thing was that I had to personally pay £290 something a day to go into Stanmore as a private patient to get it done quickly because I was in such pain. Now, I was in an NHS ward because they don't have private rooms there. Well, that's OK - I don't care about having to have a private room. But, I had to wait from November when my bladder was bad until September 6th for a National Health appointment just to have the tests on my bladder. I'd waited for 10 months nearly for an NHS appointment - it's appalling when you're in that kind of pain. So I had to pay £290 a day to jump the queue."*

*"Very often, people who are in pain go to a pain clinic in hospital with the most appalling seating accommodation. I'm talking about waiting two hours on a hard bench when you're in agony with your back - or whatever other people have pain with. I mean, I know I'm talking platitudes because everybody knows the NHS is not in a good shape."*

*"In Stanmore, they were brilliant - after the operation, while you're in hospital. Physiotherapy, occupational therapy, how to wash your hair, how to cope with stairs - brilliant, very very good. But, then you're out and you're on your own. I would quite like to have some hydrotherapy like I had after my operations. But, I had it in hospital and then I was chucked out because there wasn't enough physiotherapists and there wasn't enough places. So, I had to go."*

*"I can't swim because I'm hung up about putting on a swimming costume, and always have been. Now that's another thing. There are swimming classes for the disabled, but I don't go. I haven't been - I'm scared of the water. I'd need someone to take me and go in the water with me and say - don't be scared, you're not going to drown. I was told by the surgeon that I mustn't do any sport at all at the moment except for swimming. But, I can't do it - I'm terrified of the water. I'm scared of doing things on my own. I'm 47 and scared of doing things on my own - I need somebody with me. I suppose (my daughter) might go with me, but my husband wouldn't. My husband is selfish. He doesn't like swimming pools and I don't think he'd come. I might be doing him a terrible injustice, but I don't think he would."*

*Researcher: Have you ever talked to your husband about some of the things you've been saying?*

*"Yes I have, but he's sick of it. I did talk to him up till about 10 years ago or, I suppose up to when I had my operations, but that finished him. I could see he was cracking with the thought of me going into hospital again. He's no good at being left with the kids. I run this house - as a disabled person - I run this house, I hold the bloody family together. He can't cope. So, I don't talk to him anymore about it because - a) the subject is boring, it goes on and on and b) he's sick of it."*

*"I'd like every hospital to be like the Brompton - where you can get through to the person you want to talk to. When I felt my spine was curving over, it took me ages to get an appointment (at St. Thomas's) because either the consultant's secretary wasn't there, or she'd see what she could do, or it was her afternoon off. Actually I did get an appointment when it was her afternoon off - because I asked to speak to someone else because I was so fed up. So, I turned up there and I heard him saying - I didn't tell her to come in. Obviously, they hadn't made the appointment - but it got sorted out in the end. But, you shouldn't have to go through that. I don't think - if they had a more open approach - that people would abuse it. Perhaps, with St. Thomas's being a bigger hospital, it might be more difficult - but, I just wish you could get easier access. I mean, I don't want to be in hospital if I can help it - but, when I do want help, you have this problem. And, it's no easier for my GP because she just hadn't been able to get through either."*

*"The hospitals are so pushed aren't they. Ideally, I think they should be doing more research on the effects of scoliosis - but I don't think they've got the finance. I think there would be a benefit if there were more studies. The Scoliosis Association - I think they funded a couple of studies. They have set up a fund which is purely for research into scoliosis. But, we also want to raise money for raising awareness - so that, if children develop curvature they get sent directly to a specialist and it gets dealt with before it gets out of hand. Because, hopefully, it's something that will die out because it can be dealt with. I mean, if it's there at birth, it can be sorted out before the child is very old at all - and, if it's there in adolescence, it should be able to be dealt with fairly straightforwardly. You see, a lot of people feel that, the problems they've had could have been avoided - or at least wouldn't have been anywhere near as bad - if they'd had the right treatment at the right stage. Really, what we need are more centres of excellence like they have for cancer treatment. Alright, it will mean people travelling a certain amount - but hopefully, there will be fewer people trying to deal with other things. I think that each region should have one centre for each of these things. It would be far better than going to a local hospital, and then making a bodge of it."*

*"With my particular type of Scoliosis - if it wasn't seen to, my life expectancy - even now - would be 40 or 50 if I'm lucky because it effects your lungs and your heart. I've always had trouble with breathing but, in the last 2 years, I had to call the doctor out here at 2 o'clock in the morning with a suspected heart attack. Well, it was a heart attack that I had and they rushed me to hospital for a cardiogram. They said - that's because of your Scoliosis, it definitely wasn't a heart attack. Believe me, it frightened me to death. I was pretty annoyed about that, so now I don't take any notice of them."*

*"The consultant I'm under - I think she's mainly dealt with scoliosis and the effect it does have on the heart and lungs. Because, a lot of people do find that they have breathing problems - and she's done a lot to help with that. When I was originally transferred there (to the Brompton), I was actually under Guys at the time. They were transferring patients to the Brompton so they could keep an eye on them. Actually, it was thanks to them that I actually had a child because, at that time, the idea was that - if you had scoliosis - then you couldn't have a child. But he (consultant) said he couldn't see any reason why I couldn't. He said to go ahead and that they'd keep an eye on me while I was pregnant. So, that was really great."*

*"They're really good they keep an eye on you for any problems that can arise. So, it's great - because you always have that support. If you have breathing problems or anything like that, they give you an emergency number so that you can contact them and you can go there anytime. It's very good, but not everyone knows that they could go there - it depends whether you heard it. But those who have had that contact with Brompton - it's great. You see, Brompton is the heart and lung hospital and it's because it can be a strain on the heart with scoliosis that it's important to have somewhere like that. Once you are under Brompton's care. It's wonderful - it really is. It's user friendly - and it always has been. It's a marvellous hospital."*

*"I'm a great believer in self-help. And, in my experience of the medical profession - because I've got so many different things wrong with me - they each specialise, and they don't know about disability, unless you go to someone who deals specifically with disability, which most of them don't. I mean, I know my body now"*

*extremely well after 47 years, and I know what suits me. I've also learnt over the years - I get very tired, which is common with a lot of disabilities - physically drained, and I need an awful lot of sleep. When I was younger, I would go at life hell for leather - and I was constantly ill. Now, I lay in bed extremely late - mornings are quite a mystery to me - unless I've got to get up for something specific. Then, I do a bit of work and then I sit, and then I do another bit of work and I sit. So, I pace myself very carefully - and that works for me. It keeps the asthma at a reasonable level, and my general health is greatly improved actually through being sensible."*

*"I have come to get satisfactory help from the medical profession through helping myself and keeping my own eyes and ears open first. For example, I had never heard of a pain clinic until I heard something mentioned on television. I then went to my GP and said - please can I go to a pain clinic. Then, I was sent to a pain clinic - and I've gradually gone sort of up and up and up in medical circles through keeping my own eyes and ears open. For example, joining this self-help group. A friend of mine heard about it on the radio and put me in touch with it. Through them, I've heard that other people of my own age have had operations and therefore I've looked into the possibility of having operations - which were not suggested to me originally by the medical profession. So, any kind of medical help - and it's very competent help I think I've had in the long run - I have eventually come to it through my own initiative."*

*"I had a gut feeling that surgery was going to be my only answer and if surgery works as I think it may - I don't think I'll ever be totally without pain - but if I'm left with very little pain, or less pain, then it will be surgery. None of the alternatives work for me. I'm very very anti hypnotherapy, acupuncture, relaxation and all this kind of thing. I have turned, in my middle years, to being totally anti and totally fed up to the back teeth with it. Someone only has to say to me something about playing relaxation tapes for pain and I just want to say - shut up, go away, it doesn't work. I feel very disillusioned about fringe remedies. I do try to eat a healthy diet, which I have to have anyway because of taking pain killers and this kind of thing, to combat the side effects of pain killers which can make you constipated and this kind of thing. But, I have had such severe pain. My body is still completely deformed - and I'm totally convinced that this kind of remedy (herbal remedies, etc.) is not going to work. Healthy food - yes. But, as regards to the killing of pain, I don't think so."*

*"I have a check-up every two months on average at the moment. I do think they're thorough enough, yes. But, it's mainly a question of just discussing how I've been getting on since the last time. He only needs to do any actual checking if there's been any change. Then, if there is, he might suggest changing my drugs or something else I might want to try - that's the way it works. It's a very good service. I always have open access to the doctor - and the specialist, if there's ever anything wrong."*

*"I suppose check-ups should be with a specialist mainly. But, I do think a lot of the more routine testing could be done along with the kind of checks that GP's do all the time. I mean, my GP already does regular tests for blood pressure and things like that. Where you could have a problem though is with things like lung function tests - I don't know how a GP could manage that, because they wouldn't have the equipment even if they knew what to do. Actually, that is one thing I am a bit worried about - my hospital (Kingston General) is opting out, and I am a bit concerned that some of these sort of non-standard tests - which only a few people might need - they might not be so easy to get hold of. I mean, what if (local) hospital says - 'we're not going to do lung function tests any more, because its too expensive' - or something like that? Where do you go then? Mind you, I saw my doctor a couple of weeks ago, and he didn't say anything, so maybe it's alright."*

*"I have two year check-ups at the Brompton. They do a fair check - ECG, lung function, and all sorts of other tests. They could be more regular if I wanted them, but they're a very good hospital - you just phone them up and you can get an appointment very quickly you get straight through to the consultant - I've never known another hospital and all this - I take tranquillisers before I phone St. Thomas's - I don't need that, I really don't."*

*"It (physio) doesn't help me at all - I've tried it. I've had physio and I've had hydrotherapy. Anyway, it's quite difficult to get it arranged. There's only one hydrotherapy pool around here (Ashford Hospital), and it's only 6 or 12 sessions that you get - it's not really enough. But, I am going to go before I have the operation because, obviously, when you don't get around so much the muscles get shrunk. So, that's going to build me up in preparation for the operation. The only thing is, I wish it was more local - it is quite a long way to travel. I think they should have things like that as part of the general hospital services because there are a lot of people with disabilities who'd want to use them."*

*"I have been working on getting some of my strength back. I do all the exercises they gave me to do (physio at local hospital) and that is helping. Then, I am much more careful about what I do now. Like going up and down stairs - I tend not to go upstairs unless I have to."*

*"I've been to the Disabled College at Leatherhead (QETC). I was learning a trade - wiring (electrician). I went to a job after that - but, I only lasted 2 weeks because of the pain. So, I had to leave my job after 2 weeks - I just couldn't handle the pain. Since then, I've not worked - I was about 30 then when I last worked. That was 8 years ago - so, I've just had 8 years of mucking about. I hope after I've had the operation that I can get back to work - I hope so anyway. I'll just have to wait and see."*

*"There are things that would have been useful to know about in advance so that you have some warning about what to expect. With me, everything has really come to a head in the last 3 or 4 years. I've had really chronic bronchial problems - it nearly killed me to be honest. Of course, I know now that a lot of people with scoliosis have breathing problems - because it does tend to deform the lungs, but nobody ever said to expect that, so I didn't have any warning at all. It would have been much better if I had because I could have organised my lifestyle in a different way - taken things a bit easier. Also, I would have done more exercise, and different kinds of exercise - you need to keep the rib cage from caving in - that sort of thing."*

*"Personally, I feel that I'm very well served by the health service. I have a very good specialist - well, I do now. That was only since I was diagnosed as asthmatic and started going to the chest clinic - I didn't see a specialist before that."*

## **PRACTICAL AND PERSONAL SUPPORT NEEDS ASSOCIATED WITH AGEING**

Like many other groups within the ageing population, people with long-term Scoliosis are often likely to require some additional practical and/or personal support when they are older. In some cases this follows from the physical problems/changes experienced with ageing (eg. reduced mobility); usually, however, the kind of support needed will ultimately depend on the personal, financial and practical resources already available. For this reason, support needs should always be evaluated on an individual basis, although there are some common concerns reported in the study which are summarised below:-

- \* Older people with Scoliosis may need additional practical support in the form of assistance with transport; domestic help with cleaning and shopping; alarm calls (particularly for people living on their own); provision of mobility aids; district nursing services; day care facilities; and, in several cases, personal assistance.
- \* A few people had, or were considering, making changes in their living arrangements and this most often meant moving to warden controlled sheltered accommodation; along with other groups of older people, however, there is often a problem in finding sheltered accommodation at an affordable price; also, the standard of back-up cover available is extremely variable. Some people were very concerned about the possibility of having to enter institutional care if they could not obtain appropriate support at home. Some also highlighted difficulties in obtaining information on alternative living options which may be available. While statutory agencies should be providing such information, they often fail to do this so there is a potential role for the Scoliosis Association and other voluntary organisations to act as 'information brokers'.
- \* Some older people with Scoliosis (particularly women) are themselves giving personal support to other family members (who may also be disabled). This is always likely to become more difficult over time - even without the additional problems which may be associated with ageing with a disability. Some people have also highlighted a need for practical support to families and back-up for informal helpers; several people are concerned about the additional strains being placed on their families by the lack of such support.
- \* Some people highlighted various problems relating to information about, and eligibility for, disability benefits. There appears to be a lack of accessible advice on benefits and it is quite likely that some members are not receiving benefits to which they may be entitled. Obviously, this is an area where additional support and information could be given to members by the Scoliosis Association.
- \* There are also problems with claiming benefits and some individuals reported having experienced difficulties in establishing their entitlement to benefits such as Attendance Allowance and Mobility Allowance. Delays of several months are not uncommon and one or two people reported struggling over several years in order to establish eligibility to benefits. While this is a common problem for many groups of people, the situation is also a reflection of the lack of knowledge about the long-term physical/health consequences of ageing with Scoliosis discussed earlier.
- \* Some individuals specifically mentioned the need for more local self-help groups which would give members the opportunity to discuss matters of mutual concern, and learn from each others experiences. This was most often discussed in relation to the need for practical information on matters such as obtaining equipment and benefits, but also in the context of mutual support in discussing anxieties about health matters and ageing in general. This also reflects a wider issue which the study has highlighted, not just for people with Scoliosis but many other groups also; people who have lived for 20, 30 or more years with a disability or disabling illness have a vast amount of collective experience which can be an extremely useful resource to others. At present, however, these resources are not being fully utilised. Those who were regular members of a local self-help group on the other hand, had mostly found this to be very helpful.
- \* There is also a clear need for organisations like the Scoliosis Association to engage in a more pro-active strategy for responding to the needs of older people from black and ethnic minority communities. As mentioned earlier, many people in these groups are not even aware of what support and advice may be available or where to go for information. Consequently, they are often extremely isolated. However, tackling this issue would involve far more than simply providing information as the long-term consequences of this isolation often means that people do not have the confidence to articulate their needs. Clearly, these problems cannot be solved by any simple means. However, we would suggest that closer alliances with existing black and ethnic minority community groups would be a useful starting point.

## PRACTICAL AND PERSONAL SUPPORT NEEDS (Quotes)

### (1. Personal and domestic assistance)

*"I'm just putting in for attendance allowance. I'm waiting on that - I've had the doctor round and he reckons there'll be no problems. That will help - because, I need help to get in and out of the bath. I physically cannot get in and out of the bath myself. That would be more or less everyday. You see, I wear a brace so, obviously, you've got to have a bath or a shower everyday. Then, I also need someone to keep an eye on my at nights to make sure I take my drugs and if I can't get off to sleep. Sometimes it takes me ages to get to sleep - sometimes I've been in here till sort of 5 o'clock in the morning without any sleep."*

*"Basically, I'm looking at someone coming in twice a day, or, I'm going to have to see about maybe getting someone to live-in. You see, my mother used to help me when she was here but she's just gone into a home. She's just recently gone. She had an operation 3 or 4 years ago to remove a cyst on the brain, but since then her brain and her memory has gone completely. So, she'd become a danger to herself and she's now in a home. I'm just in the process of sorting all that out and that's why I'm now left here on my own. The social worker is helping me out."*

*"I don't really think I'm going to want very much in the way of help - not unless something drastic happens anyway. And, in that case, I'd be in a home anyway, so you'd have the help on hand if you needed it. Personally, I don't feel that I need very much to keep me going. I've always believed in leading as simple as life as possible, and being as self-sufficient as possible. I was used to rationing and all of that during the war, so I know what it's like. But, when you think of that, it makes you realise even more that you don't need all that much to be happy. A lot of people today seem to want so much - they don't stop to think how much of it they really need."*

*"In my experience - but, I have been disabled for an awful long time - you just cope each day as new things occur. But then again, it depends on the individual. I mean, I'm married and I've got the support of a husband. Not everyone is in that situation. If they were alone, then obviously it's a very different kind of thing. I mean, my husband has to do a hell of a lot of housework in addition to going to work - the things that, physically, I'm just not able to do. We did try to get a home help a couple of years ago because I got worried and I thought - it's just not fair, he's knocking himself out. The borough said that I qualified for a home help but, because my husband was working - even though he's in a low paid job - we'd have to pay. In fact, we would have had to pay more per hour than my husband earns. You know, we thought - that's got to be a joke. So, we just said - no thanks, we'll carry on. So, in that respect, there's not a lot of support when you're older. I can understand it in a way - economically. But, all the time you're coping, they don't wonder why - they're just damn glad that you're not bothering them. It's those that can't cope - for whatever reason - that are helped. Those that are prepared to struggle on don't get any help at all. I've always said that the system has been geared not to those who help themselves but to those who, for whatever reason, don't. In a way, that's sad. But then again, I'm the sort of person that doesn't really like asking for help anyway - and I'm sure there's a lot like me. Actually, I recently acquired a battery operated wheelchair from the Rotary Club of all places which has opened up a new world to me because I can now go to shops with friends - and I haven't been able to do that for 20 years or more. So that's wonderful. But, of course, I can't use the car because I can't set the chair up myself. Actually, planning something like that (going to the shops) is a major operation. It's - how do you get three disabled people to a particular place - it's like synchronising a battle - it's awful. I phoned the local Dial-a-Ride, but they wouldn't take us to where we wanted to go because it's out of the borough. So, what we do is - there's a new cab service for people who are disabled, and they got us over there. It cost me £5 but it was worth it in the end. So, yes, life does become more difficult as you get older - definitely."*

*"My parents are in their seventies. I mean, my mum comes over to help me. I'm also a member of the church and I have got some good friends who I can rely on - but, you prefer not to. But, I do have two friends with cars and I can always phone them and say - are you free, can you take me to the doctors and that sort of thing. But, it would be much better if you could have the same kind of support - but as a local service - that would be great. Because, with friends, it's hard for friends to say no. If it was more personal things - I'd rather have somebody who was trained rather than have to ask the family. I mean, with something like that you can have all sorts of*

*problems with the person whose helping you - you can both end up damaged, can't you. So, if I was in that position, I'd first go to my doctor and see about a nurse perhaps - because, they know how to help you - you're dealing with somebody whose qualified."*

*"Yes, I can see how that (on-call support) would be very handy for some people - especially if you've got a lot of elderly people living on their own. I don't think I'd ever need that for myself but, in a way, we already have something like that here because we (ie. neighbours) all chip in and help each other whenever anybody has any problems."*

*"I'm trying to find out if there is a service locally. It would have to be a professional service because, with my type of condition, if I fall or anything like that - it can create havoc with my spine and all that. That's why I would prefer someone from a professional agency rather than employing someone myself."*

*"I am thinking about getting someone to live-in on a permanent basis. But, it would probably be better if they could come in sort of in the mornings and at night and stayed a few hours to make sure I'm alright, and make sure I take my drugs properly. Because, I tend to overdo it with my drugs sometimes because of the amount of pain - I take more drugs to try and kill it, to kill of the pain. You see, I've been taking them for a long time and my body becomes immune to it - to the drugs. And, there are side effects with the particular drugs that I'm on - especially morphine. It is a narcotic drug anyway, and I've been advised to come off of that and I'm trying to do that now with the help of the doctor. But, that doesn't really solve the problem because I'll have to replace it with something - I definitely wouldn't be able to manage without. But, I don't really know if there are any safer alternatives. I've just recently had an epidural - which has helped, and I'm going to go back to the pain clinic next month. I've been under the clinic for about 4 years, so I've tried some alternatives there - but I'm still getting the pain. I don't really think they can cure it at all because the nerve is getting rubbed all the time."*

*"At night, I do want someone who can come in regular - but not necessarily to stay overnight. I'd only need them to stay sometimes. You see, if I had someone living in permanently, a lot of the time they're going to just be sitting around. So, I want something a bit more flexible - but it's pretty difficult to get organised. The options you have at the moment - well, the options are nil really. But, the district nurse - I should be able to get that. It is quite important, but they stopped it and said it was due to the financial cuts - they haven't got enough staff to do it. What I'm looking for - well, it's got to be a professional - they've got to know what they're doing. Especially with having to watch out for my spinal column - like when you're washing. I have to be so careful - so, they've got to know what they're doing. The one that used to come (district nurse) - she used to wash my hair, and wash my back - because I physically cannot do that. That's the sort of thing - that's very important, especially when you're wearing a brace in the summer. I sweat quite a bit so I have to bath on a regular basis or have a shower. It's mainly a bath now. I've got a shower in there, but you've got to stand up and I can't stand up now - that's the problem."*

*Researcher: Did they offer you any alternative?*

*"No. They just stopped it. If I can get someone with my attendance allowance, then they might be able to help me with the bath instead. Then, I wouldn't have to have the district nurse as well. It doesn't really matter - as long as I get it. That's the important thing. It causes all sorts of problems. Not only medical wise - with the sores, which you just cannot afford to have when you're wearing a brace - it's most important that I get a regular bath. That's another thing. I get through so many t-shirts - they get wringing wet. I've got no-one to help me with the washing - my mother used to do that. So, that's something else I've got to try and get sorted out. It takes me all day doing that lot. I've got a washing machine out there - but I can't bend and it's low down. I've just been in contact with the social services and asked them to come round and see what they can do. Maybe there is a way of positioning things in a different way. It's not just the washing machine. The cooker, and the cupboards - I just cannot get to them. With the cooker, I can only do it if I get down on my knees. But, the problem is getting back up again."*

*"After I had my operation I had to have someone help me with a shower because I couldn't turn. I'm not supposed to turn even now - I'm not supposed to bend my spine. If I've been working all day and I come in in the afternoon, then sometimes I'm in agony, I'm fit for nothing except for flopping down. So, the children get there own meal and I just about manage to get our meal when my husband comes home. I have somebody to come in once a week because I can't Hoover, so somebody comes in once a week to do the cleaning. That's a private arrangement. I was told I couldn't have a home help. That was in 1987 when I had my first operation. I was told I wasn't eligible because my husband earns a lot of money and I'm never counted as being financially*

*independent - even though I have to be regarding our own domestic arrangements. My money is my money, and his money is his money, from the point of view of anything else, we have to be counted as a married couple and I'm not eligible for anything. So, my domestic comes in for one afternoon a week for 3 hours, and I pay her out of my own salary."*

*Researcher: Have you heard of care attendants (personal assistants), or anything like that?*

*"I think I've heard the expression. But, I'm not eligible for anything like that. I'm eligible for absolutely nothing. When we tried, when I first came out of hospital, to get a home help or whatever they're now called we were told we would have to go to a private agency and pay. But, he (husband) wouldn't do that. He'd rather do anything than part with his money. I do my shopping on my own. I go to Safeway because they're very good and they pack the shopping for you. But, of course, when I get home you've got to unload it at the other end and that is difficult. Shopping is a good case in point. Sometimes I go down to the village to get a few things, but heaving the trolley back up the hill is bloody difficult, I get home shattered - nobody gives a damn. I feel - and I'm sure lots of people feel like this - but nobody understands. Perhaps my children do, but my husband doesn't. When he comes in in the evening, I can't say to him - I feel bloody awful. I can't say that every night. Either I'm an invalid, or whatever you care to call it, or I'm not. I fall between the two. I think that you sitting in a wheelchair - when you obviously have some kind of physical problem - maybe it's easier than when you're kind of walking around pretending you're ok. When I was wearing my brace which was a huge thing and it was very obvious there was something a matter with me, people were quite helpful. Maybe I should wear the brace all the time. Maybe I would - but its very hot, especially in this kind of weather. I don't know. I'm a weird mixture. Half of me wants to look sort of normal and half of me wants people to know that there's something wrong with me. So, what the hell do I want? You want people to take your needs into account, but none-the-less to be treated like normal. People don't see anything, do they other than - like when I was wearing my brace - they don't see me as a person, they just see me as someone who's broken her back or something. That's all people see. But, I've never come to terms with it - I'll never come to terms with this, never. I'll never come to terms with the injustice of life. I mean, we all know that life is bloody unfair, and what's the point of going on about it. But, I'll never come to terms with it. I'm not only saying life is unfair for me. I do think life is unfair for me. I suppose it boils down to just not being able to stand the concept of there being any kind of just God. I mean, I don't want to get religious because it's off the subject, but it just makes me so utterly furious when anybody dares tell me there's a point to this. Because, I used to think - when I was younger - that my suffering, my pain, made me kinder, more understanding - made me a better person. Now, it just makes my bloody bad tempered. It's not doing anything for me at all - that's the difference. I'm not religious. If I ever think about it at all it's just to think that - if there is a God, he's a right bastard - or she, or it. Don't tell me there's any point to this."*

*"It would be much better if there was the opportunity to employ somebody. Because, not everybody has families. And, even if they do, they don't always feel that they can ask. As I say, I'm not in that position at the moment but it would be nice to know there is somebody there if you do need more help. The other thing is that, for a lot of people, there does come a time when their families just can't cope any more and they will have to have more help. So, something like that (on-call support) would be marvellous. Just knowing it's there would be a great help in itself. You think - oh well, I can cope today but if I feel bad tomorrow, I know there's someone there. A lot of it is just knowing that the structure is there - it does make for confidence. And, I mean - with that set up - if it keeps someone out of a residential home, how much is it saving. It's good economics too. I'd hate to think I'd ever have to go into a residential home."*

*"I would think that would be too much hassle. It's too much trouble for me to organise. But, it's all hypothetical at this stage. There is a risk I could end up in a wheelchair - but, it doesn't bother me. I'm used to seeing people in a wheelchair, I've got friends who are in a wheelchair - it doesn't bother me that much. If it happens, it happens. It's just one of those things. But, it would make a difference to the help I need."*

*"It has changed. I feel pretty angry that they didn't find out earlier and could have done something. You know, instead of me slipping through the net. But, now, I've got to say - right, I've got this disability and you've got to get on with it. I will fight it all the time because that's in my nature. It makes me feel more positive in any case. Like, I will chase people up, hassle them, and really get on top of them - that sort of thing. It makes me very determined. It's the same with having to fight to get this operation. I'll always fight and beat them in the end. When I was born, I was born premature and I was only 3lb 2oz. I didn't think I was going to live then - but I've proved them all wrong. So, that is in my nature - I'm a fighter by nature, and I shall always be that way. I won't let it defeat me. I am physically and mentally prepared to fight all the way. I mean, it's a funny thing - you get*

*people who are independent and will fight and won't let anybody try and pull the wool over their eyes - which you do get, especially some places I've been to."*

*"I would say that, at the moment, that wouldn't suit my lifestyle. There may come a time - if I worsened - that I might have to consider that. But, it's not my ideal choice. But, if I didn't have my husband then certainly I would have to think about it more seriously. That really frightens me because, without my husband, I couldn't cope. I can only cope as well as I do because of him because he's so supportive. We've been married for 28 years and he knows the things that I can't do. So, automatically, a system sort of evolves and you don't really need to worry about it. I mean, I know that the care attendant system is marvellous for people that do have carers. But - I know it sounds silly because it's meant to give you independence - but, to me, that would be taking away my independence. I know that, logically, that doesn't make sense but - emotionally - I would fight against that. I'd think - oh no, a stranger coming into my home - it's silly I know but that's how I feel."*

*"To me, that would definitely sound much better. Because, it must be absolutely awful if you've got somebody coming in and there's a clash of personality or you just can't stick them - that must be awful. So, it would be much better if you could choose them yourself. Certainly, you'd feel much more independent - that you had some say in your life. I mean, you accept that there would be more responsibility that goes with that - but you'd definitely be better off. Really, what it comes down to is having control. Because, when you're disabled, there are certain areas of your life that you don't have so much control over - then you fight very hard to keep the amount of control that you do have. I mean, although emotionally I can allow my husband to do all these kind of things, I would find it harder to accept that from somebody else. I'm fortunate that I don't need help in very personal matters like dressing and feeding or whatever. I would find it very difficult to accept that kind of help should I ever require it."*

*"That is an extremely good idea because there are a lot of disabilities where sometimes you're better than others, so that would certainly be a very good idea. If I ever had to live alone I would certainly have to have some kind of help on a regular basis and that frightens me because I know that, without my husband, my independence is virtually gone in many ways although, obviously, not in every way. But, it's probably much more of an emotional thing, rather than actually having the physical help. It's this question of having to ask for help isn't it. I find that very hard, and I know a lot of other people who do. I mean, I've never had a regular social worker - certainly not since I was a child. That's because of the experiences I had - I didn't want to be sort of constantly monitored and told what to do. My attitude was that - if I desperately needed help, well I knew where to ask, but I prefer not to ask if I could possibly not. But, if I was employing a person, then I would feel that I could ask them far more than if somebody else was employing them on my behalf. Then, I would probably feel - oh no I can't ask them to do that. I mean, it's like with the home help. I know there are certain things they are allowed to do and certain things they're not allowed to do. Quite probably, the things they're not allowed to do are the things I probably need them to do. So, certainly a carer that you employed to do the things that you really do need them to do is a much better bet. Yes, I think this feeling that you are employing them does eliminate that horrible feeling that - well, it's all being done for you, it's all out of your hands and you're not in control."*

*"Well, at the moment, the main thing is the district nurses. They are very important. But, they are lacking in this area - and that's through government cuts basically. they are essential - especially for people like myself who physically just cannot get in and out of the bath. I'm also having trouble with my bowels anyway - that's all part of the Scoliosis. So, obviously, you need quite a lot of attention - quite a lot of physical cleaning and with the catheter and all that. Actually, that's only recently happened - about 4 weeks ago. I've had a couple of accidents. So, I've had to see a specialist about that and have this catheter. Then, there's things like picking things up off the floor - it's impossible for me. I've got one of those pick-up aids. I've found it's OK - but it hasn't really got the proper grips. It's alright for some things, like bits of paper but with big things, there's just no way you can pick them up."*

*"I need help with getting dressed. The district nurses didn't actually do that - but I still need someone to help me - it's just physically impossible now. You need help with these kind of things so you can live a normal life and do all the things you would normally do. But, trying to get that across to people - it's impossible. It's getting better, but there's still a hell of a long way to go."*

*"She (home help) is a very nice lady. She does my shopping for me on Wednesday's and on Friday's she comes back and does a bit of cleaning - because, I physically cannot bend down or Hoover in here or do anything*

*like that. So, that's just for the 2 days but maybe it's going to increase - for obvious reasons, because I can't do anything for myself. I'm going to see what happens after my operation - it all depends - but, I will definitely need more help than I have now because I will probably be in plaster for about 9 months and I won't be able to do anything. I used to have meals on wheels and I might need to do that again because I'm not really getting enough food because I can't cook for myself. They're pretty good around here. Actually, all the social services round here are pretty good (Hounslow). But, there is one thing that I was annoyed about - they stopped the district nurse coming in on a Monday to help me wash and bath. They said that's because they're short of staff and I was a bit annoyed about that. So, now I'm in the process of trying to find someone to do it on a regular basis. That's why the social worker got me to apply for the attendance allowance."*

*"I would definitely want a home help - although we can't afford to pay. It wouldn't need to be every day. A couple of days a week would be enough. I mean, I do all the cooking and most of the cleaning - but I am finding it more and more difficult. Even with washing up, because I can't stand. But, the thing is - I've got a stool - but I've got a very tiny kitchen, so it can't stay out there. So, I think to myself - which is more effort. Standing here doing it, or going and getting the stool and carrying it out to the kitchen. It's silly isn't it. I think that anybody who is disabled, is a great studier of time and motion. We have to be very economical in our movement. When I look at other people, I think they're walking unnecessary steps and making unnecessary movements. But it's no effort for them, but for me, everything I do I have to think - what's the easiest, and what's the least effort. So, yes, a home help to do certain things would be great. On the other hand, you don't really stop to think - what help do I need? Because you're so used to just muddling along in your own way."*

*"I feel guilty sometimes when he (my husband) has to cook when he's tired. So recently, as I have been feeling better, I have been doing a bit myself. Then again, he does the shopping on his way home. He doesn't mind - but, I would like to be able to sort of say - well, I'll do it this week. I could do it, but I'd be shattered I have a home help to do the cleaning - a private one. I used to have a council one. But the problem there was that - when they had staff shortages - they used to send them to just the housebound. So, you know, you'd stay in and they wouldn't come because they'd been diverted. I used to get depressed because - you know, you'd got yourself ready and tidied round and everything - and then they didn't show up. So, when my health broke down, I got somebody privately and that's a better arrangement because if I want to go out, I can - it's much more reliable. So, that's the cleaning but - with shopping - it's very hard to shop for someone else. It's hard to think of everything before you go - I'd be much happier if I was able to do it myself."*

## **(2. Aids and adaptations)**

*"My disability was worse when I was wearing the brace and the bathroom could well have done with being adapted then. We did have a shower put in, because I couldn't have a bath. But, it's very small and it's very difficult to manoeuvre this huge plastic brace in a minute bathroom, but it couldn't be adapted."*

*"I did get a raised lavatory seat. We asked for that and there wasn't any problem. I would really like to have a larger bathroom because you need to be able to manoeuvre. The bathroom is a very important room when you've got a disability. A bath is a very important part of the day but our bathroom is minuscule and very uncomfortable. I don't expect we'll ever have it, but as a hypothetical concept, a bathroom is important and I shall make sure that when we move - if we do - that I've got a decent bathroom."*

*"I got the shower put in by social services, and this chair (armchair) the only other thing I had before that was a proper hospital bed - that came through the social services as well. So, I need something done about the washing machine. Even if the home help was to do it (laundry), I'd still want to use it myself some of the time. The only thing to do is to have it raised so I don't have to bend I need the cupboards in the kitchen sorted. I want them all taken out and put new cupboards in higher up. But, sooner or later I might have to move out of here anyway into a proper disabled flat. That's going to take an awful long time. It's not going to be straight away - it's going to be 3, 4 or maybe 5 years. It's a long time. Obviously, that's partly going to be decided by the operation. But, I would go but I want to live somewhere on this estate. You see, if the council turn round and say - you've got a two bedroom flat and we need it for a couple, sort of thing. What I'm going to turn round and say is -- OK, I'm prepared to move. But it's got to be in this estate here and it's got to be on the ground floor, and it's got to be a disabled flat. They have got some on this estate - there's 4 flats round the corner. They're what they call wheelchair flats - that would probably be much better. I couldn't go into one of those mobility flats - they're useless. Trouble is, they don't seem to understand that a disabled person has got a lot more physical needs - especially if you're in a wheelchair. You know, places that they've built - they're not really designed for disabled people. But, having said that, even one of those would be better than this because I wouldn't have to climb those stairs. There's no lift here - that's what creates all the problems. I walk down the stairs and - as soon as I get there - I'm in agony. It's no good at all. I have seen them (wheelchair flats). I've got two friends who live round there. They're all right - but they're a bit small - you need a bigger place really so you can move around. This one is alright - I've got plenty of space. The only thing is, it's on the 3rd floor. If it was on the ground floor I'd be alright. And, with all the adaptations done - it would be even better. But, if I do move into one of the ground floor flats, I'll still want the adaptations done the same as here - I'll have to do that. It should be alright. The social services (Hounslow) are pretty good round here. They've got a disablement officer at the civic centre and they are sorting out things like access for wheelchairs and equal opportunities. I think they're beginning to find out. I mean, most of the people I've spoken to - they just want to be treated like normal people. Just because you're in a wheelchair, it doesn't make any difference - but the access is important. I agree with that - it is a major factor. With me, it's the stairs - same sort of thing. So, this is quite a good area for getting things done like that. But, I would still like to see more social services facilities for people such as myself, if you need anything."*

*"I don't use any (mobility aids) - I just suffer pain. I feel sometimes that I'm a bit of a sham because - here are you interviewing me with a disability - and I definitely do have a disability, but at the same time, I try to carry on as normal. I basically drag myself through life doing - in inverted commas - normal things, in pain."*

*"Even if I had a lighter chair, I still wouldn't be able to get it in and out of the car on my own. Then, with the battery chair - the battery chair is great, but the batteries are heavy. Also, I do have a manual as well - but I can't push myself. So, whichever chair I use, I've still got to have somebody come with me. I mean, if I want to go to the shops my husband will always come with me. But he works, so it has to be on a Saturday which is far from ideal."*

## **(3. Transport needs)**

*"I've got to get a new car. I've had the assessment done at Banstead, but the adaptations might cost as much as ,1,000. I'm hoping that the motability will pay for the deposit and the cost of the adaptations - I can manage the rest after that. Obviously I'm going to have to take lessons to get used to the hand controls - I can do that at Banstead. All I've got to do now is wait for motability. But, as it has to go through the charitable funds, you have to wait 3 months just to get a yes or no. I hope they don't say no because - without the new car - I'm going*

*to be even more stuck. I suppose if they can't do it, I'm going to have to try and find the money somewhere else. But, it don't grow on trees - especially when you only get ,52 a week."*

*"Transport has become a lot harder. I mean, the Dial-A-Ride is a great idea. It's marvellous in theory but in practice it's not always so convenient. I do understand their problems and the financial limitations and I suppose that there can never really be an ideal situation. But, ideally, we'd like to do what everyone else does and just be able to say - oh, I think I'll go to so-and-so today - and just be able to go. But, of course, you can't do that. With our local Dial-A-Ride you have to book 2 days in advance and that's provided you can get through and they're not fully booked. Then, they will only take you to somewhere within the borough. They did used to take us to (shopping centre) outside of the borough because it was so good for disabled shoppers. Actually, that's why I got so excited about it. But, I've only ever been twice because, then they decided it wasn't allowed so that's no good. But, we thought there has to be a way round it and we eventually found a taxi service who could get me and the chair over there. But, this is the thing, you're constantly on the phone and banging your head against the wall trying to get these things organised. So, it's good that you have the Dial-A-Ride but, for me, there's no point then taking me somewhere where I can't walk round anyway. But, what to do about it, I don't know. Financially, it's just not viable for them to be able to take people here, there and everywhere, wherever they want to go - it is a great problem. As you know, disability rights is becoming very strong and they want the right to be able to use public transport. But, I have to ask myself - do I really want the right to sit in the freezing cold for half an hour waiting for a bus too full up for me to get on when it arrives. I'm not quite sure that I would like that right. In theory, it's good - but the transport system would have to be a lot better first."*

*"I would rather there was some kind of help with transport, so I didn't have to rely on friends or my husband all the time. But, you see, somebody mentioned about Dial-A-Ride. But, I feel that - as long as I can get on a bus - however difficult it might be - knowing that Dial-A-Ride are heavily oversubscribed with people who couldn't possibly get out any other way, I wouldn't even go as far as finding out about that because I can still get out at least some of the time."*

*"I do still drive, but I can't drive for anymore than an hour at the most - that's the very maximum. I couldn't do a long journey - even just sitting in the car as a passenger kills me."*

#### **(4. Housing needs)**

*"Well, the council are obliged to house us but, obviously, because of disability that is a problem - plus the fact that they've sold off nearly all of their houses. I would hate to be in a flat somewhere, because I would just curl up and die - I love the garden and so on. We do think about it occasionally but - I don't know is the answer really, I just don't know. I think I'd rather worry about that when the time comes. Ideally, a disabled bungalow - but they're very few and far between. I think, obviously, that's something that we'll have to go in to when the time comes. I mean, you've got to look ahead to some extent. But, to me, it's now that's important. In any case, I've always thought that I won't die of old age. I know that sounds morbid, but I think it's a more a case of being realistic. You know, I don't think I will die of old age. I know my disability is worsening. My best friend died two years ago who had polio as a child and was very badly disabled. Obviously, it's a different disability to mine but, when she died, it boiled down to the fact that it was her disability that caused her death and the doctors were amazed that she'd lived to the age she was. So, I think that sort of thing is on your mind. Throughout my life, I've known disabled people dying through their disabilities and so I think there's a certain acceptance there - that the law of averages is against you really."*

*"Wherever we go, it would have to be somewhere where there's no stairs, because I know there's going to come a day when I can't manage stairs. So, it would probably be a bungalow. But, we've always been very interested in mobile homes - mainly because, when we first got married, we lived in a caravan. Really, that was ideal for me in many ways. I could certainly manage it housework wise - because there wasn't a lot of it. Now, mobile homes are like bungalows - but, they're an exorbitant price. So, that's pie in the sky as well - that's just my daydream."*

*"Yes, my ideal kitchen would be not too big, because the less paces I walk the better. But, it depends on the disability doesn't it. I mean, if someone's in a wheelchair, they need space to manoeuvre and turn round. But, for me, smallish rooms are much better. Although, I would still need to have it big enough so that I could have a perching stool so that I could put it under something out of the way and just get it out as I need it to sit on - that would be marvellous. That would make my life a lot easier. Then, with the bathroom - we did have a shower installed by the social services because I could no longer physically get down into the bath. Well, actually, I could get into the bath - it was getting out again that was the problem. It was getting impossible, and I was getting very frightened of falling. I mean, all my weight is on one leg. So, it only takes for that leg to slip and I've had it. So, social services put the shower in and I've got a board across the bath which I sit on - so that's solved that problem. I don't need any rails inside the house or anything like that. I have got some rails by the steps outside the back door because I can't go down the steps without holding something to balance me. Actually, that's something that's got worse with age as well - balance. When I get up and walk, I have to concentrate - you tend to lose all co-ordination. But, really, if I had my ideal house - it wouldn't really need all that much adaptation. It would all be quite straight forward. I mean, looking back at all the places we've lived. When we were in the caravan, that would have been ideal had it had a toilet and running water. After we left there, the council gave us a flat but it was one floor up. Well, I could manage that but when my son was born I was housebound, because I couldn't carry him down the stairs. We were there about two years and then they finally gave us a groundfloor maisonette which certainly was a great improvement because I could manage quite well there. But, you don't always want to live your life because of disability. Obviously, you've got to take it into account, but you don't want it to totally take over your life. Obviously, you have to live within your physical limitations. But, I suppose that's the worse aspect - you can't be spontaneous. Every time somebody says - do you want to go to so-and-so, you have to think am I going to be able to manage, is there going to be a toilet. You know, there's no spontaneity when you're disabled and that obviously increases with age."*

*"I'm not planning on retiring for a while yet, but we have thought about moving when the time comes. Ideally, what you want to be able to do is sell up and either get a cheaper place, or rent, so that you have the money that's left over to live on - that's the basic plan. Preferably, a two bedroom ground floor retirement flat with all the services on hand (ie. sheltered flat). That would suit us very well if we could get somewhere like that. That is a problem though. the housing associations don't have enough places for people to rent. There are a lot more private developments - but, buying is alright if you've got cash to spare, otherwise you really want to rent so you can have the money from the house to live on. It defeats the object if you don't actually have enough to live on when you move."*

*"I have sometimes thought that I might eventually have to end up living in a bungalow. But, I'm not very keen*

*on bungalows - but I just don't know."*

*"When I do retire, I think it's almost certain we will move from here. It's just not practical to keep on with a place this size. I'm already having trouble keeping up with all the housework - not that I'm particularly bothered about that, but you might as well not have to deal with so much of it. Then there's the garden - there's no way either can manage a garden that size anymore, so it may as well go to someone who can get the full benefit. And, it would probably be a good idea to get somewhere without stairs because I know that's very likely to get more of a problem the longer it goes on. So, as soon as we can afford it, it looks like we will be going."*

*"Personally, I would want to go to a residential home so that I could have the security. I'd actually prefer that to having help at home because I would be all on my own without any companionship if I stayed here. I need to have people around or I'd get very fed up. Anyway, there's no way I could manage a place this size if (my husband) wasn't around. The National Union of Teachers have a couple of homes for retired teachers - I'd be quite interested in one of those places if I ever needed it. I don't know what the facilities would be like for someone with a disability, but I'd have to check up about that."*

*"I think a lot of the time, putting people in homes is unnecessary. We tried to put it off - putting Mum in a home. But, unfortunately, it got to me and I cracked. She had to go into a home for her own safety, plus, she was forgetting things and doing silly things like leaving things on and causing a danger to herself. It was physically impossible for me to look after her with my disability. I visit her quite regularly and she's coming home for Christmas - I don't want her to have to spend Christmas up there on her own. I mean, those homes are very good for what they are. If I was ever told that I'd have to go somewhere like that, I wouldn't argue - it's just one of those things that you have to put up with."*

*"I thought about taking my own life recently - when Mum was put away in a home. But, I've got over that. I found it very very difficult - everything was getting on top of me - especially with all the aggravation I was getting from the hospital. It was all coming together - it was just like one big bombshell when you least expect it. But, it was the right thing to do for Mum. And, now, I've got to think of myself - think of my needs and carry on enjoying life as much as I can."*

*"I haven't really thought about it. I think, probably one of the main reasons would be if I ended up in a wheelchair. If that happened, I would seriously consider getting professional people to look after me. I wouldn't mind going into a home. But, I would like to be independent at the same time. So, probably, I would prefer to stay at home and have somebody living in if it came to that. But, if I really couldn't manage, I would go."*

*"It's something I have thought about, but then put at the back of my mind. I'll cross that step when I come to it. You can plan for any contingency if you want to. But, you see, my mother had a neighbour - she had a wheelchair already for in case her health declined. She got better, but she used to go out in her wheelchair every Saturday just to get used to it. She got the council to totally adapt the ground floor of her house. She was always looking forwards - to being more disabled. It was as if she was looking forward to being looked after. But, I can't think of anything worse than being dependent on someone who has to look after you - or, letting yourself get dependent. I mean, you don't always have the choice. But, she was working on the principle that it was going to happen. So, I suppose, that's always been at the back of my mind - I'm not going to cross that till it happens. Anyway, it can be a self fulfilling prophecy. But, in my case - I think, with scoliosis, it's unlikely that I'll ever get to that point."*

*"When my husband's mother died, we decided to move to a smaller house. It's a shame in a way because, had I stayed there, I would have been able to get around more - so I would have felt more independent in a way. This house is very cramped, which does cause a few problems for me at the moment. I'm not too bad at the moment, but if I have more problems with my legs, I won't be able to manage the steps - and, I'd like to have the bathroom downstairs."*

*"If we needed to make any changes - we'd have an extension built. That would be the easiest thing to do. Ideally, it would be nice to have a bungalow. But, we're not planning on moving at the moment."*

## **(5. Financial needs)**

*"We're lucky because my husband's got a decent job that pays a reasonable amount. But, I realise how lucky we are because I couldn't live on my benefits and yet, a lot of people have to."*

*"Up to two years ago, I had to have assessments every 6 months. But then, my GP wrote a letter and it was established so I didn't have to go back. I know they do it in case you get better. I suppose, with some conditions, you may get better, but not with something like this (ie. scoliosis). It's bureaucracy, that's all it is. It used to really irritate me - and it's a waste of the doctor's time. I mean, he just says - turn round, yes, it's still there. Anyway, I'm glad that's all been sorted out know."*

*"I'm just sorting out a new car now through the motability. That's going to take about 3 months because I'm doing it through the charitable fund because, obviously, with what I get - especially now Mum's gone into a home - I'm finding it very difficult financially. I can't really live on the money I get from the government - I think it should be a lot more. I mean, a single person's got just as much money to pay out as a married couple. My money at the moment (1990) stands at £52.10. Now, out of that I've got to buy my food and I've got to pay my rent. I get a reduced rent, but it's still not enough. So, that's with the income support, the mobility, and the severe disablement allowance - that's it, that's all I get. I'm finding it very very difficult. The mobility's recently gone up to £105, but I still don't think it's enough. You see, the married person gets all the benefits but what the government don't seem to realise is that an ordinary single man - even though he's single, he's still got the same bills to pay. This is where they fall down. It cost's just as much to heat the house whether there's two people in there or not - it makes no difference. I think that the amount of money you should get should be enough to live on - I don't mean live comfortably - just enough to live on and have the bear essentials. I mean, that £52 a week - being disabled, it makes a hell of a lot of inroads into my life. I can't buy things, like proper food that I should eat and things like that. But, they just don't seem to understand. It's hard enough just trying to run a car. I've had to change from hire purchase to hire (Motability), just so I could pay for the insurance, or even to carry out any services on it. So, now I'm leasing it through Motability which seems to be the best way round it. But, I've still got to find the deposit - I've asked the charitable fund for the deposit and the cost of the adaptations. I don't know whether I'm going to get that yet - it takes them so long to sort it all out. I've been trying to find out if there are any other charities who might be able to help with the cost of the adaptations - but, it's not easy trying to find out. Then, I'm going to have to change to a bigger car in any case. I have been down to Glanstead Place - that's where they told me about the Metro. But, that was the worst car in the world for me because it was too small. So, you have to try and figure all that out for yourself as well."*

*"I have thought of applying (for benefits). When I get very depressed about work and think - I'm tired, I'm in agony, why don't I apply for a disability pension? Then I think - I'd be sitting around at home all day and you'd lose your independent friends and independent life which I enjoy. So, I think I haven't applied because I don't want to. And, I've had very varying reports from doctors I've mentioned it to. One of them has said - I'm pretty sure you'd get it. Then, somebody at Guy's hospital I was talking to said - I don't think you'd get it anyway. I don't know, I've never tried. It's a fall back in my mind. If things get really bad and I can't work, but I haven't been into it."*

*"I know you have to go through some kind of medical. Whenever I've been asked these sort of questions, it's difficult to know what to say. I remember filling in one of these questionnaires from the hospital. They say how far can you walk? Well, the answer to that is - quite a long way. But, they never seem to take into account whether or not you're hobbling along in agony. If you can walk, you can walk - that's what it seems to be. When you've hobbled around in pain for 25 years, you're used to it. It sort of becomes a way of life I suppose, so you don't realise."*

*"I've been careful to try and make sure we have a decent pension for when we retire. I do think that's very important - especially if you want to move, which I'm pretty sure we will when the time comes."*

*"Really, I don't want to be working full-time at all now. But, the thing is that - with my pension - it's based on the last three years, so I can't afford to go on to part-time. That is a problem with a lot of older workers I think. I mean, no-one would mind a reduction in salary if you could have a reduction in hours so you could keep working. But this isn't practised anywhere. There's fewer people working, and so older workers are being forced to work longer hours. It's not fair on us older workers at all."*

*"These days I find that work is cramping my leisure time more than ever. I am getting slower, and I get a lot more tired, so I feel as if I have lost some quality of life through having to keep up working. But, when I retire, I'm sure I'll be able to get that back because I should be able to do a lot more."*

*"I'm very disillusioned with teaching anyway, so I may well want to retire early. But, I won't get a pension because, like a fool, I drew out my superannuation when I got married. So, it won't pay me to retire early. I won't get a pension so, I think I might want to, so I'll probably have to drag it out until I'm 60. But, I have always paid my own stamp so I will get an old age pension in my own right."*

*"I have to have a car now. I did not have a car before I was in a lot of pain. So, whereas a car would have been a luxury item before, now I have to have a car - there's no way I could manage without a car. If anything ever happened to the car - I'm done. That's an absolute essential."*

*"No, I've just traded my car for another secondhand car. I have to buy my own car - my husband has a company car. I had an old Y registered Polo and I've just traded it for an E. I can't afford to be choosy. I mean, I earn a part-time salary and I have to be financially independent and I don't dare to commit myself to any kind of HP deal because you never know - are you going to be in a fit state to be working in one year, or two years time. So, I take what I can get. You see, either I'm going to get better and I'll be able to say in a years time - I don't even remember what it was like to be in such pain - or, I think I'm going to sink to rock bottom. That's how I feel at the moment."*

## **(6. Self-help groups)**

*"Things are improving a little bit. It's like, I have a friend who's in a wheelchair - she had polio. She's been quite mobile but, as she's getting on, it has been causing more problems. She was saying that she was waking up with headaches which is one of the signs when your breathing's not good at night - that you're not getting enough oxygen through your system. So, I said to her about the blood gases test at Brompton which she might find useful. You see, she'd been going to see her GP but, it's not something a GP would know about. So, all the time, there are these things coming along which could help people. It's just getting the communication set up, isn't it. There is a lot of collective experience - but it needs to be pooled. I mean, it is through self-help groups - but, not everybody wants to join groups. But, for me - with the Scoliosis Association - it's helped me, so I want to help it. So, when things have happened - or you find things out - I always want to share in discussions with various people. Like, if somebody wants to start a family, they can get in touch with someone who's about the same age and the same state so you can swap notes and, you know, find out about what it's like. There's all sorts of problems which people could want information about. I mean, it's like with my breathing troubles - if you neglect it, it can cause an awful lot of hassle later. I've seen people who have left it and it's a lot more disruptive later than it is if you deal with it when it's first diagnosed. So, I've told the doctor that, if she gets anyone else like that, to put them on to me if they want to talk to someone. It's not to give them horror stories or anything like that. It's just to warn them that, if it is neglected, it can lead to quite severe problems. It's a lot easier to be master of your own life if you're healthy. I don't mean, being not disabled - but, I mean being fit within your disability. So, that's where information can be a help. If you're told - behave in this way and it will shorten your life and, behave in that way and you will have a longer life but you're going to be bored out of your mind - I think it's a person's choice to decide which way they're going to go. It's up to them - it's got to be a personal decision."*

*"They (Scoliosis Association) have been very good - very, very good. They're only a small organisation. They can't help you in physical terms, but it's nice to have a group of people who are in the same position as you're in - that sort of environment. They're very good on providing information - and it comes from people who know. It's like with me, after all these years I know quite a bit about Scoliosis - you can pass that on."*

*I do think it's important for people to be able to pool their experiences. Actually, this is one of the reasons we started our club for disabled people - because, we all gain so much from it through hearing other people's experiences. And, also there are some people in the club who are recently disabled - paraplegics disabled through accidents or whatever - and they can gain through our experiences. Also, there's no real information - I mean, if you suddenly become disabled, apart from having to cope emotionally and physically, no-one actually comes along and says to you - look, this is available, that's available. These are the aids which you can have to help you, these are the monetary allowances you can have. There's absolutely no information given - so we provide that service for each other. Also, emotionally - there's no emotional back-up at all. Physical needs are taken care of, but there are a lot of emotional problems attached to disability."*

*Researcher: Who do you think should be doing that?*

*"Disabled people who are disabled - definitely. I mean, our club - we're very strong about the fact that I know we discriminate - we don't allow able bodied members, and everyone on the committee is disabled. We felt that that was essential because - certainly in my experience - I got very fed up when I was young of being told what to do with my life by social workers. I mean, any disabled person makes the sign of the cross when they hear social worker - social worker is a rude word to us I'm afraid. I'm sure there's a lot of good ones - but I haven't met one. They've got the best of intentions, but they really don't know what's right for us - it's only really disabled people who know what's right for them. I mean, really, we just want the same as everyone else. We don't want more - we just want the same opportunities, the same rights of access, and whatever. You know, this idea that we should be pitied - we hate that. Going out with a begging bowl, you know, that's a horrible attitude. For instance, speaking for myself - and a lot of disabled people that I know - we can't bear Esther Rantzen's programme on television when she trot's out all these disabled children and says - aren't they wonderful, here they are. We just cringe. It's awful - it just aims at everything we don't want. It's just pity - which is the last thing disabled people want. It's horrible."*

*"I think the main problem is that there are lots of different groups. There's lots of different societies for each disability. There's lots of individual clubs like the one I'm involved in. But, there's no central information. If someone wakes up one day and they're disabled, they don't know where to go and they wouldn't know who to*

ask to find out. I really think that, as soon as someone becomes permanently disabled for whatever reason there should be someone - either in a hospital situation, or a GP situation, or whatever - who says - right, this is where you need to go to find out everything you need to know. But nobody's doing that, and that's the difficulty I think. You know, I actually had a social worker not too long ago who said - there's a lady living in your road with motor neurone disease, and she's finding it very difficult to cope emotionally and I wondered if you'd mind popping along to see her. Well, my first thought was that she may not want me to. You know, what right have I got to go knocking on her door and say - hello, here I am, and this is what it's like to be disabled. You know, I thought I had no right to do that. So, I rang her and we were both the same - very tentative - but, I did go to see her and we hit it off and we became very good friends. But, the thing is that she'd had a social worker, but she'd had no information whatsoever. I couldn't believe it. I mean, I was the one saying - did you know about this, did you know about that. She'd had nothing, but these are the people who are supposed to be doing the job. I find that appalling - and it's always been like that. It amazes me that, in 47 years that hasn't changed one bit. That is the job they're supposed to be doing but somehow they're not doing it right. It's sad because, generally, the public awareness of disability is fine. I mean, I can remember as a child people - adults - staring at me in the street. They still do occasionally. I do object to that - I've never been able to get used to that. I've stopped going to the public swimming baths for that reason, because I felt very uncomfortable. So now, I go to a club for disabled people and that's fine - we're all in the same boat. Yet, for years, I shied away from this idea of having all disabled people together. Because I'd fought so hard to break out of the mould and mix with people who are able bodied, that it took me a long time to come to thinking - it's no good, it's disabled people who need to get together and fight these prejudices. I know we are segregating ourselves. But it's not happened in 47 years, so we've got to keep plugging away. Honestly, I don't think it's going to happen in my lifetime, but I think it will eventually - it's got to. I mean, I had a bloke come to our club recently. He was a paraplegic - he'd fallen off a ladder, and he said - you know, before I became disabled, I know now that I knew nothing. I thought that, if someone was in a wheelchair it meant that they wouldn't always be because they were going to get better. He said that it didn't occur to him that there were disabilities that never got better. That astounded me - that people were that ignorant about disabilities. But, anyway, we are segregating ourselves - yes. I always fought against clubs for the disabled, because I thought - that is awful. I did feel quite strongly, for most of my adult life, that we should just be out there plugging away and doing what able bodied people do. I've always just done that. I wouldn't register as a disabled person - I only did that in recent years. Because - when I did go to work - I wanted to know that I'd got a job on my merit and not because I was disabled so that they felt they had to take me. I wanted to compete on equal terms with everyone else. But, this club situation just occurred because - somebody through a road accident became disabled. I'd got to know her and she was emotionally shattered and needed something to pick herself up, so she had this idea of starting a club. I said - well, I type - so she said - right you're secretary and that's that. So, it just started like that. But, I suddenly realised that perhaps I'd been wrong - that there's so much gained there. But, it doesn't mean that, just because we go there on a Tuesday that - on the other days of the week - we can't be out there with everybody else. You know, it's important I think to do the two. I certainly don't think that disabled people should just be with other disabled people - we'd be defeating our own aims. But, when it comes to helping each other and providing information, we have to - because there is nobody else. I mean, after having been to schools for disabled children. You know, I was taken by schoolbus to school and the only able bodied people I ever saw really were my family. And I went to a college for disabled people. Then, suddenly at the age of 16 I was in a job - and I was the only disabled person, and I couldn't handle it. You might not believe it now but then I was incredibly shy and I just couldn't cope with being the only disabled person in a group. I found that ever so hard - and it's taken me a hell of a long time to overcome it. Over the years, I've deliberately chucked myself in at the deep end and done masses of things, trying to overcome that. That to me is the worse thing about segregating disabled children - because, they just don't know how to cope with being with able bodied people. Kids can be incredibly cruel anyway. No, I don't think the emotional aspect is really taken into account - it never has been really."

"You know what we were talking about earlier - the emotional aspect. Well, I think that whenever anybody becomes disabled, there should be someone that can give them a phone number or an address to contact. I mean, obviously it's got to come from them - I don't think people should descend on them, it should come from the person themselves. Although, perhaps emotionally, they're not able to at that stage. I don't know, it's a tricky one. It's the dividing line between intruding and helping. But there should be someone to contact so that they can go along and say - this is what's available, or this is where you can go if you wish - you know, without trying to take over them completely. And, as for me, I do think sometimes that perhaps there is knowledge somewhere out there that I don't know about that could help me. I don't know how to find out, and they don't know where I am, so I don't know how that could come about."

## **THE NEXT STEP**

In highlighting the needs and experiences of people who are ageing with a disability, we have not tried to be particularly prescriptive about how organisations like the Scoliosis Association should respond. Rather, we have simply pointed out some of the most important practical implications and highlighted the key issues which older disabled people themselves are most concerned about.

Clearly, then, the onus is on all organisations of and for disabled people to consult with their own older members and to work out whatever strategies they feel are most appropriate to their own needs. However, we hope that we have at least made a contribution by raising the profile of people's concerns about ageing with a disability and pointing to some of the practical measures which are most urgently required.

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## Appendix A: Details of project participants

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### Breakdown of impairments (by gender)

<u>Disability/impairment</u>	<u>Total respondents</u>			<u>Interview sample</u>			
	Male	Female	Total	Male	Female	Total	
Polio		25	40	65	9	20	29
Multiple Sclerosis		7	30	37	2	12	14
Scoliosis	4	10	14	2	7	9	
Arthritis	3	16	19	1	17	18	
Amputees		13	1	14	13	1	14
Diabetes	43	54	97	6	9	15	
Parkinsons		10	4	14	3	3	6
Coronary disease	3	2	5	1	2	3	
Muscular Dystrophy		3	0	3	3	0	3
Friedreichs Ataxia		1	0	1	1	0	1
Cerebral Palsy		2	2	4	2	2	4
Stroke		0	3	3	0	3	3
Asthma	0	3	3	0	0	0	
Hearing impairment		0	1	1	0	1	1
Others/not-specified		16	28	44	2	3	5
<b>TOTALS</b>		<b>130</b>	<b>194</b>	<b>324</b>	<b>45</b>	<b>80</b>	<b>125</b>

## Appendix A: Details of project participants

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### Current age by gender and race (interview sample)

	Males	Females	Black/Ethnic Minority	White	All		
			%	%	%	%	%
Under 40			4	10	15	5	8
40 - 49			2	13	3	11	9
50 - 59			13	18	12	17	16
60 - 69			33	26	30	28	29
70 - 79			33	26	27	29	29
80 or over			13	8	12	9	10
(Base totals)	(N=45)	(N=80)	(N=33)	(N=92)	(N=125)		
Average age			67	61	62	63	63

### Number of years disabled by gender and race (interview sample)

	Males	Females	Black/Ethnic Minority	White	All		
			%	%	%	%	%
Upto 30 years			24	45	70	26	38
31 - 50 years			51	40	30	49	44
Over 50 years			24	15	0	25	18
(Base totals)	(N=45)	(N=80)	(N=33)	(N=92)	(N=125)		
Average years			42	34	24	42	37

## **Appendix B: Dissemination materials produced**

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### **Publications arising from the research**

Zarb, G. (1990) 'Ageing with Polio' British Polio Fellowship Bulletin, Vol.28 (5)

Zarb, G. (1990) 'Ageing with Diabetes' Balance, No. 119,

Zarb, G. & Oliver, M. (1991) Ageing with a Disability: The Dimensions of Need - Preliminary Findings, London: Thames Polytechnic

Zarb, G. (1991) 'Creating a Supportive Environment: Meeting the Needs of People who are Ageing with a Disability', in Oliver, M. (ed) Social Work: Disabled People and Disabling Environments, Jessica Kingsley Press

George, M. (1991) 'Unmet Needs', Nursing Times, Vol. 87 (21)

Zarb, G. (1992) 'Changes in health care: a British Perspective', Chap. 25 in Whiteneck, G. et al Ageing with Spinal Cord Injury, New York: Demos Publications

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Zarb, G. (1992) 'Forgotten but not gone: the experience of ageing with disability', Chap. 2 in Arber, S. and Evandrou, M. (Eds) Elderly People. Independence and the Life Course, London: Jessica Kingsley Press

Zarb, G. (1992) 'The dual experience of ageing with a disability', in Swain, J., Finkelstein, V., French, S. and Oliver, M. (Eds) Disabling Barriers: Enabling Environments, London: Sage/Open University Press

Zarb, G. (1993) 'Ageing with a disability: A biographical approach', in OU Course Reader K256: An Ageing Society, Milton Keynes: Open University Press (forthcoming)

### **Main project report**

Zarb, G. and Oliver, M. (1993) Ageing with a disability: What do they expect after all these years?, London: University of Greenwich

ISBN 0 900822 04 X

Price: £8.50 plus £1.50 post and packing (Available February/March 1993)

### **Briefing papers**

## Appendix B: Dissemination materials produced

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`Ageing and Diabetes: Briefing Paper' unpublished paper prepared for British Diabetics Association, February 1991

`Researching ageing with disability amongst ethnic minorities', unpublished discussion document prepared for Project Advisory Group, March 1991

`Ageing with Polio', University of Greenwich, Autumn 1992

`Ageing with Multiple Sclerosis', University of Greenwich, Autumn 1992

`Ageing with Arthritis', University of Greenwich, Autumn 1992

`Ageing with Scoliosis', University of Greenwich, Autumn 1992

`Ageing with Parkinsons Disease', University of Greenwich, Autumn 1992

`Ageing with a disability: The experience of long-term amputees', briefing paper prepared for BLESMA, Autumn 1992

N.B. Copies of all briefing papers and the main project report are available from:-

Cathy Lewington  
c/o School of Secondary Education  
University of Greenwich  
Bexley Road  
London SE9 2PQ

Tel: 081 316 9587

For further information about the project, contact:-

Mike Oliver, Professor of Disability Studies, University of Greenwich, Bexley Road, London SE9 2PQ

(Tel: 081 316 9588)

Gerry Zarb, Senior Fellow, Policy Studies Institute, 100 Park Village East, London NW1 3SR

(Tel: 071 387 2171)